

Virtual communities for parents of children with special  
needs in Taiwan: Emotional support, information, and  
advocacy

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## List of Contents

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<b>LIST OF CONTENTS</b> .....	1
<b>LIST OF TABLES</b> .....	6
<b>LIST OF FIGURES</b> .....	7
<b>ABSTRACT</b> .....	8
<b>DECLARATION</b> .....	9
<b>COPYRIGHT STATEMENT</b> .....	9
<b>ACKNOWLEDGEMENT</b> .....	10
<b>GLOSSARY</b> .....	11
<b>CHAPTER 1. INTRODUCTION</b> .....	14
<b>1.1 Parents in the virtual world</b> .....	14
<b>1.2 Support for parents</b> .....	15
<b>1.3 Structure of this thesis</b> .....	18
<b>CHAPTER 2. BACKGROUND ON THE TAIWANESE CONTEXT</b> .....	21
<b>2.1 The Taiwanese context</b> .....	22
2.1.1 Brief historical context .....	23
<b>2.2 The Taiwanese culture of Face</b> .....	26
2.2.1 The Confucian influence on the concept of Face .....	26
2.2.2 The Buddhist influence on the concept of Face .....	27
2.2.3 The influence of Westernisation and capitalism .....	28
2.2.4 Culture and the experience of being a Taiwanese parent .....	29
<b>2.3 The support services for parents</b> .....	30
2.3.1 Healthcare .....	31
2.3.2 Education .....	33
2.3.3 Other support services and local organisations .....	34
2.3.4 Parents' experiences with support services .....	35
<b>2.4 Using the internet for support</b> .....	37
<b>2.5 Summary</b> .....	38
<b>CHAPTER 3. LITERATURE REVIEW</b> .....	40
Terminology .....	41
Literature search process .....	42

<b>3.1 Virtual communities and parent support.....</b>	<b>43</b>
<b>3.2 Accessing information in virtual communities.....</b>	<b>50</b>
3.2.1 Searching for information together .....	53
3.2.2 Online professional support services .....	54
3.2.3 The limitations of searching for information through the internet .....	55
<b>3.3 Emotional support in virtual communities.....</b>	<b>58</b>
3.3.1 Overcoming isolation.....	59
3.3.2 Building self-esteem .....	60
3.3.3 The limitations of online emotional support.....	61
<b>3.4 Advocating through virtual communities .....</b>	<b>64</b>
3.4.1 The limitations of advocating through the internet.....	66
<b>3.5 The gap in the current literature.....</b>	<b>68</b>
<b>3.6 Summary.....</b>	<b>69</b>
 <b>CHAPTER 4. METHODOLOGY .....</b>	 <b>71</b>
The aim of the study.....	72
<b>4.1 Theoretical stance: A qualitative research paradigm.....</b>	<b>72</b>
<b>4.2 The research design.....</b>	<b>73</b>
4.2.1 Identifying the cases in this study .....	77
Platform selection: Facebook .....	77
Case selection.....	78
4.2.2 Characteristics of the three cases .....	81
Little Star.....	81
Lovely Dove.....	83
Speak Out.....	84
<b>4.3 The research methods .....</b>	<b>87</b>
Pilot study .....	88
4.3.1 Data collection: Web-based observation .....	88
Limitations of access and ethical issues .....	93
4.3.2 Data collection: Semi-structured interviews .....	94
The inclusion criteria for the interviewees and the sampling strategies .....	95
4.3.3 Research diary.....	103
<b>4.4 Establishing trustworthiness.....</b>	<b>105</b>
4.4.1 Validity and reliability .....	106
4.4.2 Language and translation .....	107
<b>4.5 Ethical considerations .....</b>	<b>108</b>
Interview .....	108
Web-based observations of public archived data .....	109
4.5.1 Researcher positionality.....	110
<b>4.6 Data analysis.....</b>	<b>111</b>
4.6.1 Analytical framework .....	112
4.6.2 Analysis process.....	115
The first stage of analysis: Within-case analysis.....	115
The second stage of analysis: Between-case analysis .....	119

<b>4.7 Summary</b> .....	124
Presentation of the findings.....	124
 <b>CHAPTER 5. NEWS ABOUT A FATHER MURDERING HIS SON: A CRITICAL INCIDENT</b> .....	126
<b>5.1 The news</b> .....	126
5.1.1 Content of the news articles.....	127
5.1.2 The cultural influence on the reporting style .....	131
<b>5.2 The response to the news from each virtual community</b> .....	133
5.2.1 The response of Little Star.....	133
5.2.2 The response of Lovely Dove .....	139
5.2.3 The response of Speak Out .....	143
<b>5.3 Summary</b> .....	147
 <b>CHAPTER 6. DEVELOPING PARENTING SKILLS</b> .....	149
<b>6.1 Information</b> .....	149
6.1.1 Child development.....	149
6.1.2 Parenting skills related to raising children with special needs .....	150
6.1.3 Formal parenting instruction.....	154
6.1.4 Raising the siblings of children with special needs .....	157
<b>6.2 Emotional support</b> .....	158
6.2.1 Encouragement and affirmation through reading positive parenting experience .....	158
6.2.2 Solidarity through sharing the experience hardship of parenting .....	161
<b>6.3 Advocacy</b> .....	162
6.3.1 Sharing about their children’s growth to raise awareness: from private diary to diary for other users .....	162
<b>6.4 Summary</b> .....	169
 <b>CHAPTER 7. ONLINE MEDICAL RESOURCE</b> .....	170
Definitions of different types of online medical resource .....	170
<b>7.1 Information</b> .....	171
7.1.1 Formal medical information .....	171
Information about face-to-face support services .....	174
7.1.2 Information about medication.....	176
7.1.3 The accuracy of online medical information .....	181
7.1.4 Informal medical information .....	183
<b>7.2 Emotional support</b> .....	188
7.2.1 Seeking for comfort .....	188
<b>7.3 Advocacy: Direct contact with professionals</b> .....	190
<b>7.4 Summary</b> .....	191
 <b>CHAPTER 8. EDUCATIONAL PROVISION, WELFARE, AND LEISURE</b> ..	193
<b>8.1 Educational provision</b> .....	193
8.1.1 Information: Educational placement.....	193
8.1.2 Information: School activities and school life .....	198

8.1.3 Information: Communication with teachers in school.....	200
8.1.4 Advocacy: raising the awareness of the issue of bullying in school.....	204
<b>8.2 Welfare .....</b>	<b>209</b>
8.2.1 Welfare information.....	209
<b>8.3 Leisure .....</b>	<b>212</b>
8.3.1 Social gathering Parent's social gatherings and events .....	212
8.3.2 Entertaining information not related to parenting or special needs .....	215
<b>8.4 Summary.....</b>	<b>216</b>
<b>CHAPTER 9: DISCUSSION .....</b>	<b>218</b>
<b>9.1 How do virtual communities provide support for parents of children with special needs in Taiwan? .....</b>	<b>219</b>
9.1.1 Information .....	219
9.1.2 Emotional support.....	220
9.1.3 Advocacy .....	221
<b>9.2. What motivates Taiwanese parents of children with special needs to search for support through virtual communities?.....</b>	<b>222</b>
9.2.1 Finding Face: Public self-image and identity .....	223
The social stigma of the person with special needs .....	223
Finding Face through joining virtual communities .....	226
The fragmented Face.....	228
Coping with losing Face.....	232
9.2.2 Searching for and sharing information for different purposes.....	233
Formal knowledge.....	233
Informal knowledge .....	235
<b>9.3 How does support provided through virtual communities impact the relationship between Taiwanese parents of children with special needs and professionals? .....</b>	<b>239</b>
9.3.1 Becoming Friends with professionals through Facebook.....	239
9.3.2 The influence of marketisation on the parent-professional relationship.....	242
<b>CHAPTER 10. CONCLUSION .....</b>	<b>245</b>
<b>10.1 Contribution to knowledge .....</b>	<b>245</b>
<b>10.2 Summary of the thesis.....</b>	<b>248</b>
<b>10.3 Potential future studies.....</b>	<b>250</b>
<b>REFERENCES.....</b>	<b>252</b>
<b>APPENDIX 1 INTERVIEW SCHEDULES .....</b>	<b>269</b>
<b>APPENDIX 2. INFORMATION SHEET AND CONSENT FORM.....</b>	<b>273</b>
<b>APPENDIX 3. BASIC SETTINGS OF FACEBOOK .....</b>	<b>276</b>

**APPENDIX 4 RQDA DATA COLLECTION AND ANALYSIS PROCESS ....286**

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## List of tables

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Table 1. The three virtual communities .....	86
Table 2. Little Star semi-structured interview participants.....	99
Table 3. Lovely Dove semi-structured interview participants.....	100
Table 4. Speak Out semi-structured interview participants .....	101
Table 5. An example from my research diary: Interview notes (transcribed from an A5 lined notebook) .....	104
Table 6. Case study tactics and three case study design tests (adopted from Kilroy, 2013) .....	106
Table 7. Conceptual framework.....	114
Table 8. Stage 1.1: The identification of the three types of support.....	116
Table 9. Stage 1.2: Sub-categorisation .....	118
Table 10. Stage 2.1: Cross-case analysis .....	121
Table 11. Summary of the categories, sub-categories and themes.....	123

## List of figures

---

Figure 1. The geographical location of Taiwan .....	23
Figure 2 Timeline of the history of Taiwan .....	25
Figure 3. Case study design with three virtual communities as embedded cases (Adopted from Yin, 2009) .....	76
Figure 4. The basic structure of the three virtual communities in this study .....	79
Figure 5. Research Methods .....	87
Figure 6. Process of recording web-based observations .....	91
Figure 7. Research diary .....	105
Figure 8. Qualitative data analysis process (adapted from Miles & Huberman, 1994) .....	111



## Abstract

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**Title:** Virtual communities for parents of children with special needs in Taiwan: Emotional support, information, and advocacy

This thesis is a case study of three virtual communities for parents of children with special needs in Taiwan. The main focus of this research was on understanding the role that virtual communities play in providing support for parents. This study addressed the following research questions: How do virtual communities provide support for parents of children with special needs in Taiwan? What motivates Taiwanese parents of children with special needs to search for support through virtual communities? How does the support provided through virtual communities impact the relationship between Taiwanese parents of children with special needs and professionals? This thesis constructs an analytical framework that helps in understanding the concept of support in virtual communities for parents of children with special needs. Employing this framework identified three broad types of support: informational support, advocacy, and emotional support. In this study, informational support included parenting skills, advice, and access to services; advocacy referred to articulating needs and rights; and emotional support included solidarity, increased self-esteem, acceptance, and affirmation.

All three virtual communities were established by parents; two are managed by parents, and one is managed by a professional. Web-based observations were conducted in each virtual community from November 2014 to December 2015. Semi-structured interviews were held with 14 parents, 7 professionals, and 6 administrators and concentrated on experiences of, and motivations for, seeking and providing support through virtual communities. The analytical framework was used to identify broad themes in the data. A thematic analysis was employed to look across the cases to identify commonalities and differences, and finally, a systematic analysis borrowing from social network analysis was used to map the interactions among the participants.

The main findings of this study indicate that information and support related to parenthood and parenting skills was easily accessed through virtual communities. Parents were found to join together to share their experiences of parenting, comfort one another, and advocate for their needs through the virtual communities. The parents occasionally excluded members of the community to ensure that all members shared similar parenting values. In addition, parents are beginning to gain control of knowledge and their relationships with professionals through virtual communities.

This paper's main contributions to knowledge are as follows: (1) Virtual communities allow parents to redefine themselves in ways that they believe are publicly acceptable. (2) Parents are using virtual communities to exercise power to renegotiate their identity and obtain resources. (3) Parents are also starting to alter the power relationships between themselves and professionals.

## Declaration

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## Glossary

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### **Parent support**

All actions, practices, resources, information which the purpose and main goals are to support and provide help to parents are considered as parent support in this research. This includes formal/professional support, such as support service (McConkey & Samadi, 2013, p.775), and informal/non-professional support, such as mutual support (2013, p.775). It also includes the activity which parents seek for support together as a community.

In this study, I used the term parent support instead of parental support since the meaning of the term parental support is closer to support provided by parents and it does not necessarily mean supporting parents in their journey of parenting.

### **Special needs**

Under the influence of the Individuals with Disabilities Education Act (IDEA; US Department of Education, 1990), and the Salamanca Statement (UNESCO, 1994), the Taiwanese government gradually started to replace the term ‘handicapped’ and ‘disabled’ with ‘special needs’ in order to remove the stigma. However, even though the intention of using the term ‘special needs’ is to remove the stigma of being ‘disabled’, the term still refers mainly to the condition of having disabilities and did not include with different variety of needs, such as poverty or other potential challenges (Huen, 2014; Wu, 2014).

Therefore, it is important to note that in this study, ‘children with special needs’ refer mainly to children with disabilities in order to reflect the Taiwanese context where special needs do not include a variety of needs children might have when facing challenges in their life or living environment.

### **Professionals**

The term ‘professionals’ refers to people who have been trained by a particular professional body, such as the Taiwan Association of Social Workers, and who are

qualified and hold an official licence to offer support services. This category includes social workers, teachers in public and private schools, doctors, and family psychologists. The list is potentially endless. I did not include paraprofessionals, such as experienced parents or volunteers, as professionals in this study.

### **Virtual community**

In general, a virtual community is a group of people sharing interests, goals, identity, and purpose, through the Internet. The function and structure of the virtual communities vary widely from community to community due to the virtual environment, the purpose of forming the community, and the background of members who form the community (Blanchard, 2007).

### **Social network Sites**

I define social network sites following boyd and Ellison's (2008) definition, which is the 'web-based services that allow individuals to (1) construct a public or semi-public profile within a bounded system, (2) articulate a list of other users with whom they share a connection, and (3) view and traverse their list of connections and those made by others within the system. The nature and nomenclature of these connections may vary from site to site' (boyd & Ellison, 2008, p.211)

The main social network site used in this study is Facebook, one of the most popular sites globally which focused on the building social relationship between the users.

### **Formal information**

By formal information, I mean published information or information based on research evident or professional suggestions, such as medical information provided by a doctor.

### **Informal information**

Informal information refers to information which is mainly based on experience, informal source, or people who are not professionals, such as parenting experience shared from mother to daughter.

### **Xiào (孝)**

‘Xiào’ is one of the core values of Confucianism. It means the obligation of a person to respect and honour the parents and elders in the family through carrying out particular actions, such as having high academic achievement. In some studies, xiào is also called ‘filial piety’ (King & Bond, 1985).

### **Face**

The Face is a person’s public self-image and identity that have been approved and recognised by the society according to his or her behaviour, virtue, and achievement (Hwang, 2012). It is closely connected to the honour a person brings to the family.

### **Zhēngqǔ (爭取)**

爭(Zhēng) meaning to dispute; to fight; to contend; to strive. 取(qǔ) meaning to take, to hold. Together Zhēngqǔ means that fighting for resources, rights, or even for attention from the stakeholders or decision makers.

## Chapter 1. Introduction

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### 1.1 Parents in the virtual world

‘Can I add you as a friend on Facebook?’ a mother came to me and asked. I was working as a volunteer in a local development centre in the city of Taoyuan in 2011. During that period of time, I was the one-to-one teaching assistant working with her autistic daughter. ‘Yes! Of course!’ I replied, and feeling both flattered and nervous (since a parent had never added me as a Facebook friend—or Friend—during that time), I gave her my account name. Five minutes later, we became lifelong Friends on Facebook.

While working as a volunteer and as a secondary school teacher during 2011-2012, I frequently overheard parents’ conversations about their interactions on Facebook: ‘Did you see that video last night on Facebook?’; ‘I will post this message in the Group to remind everyone’; ‘The story you shared last night was really nice, can I share it with my Friends, too?’ Technology and the internet had become an important part of these parents’ lives. More and more parents around the world have also been raising their children in a digital-first culture, in which the internet and smart technology, such as smartphones, have become an essential part of daily life (Brosch, 2016). The digital world has become a way for these parents to share information, communicate, and tell stories about their children from day to day. For me, reading their narratives about their parenting experiences has led to several truly powerful moments in my life, and I have found myself sitting in front of the computer tearing up, smiling, and feeling stunned by these parents’ love and passion for their children. These are stories that have rarely been told or recognised in Taiwanese society, and if not for Facebook—or even for this mother adding me as her Friend—I would have never come across them.

I also discovered that these parents not only shared these stories individually but also created virtual communities that allowed them to connect with other parents and provide mutual support to each other. During my volunteer work in the development centre, I often overheard parents saying, ‘I will let you know on Facebook!’ or ‘Have you read that story in our Group?’ These virtual communities allow these parents to

continue communicating and sharing information, even when apart from each other. Compared to the traditional model in which information, resources, and even networks are limited by the location and time, virtual communities provide more opportunities for these parents to stay connected and even to feel empowered through their links with one another. When I read the information that they had shared in their virtual communities, I was amazed by its richness.

Due to these experiences, I realised the importance of the role that virtual communities play in supporting parents in their parenting journey. Specifically, they can be powerful in terms of giving these parents a voice to share their stories, specify their needs, and stay connected with each other in the search for more resources and useful information.

## **1.2 Support for parents**

Support for parents of children with special needs has always played a critical role in the wellbeing of children and the family (Carpenter, 2005; McConkey, 2016; Todd, 2007; Wolfendale, 1992). Parents who receive either informal mutual support from other parents or their friends and families, or formal support from specialised services, demonstrate healthier adaptation to their role as parents. In addition, they are more capable of handling parenting stress and challenges as compared to parents who do not receive support (McConkey, 2016).

Traditionally, support for this particular group of parents has been deemed highly reliant on certain organisations, parent support groups, development centres, and local hospitals; in other words, support for these parents has been restricted to physical locations and certain times (Plantin & Daneback, 2009). However, as my past experiences with parents revealed, with the development of the internet studies have suggested that support for these parents is now easier to access and is less restricted to particular times and spaces (Doty & Dworkin, 2014; Nieuwboer, Fukkink, & Hermanns, 2013; Plantin & Daneback, 2009; Scharer, 2005).

For example, parenting knowledge and medical information can be shared and searched for by each parental user through a range of virtual communities for parents



and informational webpages developed by organisations and professionals (Duquette et al., 2012; Scharer, 2005). Expressions of care and encouragement can be communicated, and parents can likewise impart their parenting experiences by interacting via platforms such as social network sites (Nieuwboer, Fukkink, & Hermanns, 2013). A detailed introduction of these virtual communities and the topic of online parent support follows in Chapter 3 (p.43).

Even though virtual communities have played significant roles in providing support for parents, research remains scant on virtual community-based interactions that support parents (Ammari & Schonenebeck, 2015; Madden et al., 2012; Zickuhr & Smith, 2012). Without a clear understanding of the interactions among these parental users and their expectations regarding the support provided within virtual communities, it is difficult for certain professionals, or even parents themselves, to provide or utilise valuable support or to develop better web-based support systems. These factors indicate a need to understand this intervention among parents.

While some research has been carried out on web-based interactions among parents, most such studies have been executed within the Western context, and especially within the American context; few such analyses have been based in East Asia (Nieuwboer, Fukkink & Hermanns, 2013). However, Western culture and East Asian culture may be significantly different from each other, especially in regard to family structures and the value that society places on parenting (Huang & Gove, 2012; Hwang, 2012). For example, due to the influence of Confucianism, in East Asian society, children's academic achievements represent the concept of 'Face', which is similar to the idea of honour in the English context (Hwang, 2012; more detailed information is provided in Chapter 2, p.26). Parents are judged by society according to their children's academic achievements. Therefore, due to their children's relatively low level of academic success, parents of children with special needs face increased pressure from their families and society; some such parents have even been regarded as losing Face because of giving birth to a child with special needs (Chang & McConkey, 2008).

Distinguishing this paper from the dominant research stream on online parent support in the Western context, my research was based in the Taiwanese context. Thus, this

paper helps to provide an East Asian cultural perspective within the current literature on web-based parent support. Moreover, this study also contributes to filling the gap in the East Asian literature as regards knowledge of internet interactions.

Thus, this study was conducted to learn more about parents' experiences with providing and receiving support in virtual communities. It examined how they navigate in search of resources and information and how they tell their stories. This study aimed to give voice to those parents and to explore their motivations in searching for support through virtual communities. In addition, it investigated the influence of virtual communities on the relationship between parents and professionals. Based on these aims, my research questions were:

- How do virtual communities provide support for parents of children with special needs in Taiwan?
- What motivates Taiwanese parents of children with special needs to search for support through virtual communities?
- How does support provided through virtual communities impact the relationship between Taiwanese parents and professionals?

This study's focus on parent support can also be connected to the concept of parent power. Parent power, as defined by Wolfendale (1992), refers to parents having control of resources and information related to their children and using those tools to influence the system and person who provides services for them or their children. Obtaining parent power has been suggested to be closely related to the quality and quantity of support that parents receive (Mittler, 2012; Wolfendale, 1992). The more parents are supported, the more confident and powerful they are when navigating the resources around them to support their family and even influence the people in their environment (Mittler, 2012). Therefore, in this study, parent power was also taken into account when exploring parent support through virtual communities.

I conducted a case study with three virtual communities as embedded cases, using qualitative research methods to investigate the role that virtual communities play in providing support to parents. Web-based observations were conducted in each virtual community from November 2014 to December 2015. Semi-structured interviews were

held with 14 parents, 7 professionals, and 6 administrators and concentrated on experiences of, and motivations for, seeking and providing support through virtual communities. The conceptual framework based on three concepts of support and my research questions was used to identify broad themes in the data. Finally, a thematic analysis was employed to look across the cases to identify commonalities and differences, and a systematic analysis borrowing from social network analysis was used to map the interactions among the participants.

### **1.3 Structure of this thesis**

The thesis is divided into chapters, as follows:

**Chapter 2** presents a brief introduction of the Taiwanese context and background, including the country's population, number of internet users, location, and history. The culture of Face, as distinctively enacted within Taiwanese culture, is also discussed. This chapter also provides an introduction to the Taiwanese healthcare system and support services for parents, and it briefly introduces studies suggesting that Taiwanese parents are using the internet to search for support. This outline of the healthcare system and support services will help readers to understand and more closely relate to the data and findings presented in this study.

**Chapter 3** presents the international and Taiwanese literature in relation to parent support and virtual support communities. The chapter is divided into three parts. The first section presents the literature on how the internet has provided access to the information that parents need and how it may benefit parents and their families. The limitations associated with accessing information through the internet and virtual communities are also discussed. The second part of this chapter describes how the internet can provide emotional support and how it influences parents and their children. Again, the limitations of that online emotional support are outlined. Finally, virtual communities' importance in terms of parents' efforts to advocate for their needs are discussed. The gap in the current literature on virtual communities and parent support is also presented. Chapter 3 provides more information on online parent support in the current literature and in the context of this study.

**Chapter 4** outlines the methodological structure and design, along with the process of carrying out the data collection and analysis. Similar to the offline world, the virtual setting features different landscapes and venues. Therefore, this chapter also introduces the environment of the virtual communities in this study. The data collection methods are likewise distinguished. Ethical issues and the topic of trustworthiness are also discussed in this chapter. Finally, I explain the data analysis process, including the thematic analysis, textual analysis, and social network analysis.

**Chapter 5** focuses on a critical incident reported in the national media—a news story about a father murdering his son with cerebral palsy. This event aroused a great deal of attention in all three virtual communities and thus provided a unique opportunity during the fieldwork to examine and discuss parents' reactions to such an incident. After introducing the reactions of the parents in each virtual community, Chapters 6, 7, and 8 describe how those parents shared different types of support.

**Chapter 6** indicates how parenting knowledge was shared in the three virtual communities. Parenting information includes knowledge about childcare, child development, and approaches to caring for the siblings of children with special needs.

**Chapter 7** presents how medical resource was shared and discussed by the parents. This chapter offers important insight into differences in how formal and informal information was shared.

**Chapter 8** presents the findings regarding how members of the virtual communities, including parents searched for and shared information related to education provision, welfare and leisure in the virtual communities. Findings on interactions for emotional support and advocacy are presented in this chapter.

In **Chapter 9**, I discuss how the parents redefined their identities and gained Face again through virtual communities. I also argue why this redefinition of Face and the negotiation of support are a complex process that may not be a particularly positive experience for parents in the virtual communities. This chapter also addresses how

different types of information were shared in distinct ways via the social network sites. The influence of virtual communities on parent-professional relationships is also discussed. Finally, the chapter presents the paper's contribution to knowledge.

**Chapter 10** concludes the study by summarising the research. It also offers suggestions for future work in this area.

## Chapter 2. Background on the Taiwanese context

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Chapter 2 aims to provide readers with a clear sense of the contextual background of this study, which was based in Taiwan.

In **Section 2.1**, a brief introduction of Taiwan's population, geography, population of internet users, and historical context is given. That information illustrates how the country has evolved into its current economic and political state, which is mainly influenced by China, Japan, and the United States. This background information creates a foundation for understanding the culture of Face, which is presented in a later section of this chapter.

In **Section 2.2**, I introduce the culture of Face, which is deeply connected to the history of Taiwan and was essential for this research. This culture of Face that is enacted within Taiwanese culture is mainly rooted in Confucianism but is also influenced by other cultures. I also present parents' experience of raising children with special needs in Taiwanese society, which is deeply affected by this culture.

In **Section 2.3**, the support services are introduced to give readers insight into how support and resources are provided by the government and the private organisations in Taiwan. Similar to the previous section, parents' experiences in searching for support via the healthcare system and support services are presented.

Finally, in **Section 2.4**, the literature on Taiwanese parents' use of the internet in seeking support is outlined, along with the limitations of current understandings of this practice.

It is important to note that due to Taiwan's expulsion from the United Nations (UN) in 1971, Taiwan is not included in most reports by organisations related to the UN. For example, Taiwan is not covered by the World Health Organisation's World Report on Disability. Therefore, most of the statistics presented in this chapter are from reports and surveys executed by the Taiwanese government and other independent research organisations, such as the Internet World Stats, which presents and analyses international internet statistics.

## 2.1 The Taiwanese context

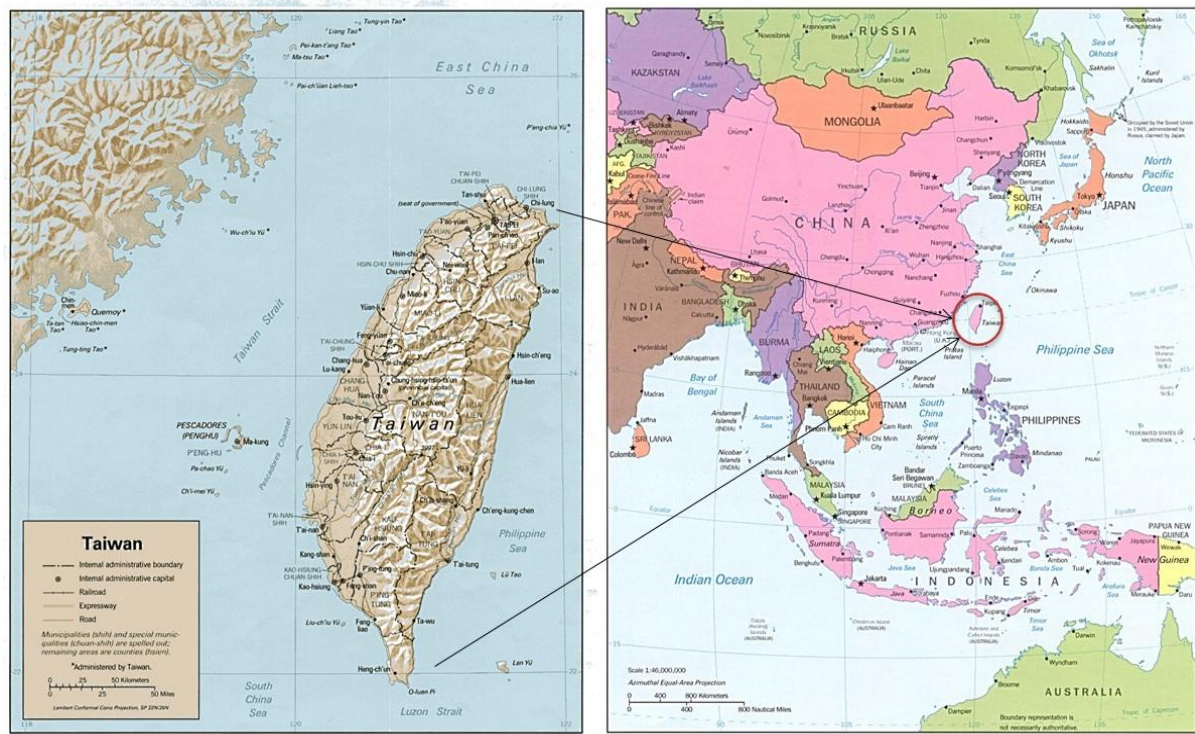
Geographically, Taiwan is an island located east of China, north of the Philippines, and roughly south of Japan and South Korea. It is also situated between two seas, the Taiwan Strait and the Philippine Sea, and one ocean, the Pacific (see Figure 1.). It is approximately 400 km long and 145 km wide, with a total land area of about 36,000 km<sup>2</sup>.

Taiwan is a developed country with a democratic government and a total population of about 23.55 million in 2017. As for family structure, over 45% of Taiwanese families are nuclear families. According to report done by the Ministry of Interior (MOI) Taiwan, over 14% of families are extended families, in which parents and their children live with other relatives, such as grandparents (MOI, 2017c).

In 2017, approximately 4.94% (around 1.6 million people) of Taiwan's population was comprised of people with special needs (MOI, 2017b). Of that group, over 90% lived at home with their families, and 88% depended on their parents, and especially their mother, as their main caregiver (MOI, 2017a).

As for population of internet users, Taiwan had the 20<sup>th</sup> highest percentage of internet users globally in 2017 (Internet World Stats, 2017). According to the Broadband Internet Usage in Taiwan (2016) survey by the Taiwan Network Information Centre (TWNIC), 18.83 million people (over 89% of the total population) are internet users. Moreover, 99% of Taiwanese citizens aged between 12 and 30 years old are using the internet, along with 92% of Taiwanese people between 30 and 50 years old. Over 80% of the entire population had smartphones, and over 87% had internet access at home. More than 85% of the internet users rely on their personal computer and other smart devices, such as smartphones, for social networking services (TWNIC, 2016). This high percentage of internet usage suggests that the internet is also an essential part of daily life for Taiwanese parents of children with special needs. Due to this high level of internet usage, this study's findings are very likely to mirror the situation in digital-first countries, a term used in reference to states with a large population of internet users and substantial smart technologies. The digital-first experience of Taiwan also reflects countries that are moving towards becoming a digital-first nation,

since most regions of the world, especially developing states, have rapidly growing populations of internet users (Castells, 2011).



(Source: <http://www.mapcruzin.com/free-taiwan-maps.htm>)

Figure 1. The geographical location of Taiwan

### 2.1.1 Brief historical context

In this section, I introduce the historical context of Taiwan, since that information is necessary for understanding the complex development of the Taiwanese culture of Face, which is central to this study.

Due to its advantageous location, which facilitated trading with most other East Asian countries, Taiwan was colonised by several nations, and in the 17<sup>th</sup> century, the Dutch and the Spanish used it as one of their business bases in East Asia (Huang, Liu, & Chang, 2004). Most of the population at this period comprised indigenous Taiwanese who were the Austronesian peoples that lived in hunter-gatherer societies. Both the Dutch and Spanish forced these aboriginal tribes to abandon their hunting culture and adopt a farming culture. However, during this period of time, the island's population could not supply all of the demanded agricultural labour, and so the Dutch and



Spanish imported more human labour from China. The entire native population was rapidly overtaken by the Han Chinese, and that group has since become the main population of Taiwan. After the period of Dutch and Spanish colonisation, Taiwan was taken over by the Ming dynasty. During the Ming and Qing dynasties from 1662 to 1895, the Confucian-based culture and educational system were established in Taiwan.

In 1895, Taiwan was ceded to Japan under the Treaty of Shimonoseki due to China's (Qing dynasty) loss to Japan in the First Sino-Japanese War. Japan colonised Taiwan for 50 years from 1895 to 1945. During this period of time, the Japanese colonial system restructured the bureaucratic organisation and built up industrial infrastructure, thereby reorganising Taiwan into a modern state (Huang, Liu, & Chang, 2004). This restructuring and development provided the Republic of China's government, which was run by the Nationalist Party of China or so called the Kuomintang (KMT), with a firm base to quickly develop of economic foundation after KMT retreated from China in 1949 (Huang, Liu, & Chang, 2004). Under the pressure of being expelled from the UN, military threats from China, and a terminated official relationship with the US, the Taiwanese government focused on developing the economy's influence on other East Asian countries (Huang, Liu, & Chang, 2004). This fast economic development produced the Taiwan economic miracle in the 1960s to 1990s and turned Taiwan into a developed country. Today, it is one of the four Asian Tigers, alongside Singapore, South Korea, and Hong Kong (Huang, Liu, & Chang, 2004). In 1987, Taiwan entered a democratic stage by ending the martial law period that had lasted for 38 years. Following the lifting of martial law, different political parties formed, and elections for president and local authorities were held in Taiwan. In 2000, the first president from a different political party from KMT was elected (see Figure 2. for Timeline of the history of Taiwan).

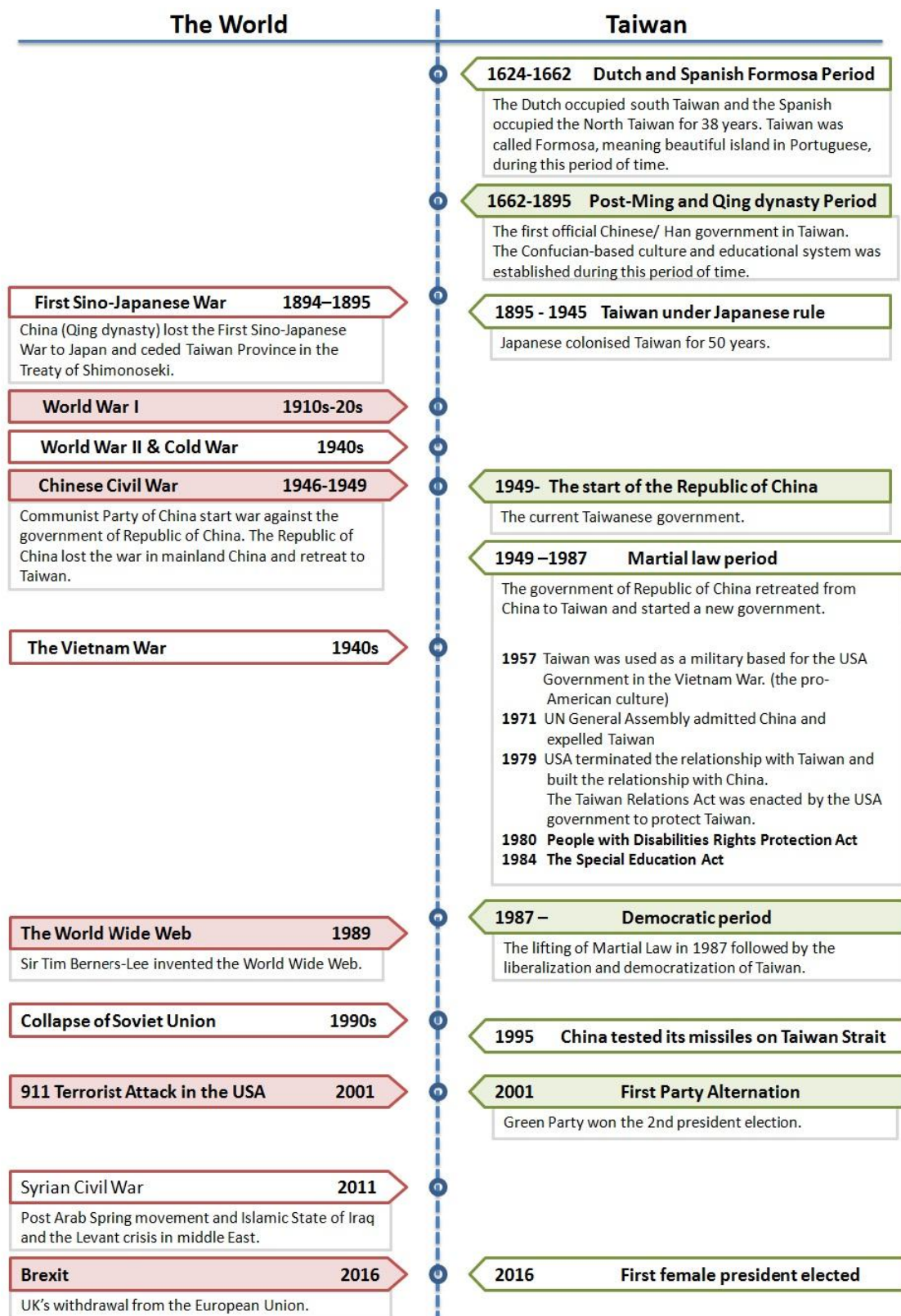


Figure 2 Timeline of the history of Taiwan

## **2.2 The Taiwanese culture of Face**

Due to its complex history of colonisation by multiple countries and the significant influence of Confucian-based cultures, Taiwan developed its unique and complex culture of Face. I argue in this section that Face, which is mainly rooted in Confucianism, has great influence in the daily lives of the majority of the Taiwanese. This culture also reflects the influence of Buddhism and capitalism. Therefore, this section is divided into three sub-sections addressing Confucianism, Buddhism, and capitalism, respectively. The goal is to paint a more complete picture of the culture of Face in Taiwan.

### **2.2.1 The Confucian influence on the concept of Face**

Face refers to a public self-image and identity that have been approved and recognised by society according to the person's behaviour, virtues, and achievements (Hwang, 2012). If a person has Face, he or she is respected and considered as successful by society. On the contrary, if a person loses Face because of a lack of honourable behaviour, virtue, or achievement, he or she loses all respects from others and is considered to be shameful by society (Hwang, 2012). It is important to point out that Confucianism has had a substantial influence on this Taiwanese culture of Face and is considered as one of its roots (Hwang, 2012). It is impossible to discuss Face without mentioning Confucian philosophy and its influence. Describing the entire philosophy of Confucianism would be beyond the scope of this paper, and so I focus only on the virtue of family honour, called 'Xiào' (孝), which is directly linked to the behaviour of Taiwanese parents and the topic of this research.

In Confucianism, the family is the central and most essential unit in society. Taiwanese people regard the family as even more important than the individual. According to Confucianism, all family members have strong and close links with each other (Hwang, 2012). The virtue of 'Xiào' (孝) demands that one's actions benefit his or her family members. 'Xiào' roughly refers to a person's devotion towards his or her parents, grandparents, and ancestors (Chen, 2001; Hwang, 2012). To honour one's family and demonstrate devotion, especially to one's parents, the right perspective of 'self' is a crucial starting point. The self, as suggested by Confucian philosophy, not

only refers to the individual but also to his or her entire family. A person's life is considered an extension of the lives of his or her parents, and an individual's identity and behaviour represent the entire family (Hwang, 2012; King & Bond, 1985). Due to this strong connection, when a person has or loses Face, the entire family is influenced by it. Moreover, all family members, including children, are responsible for having and maintaining Face for the family (Hwang, 2012).

The most common way of having and maintaining Face for the family is through achieving success and an outstanding performance in one's education and career. Furthermore, since the entire family shares the same Face, parents have the primary responsibility for shaping their children into individuals capable of pursuing success in their education and career (Hwang, 2012).

### **2.2.2 The Buddhist influence on the concept of Face**

In addition to the influence of Confucianism, the cycle of samsara and karma from Buddhism also affected the culture of Taiwan (Chen, 2001; Chang, & Hsu, 2007). Karma 'refers to the law that every action has an equal reaction either immediately or at some point in the future' (Flood, 2009). Good and virtuous action will lead to a positive result and reaction, and a bad action results in a negative outcome (Flood, 2009). This chain reaction not only affects the person's present life but also influences his or her afterlife, which is the life given to that individual following reincarnation upon death. This process of reincarnation is called samsara (Flood, 2009). Due to this traditional belief in karma and samsara, most Taiwanese people view disability or severe illness as the result of evil or sins committed in the person's past life (Chen, 2001). Being the parents of a child with disabilities means that the family owed favours to that child in the previous life and is now repaying him or her in this life (Chen, 2001). Therefore, being the parent of a child with special needs is considered to be negative and unfortunate. Given this unfortunate image of carrying past sins within traditional culture, most of these parents experience a loss of Face due to their identity as such (Chang, 2009).

### **2.2.3 The influence of Westernisation and capitalism**

Since Japanese culture has also been influenced by Confucianism, during the period of Japanese colonisation, the original Confucian-based culture that Taiwan had adopted during the Ming and Qing dynasties was kept. However, Westernisation and modernisation, which Japan sought from the 1890s until the end of World War II, also brought a change to the culture of Taiwan (Chang, 2011). Under the influence of Japanese-style Westernisation and modernisation, the notion of capitalism was introduced and started to merge with the Confucian-based culture. For example, society is starting to consider seeking prosperity as personal success and Face (Chang, 2011).

After the government of the Republic of China took over Taiwan and the country's connection with the US grew stronger during the Cold War, the influence of the West—or, more specifically, of the US—became more and more obvious. Capitalism, which was dominating American culture during that period, came to influence all aspects of the Taiwanese citizen's daily life even more obviously than did the previous Westernisation under the rule of Japan. For example, Chang (2011, p.13) has argued that under the influence of capitalism, 'Taiwanese people started to pay great attention to their individual rights and democracy and freely take stances to criticise politics and politicians', and they also 'start[ed] to enjoy the profits and improvement of life brought by capitalism'.

During the Taiwan economic miracle in the 1960s to 1990s, the Taiwanese government's emphasis shifted from strengthening the military to rapidly developing the economy of the country. This effort to strengthen rights and improve life gradually resulted in competition among individuals to achieve economic success (Chang, 2011; Huang, Liu, & Chang, 2004). Since Taiwanese culture is still rooted in Confucianism's family-centred value system, this individual competition regarding economic success became a family competition (Chang, 2011). Chang (2011) has argued that seeking economic success to maintain the family's Face of the family is unique to Taiwanese culture, which is influenced by both capitalism and Confucianism. In the original teaching of Confucianism, wealth and success are regarded as the least important elements of life. Under this Taiwanese culture of Face,

realising wealth and success became part of the duty of the members of a Taiwanese family. In other words, the wealthier that a person is, the more Face he or she brings to the family.

#### **2.2.4 Culture and the experience of being a Taiwanese parent**

Under the pressure of the culture of Face, some parents feel frustrated and anxious regarding the fact that their children might not be able to fulfil the expectations placed on them by the family and society (Gau et al., 2012; Huang et al., 2011). Parents can even feel the need to ‘hide’ their children from a family member:

In the early days it was really hard for me. I had to hide my child’s delayed development. I had to swallow all the tears and sweat. I could not even tell my siblings. I just told them that it is hard to take care of and educate a kid. They might know that it is difficult to raise my kid, but they don’t really know what’s going on. I never told them. I have to face all the problems myself. (Chang, 2009, p.42)

Certain parents are even afraid to share the child’s conditions with their family when they first learn about it (Chang & McConkey, 2008; Hsu et al., 2017). Several studies have even pointed out that family is the main source of stress for some parents, and especially mothers, in the Confucian-based society (Chang & McConkey, 2008; Chang, 2009; Gau et al., 2012; Hsu et al., 2017).

As Lewis-Gargett et al. (2016, p. 69) have argued, in a culture in which ‘disability is thought of as given’ and as the ‘result of behaviour’, whether in one’s past or current life, ‘it leads to negative views’. That is, Taiwanese parents experience a loss of Face due to their given identity and fate of being the parent of child with special needs. Furthermore, as a consequence of losing Face, they experience blame, frustration, and the result of their child being disabled.

I kept apologising to the owner of the gym and explaining my child’s situation. I tried to make him understand that [the son’s behaviour] was not his intention. However, the owner showed a hostile attitude and said my son’s situation had nothing to do with him. (Hsu et al., 2017, P. 153)

Hsu et al. (2017) has suggested that mothers are most likely to be blamed than the father by the family for giving birth to their child with special needs. A lack of acceptance of the child's condition has also been identified among the relatives of the children (Chang & McConkey, 2008).

Moreover, these Taiwanese parents are more likely to accept the hardship, pain, and disappointment alone than to seek help from society, friends, and family (Chang & McConkey, 2008). Such families hide their children from their friends. A mother in Chang and McConkey's (2008) study mentioned:

My husband is a doctor, he probably loves him, but he does not accept the responsibility. He doesn't let his colleagues or friends to know he has a special child. If we go out or have friends come to the house he always sends my daughter to my sister's home. (p.35)

Therefore, it is not a surprise that over 90% of all people with special needs in Taiwan live at home with their families (MOI, 2017b).

In addition to the pressure that parents face in Taiwanese society, inadequate support services, in terms of both quality and number, are still frequently reported for these parents and their families (Hsu et al., 2017; Tseng, 2016). However, before we discuss the issue of access to support services and resources, it makes sense to introduce the healthcare system and support services in Taiwan. Thus, the following sections turn to that topic.

### **2.3 The support services for parents**

The Taiwanese government released the first People with Disabilities Rights Protection Act in 1980 to safeguard the rights of people with disabilities and their families. Chapter 1, Article 1 of the People with Disabilities Rights Protection Act (Ministry of Health and Welfare, 2015) states:

This Act aims to protect the legal rights and interests of people with disabilities, secure their equal opportunity to participate in social, political, economic, and cultural activities fairly while contributing to their independence and development.

The act declares the importance of including people with disabilities in all social events. Following the act, in 1984, the Taiwanese government released a draft of the Act of Special Education, mentioning that the educational system should provide sufficient support services for both the children with special needs and their families, especially parents. It also stated that the educational system should cooperate with parents and involve them in their children's educational process. The government also suggested that good parenting is a key element that influence children's development and education (Legislative Yuan, 2014). In 1995, under the influence of the Individuals with Disabilities Education Act (IDEA; US Department of Education, 1990), and the Salamanca Statement (UNESCO, 1994), the Taiwanese government – Ministry of Education (MOE) – implemented the Five-Year Plan of Development and Improvement of Special Education (MOE, 1995). Parents were recognised as the central players in providing quality education for children with special needs and were invited to participate in the entirety of their children's educational process (MOE, 2014). For example, *The Special Education Act*, Article 28 noted that:

Schools under senior high should develop the individualised education plan for each and every special needs student based on a multidisciplinary team, invite parents for participation and, where it needs, encourage professionals to accompany parents for participation. (MOE, 2014)

Until the present, parents remain the key actors in supporting children with special needs.

The Taiwanese government provides support services for the parents through the local government system. In Taiwan, support services for parents and families are divided into two main systems: healthcare and education. In the following section, I introduce both and describe how parents access these services.

### **2.3.1 Healthcare**

The medical model is gradually being replaced by the social model of disability in the Taiwanese welfare and educational systems (Tsai & Ho, 2010), and the term 'special needs' is slowly supplanting the word 'disability' (Yu et al., 2013). Nonetheless, Taiwanese support services for children with special needs and their families are still



closely linked to the healthcare and medical system. It is therefore important to introduce the healthcare system in Taiwan to understand the support that parents receive in that country.

The healthcare system is mainly managed by the Bureau of National Health under the Executive Yuan, which is the executive branch of the Taiwanese government. In 1995, National Health Insurance, which is mandatory for all citizens, was introduced by the Bureau of National Health in Taiwan. Generally, a premium equal to 4.65% of each individual's monthly salary is collected (Bureau of National Health, 2015). However, persons with special needs who own a disability statement/card only need to pay 75% or 50% of that fee if they have a minor or moderate disability. If the person has a severe disability or illness, he or she does not need to pay the fee at all.

Under the healthcare insurance scheme, every Taiwanese citizen receives an integrated circuit card, which is needed to prove enrolment in the healthcare system and eligibility for benefits when visiting clinics or hospitals. The card carries the medical records of the card holder, and so the doctor or other medical professional can provide medical suggestions or interventions according to the previous medical treatment. Therefore, the card allows the holder to visit any clinic or hospital.

National Health Insurance covers the majority of the costs of medical procedures for persons with special needs, including routine medical check-ups and follow-ups, dental, vision and eye care, hospital care, pharmaceuticals, physical therapy, and traditional Chinese medicine and chiropractic care. The patient only needs to pay from NTD 50 (around GBP 1) to NTD 550 (around GBP 11) when receiving medical treatment (Bureau of National Health, 2015). All parents of children with special needs receive financial support and free consultancy services when their children are under six years old (Ministry of Health and Welfare, MOHW, 2015). Under the supervision of the local government social welfare department, these services are typically provided by local hospitals and development centres. All medical treatments, except for extra assistive devices, for children with special needs are included in National Health Insurance. Moreover, government grants cover over 50% of the tuition fees charged by these development centres for children under six years old

(MOHW, 2015). Hospitals also have the responsibility to provide free consultancy services of planning for the person's discharge from hospital for the persons with special needs and their families. Such offerings include topics such as home-care proposals and rehabilitation proposals.

As for long-term hospital care, the patient must cover 5% of the hospital expenses if staying in a chronic medical care room and 10% of the fees for an intensive care room for the first 30 days. Patients need to paid high fees for hospital care after the initial 30 days, and costs can be as much as 30% of the monthly fee. Moreover, the insurance system does not cover vaccinations or any assistive devices, such as wheelchairs or hearing aids (Bureau of National Health, 2015). Funding for assistive devices and other additional support services that are not included in the healthcare insurance scheme can be requested from the welfare department of the local government in each city or county. Each city or county has a different system for determining how to grant funding and in what amount. Parents or persons with special needs need to be aware of the system and apply for the necessary funding in accordance with their local government's rules.

### **2.3.2 Education**

For children with special needs, 12 years of compulsory education at local schools are required between the ages of 6 and 18, unless there is sufficient proof that a child is too ill or weak to attend school, such as children with severe illness or children who need to stay in the hospital (MOHW, 2015). Children who cannot attend school are provided with bedside teaching until their compulsory education is complete. Tuition fees are free in all government-funded compulsory schools, including public elementary schools and public junior high schools. Bedside teaching has also been free since 2015 (MOHW, 2015). However, all students need to pay extra fees for school maintenance and teaching materials (MOHW, 2015). Private schools are not included in the free tuition policy. Therefore, parents need to pay the full tuition fee if their children attended such institutions. Parents can apply for a discount on tuition fees, but the percentage of the discount and the qualification criteria differ across local governments (MOHW, 2015).

Since in Taiwan, most of the educational support, lesson plans and additional support for children with special needs are based on the individualized education plan (IEP), the Act of Special Education Article 28 (MOE, 2014) specifically emphasis that parents should participate in the IEP meeting. Parents are given the both right and responsibility to participate in these meetings in order to provide best educational support for their children. The schools are also responsible to provide support services to help these parents fully engage in their children's education. However, there is no specific code of practice for such parent support services. Therefore, the ways and frequency of including parents in the process of IEP and the quality of the support services which enables parents to be fully engaged in their children's education may vary greatly among schools.

After finishing the 12-year course of compulsory education, children can decide if they want to continue to senior high school and/or college or university. Even though parents need to pay full tuition fees for their children in these stages of education, similar to private education, they can apply for a discount from the local government. After graduating, the local government also provides occupational counselling and support to help all people with special needs find permanent occupations. Again, the policies governing these occupational support programmes differ across local governments (MOHW, 2015). People of all ages with special needs from a low-income family can also apply for monthly financial support from the local government (MOHW, 2015).

### **2.3.3 Other support services and local organisations**

Other than medical and educational support services for parents, most other types of support services for parents of children with special needs in Taiwan are provided by local private organisations. Local governments are responsible for financially supporting and supervising these organisations to ensure that they provide sufficient support services for the parents and other family members of people with special needs (MOHW, 2015). These organisations provide a wide variety of options for parents, and offerings commonly include different counselling and psychotherapy sessions for parents, home-care services, and respite care. In Taiwan, counselling and psychotherapy for parents of children with special needs have gradually become an

important support service for those individuals. As Cheng (2011) suggests in her report on the needs of parents of children with special needs in Taiwan, family counselling and psychotherapy services are one of most-demanded support services by those parents. It is also essential to note that the Taiwanese government requires all professionals providing support services to parents and their children with special needs to receive official and professional training and certification (MOHW, 2015). This policy is intended to ensure the quality of the services provided to parents.

### **2.3.4 Parents' experiences with support services**

Even though support services are regarded by the Taiwanese government as essential for parents of children with special needs, there are still potential issues. Due to the lack of resources on the part of local governments and the lack of a consistent guidance on how the services should be provided, the quality and quantity of support for parents are inconsistent and may be low and insufficient in some areas (Chiu, 2013; Hsu et al., 2017; Wu, 2014). According to Hsu et al. (2017), most Taiwanese parents of children with special needs have to wait for more than an average of six months to enrol in a programme or receive support services for themselves or their children. Other parents find themselves unable to meet the application criteria for these support services. For example, parents might hope to apply for day-care or respite care services only to be told that their children need to have more severe conditions (Chiu, 2013; Hong & Wu, 2015; Hwang et al., 2015).

Since only less than 5% of local funding goes to these organisations, most such services are not free for parents. That is, for their main source of income, these organisations still rely on the fees paid by parents or on donations (Chang, 2010; Chang & Yan, 2011). Chang and Yan (2011) pointed out that due to the limited government financial support, the support services provided by these private organisations are forced to be marketised. Under the logic of marketisation, the private organisations compete with each other to attract more potential customers to receive their services (Chang & Yan, 2011). This influence of marketisation may be potentially beneficial for the parents since parents are provided with more choices and even better quality of services. However, Chang (2010) argues that under this logic of marketization, persons with special needs and their family also become the customers

which carry the fanatical burden in order to receive quality support services. And Chang (2010) also pointed out that some organisations even withdraw their support services from places which the government fundings were insufficient or places with low market potential. As a result, in most of the rural areas of Taiwan, support services for persons with special needs and their parents are often left insufficient (Chang, 2010).

In order to receive sufficient support, parents face tremendous financial pressure since most of the support services are not free (Chang & Yan, 2011). In Cheng's (2011) study, parents with lower income levels tended to be less likely to receive sufficient support services. Some of the fees were prohibitively high and thus discouraged the parents from applying (Cheng, 2011). This situation then results in a negative cycle of not being able to receive support services and in the needs of parents and children remaining unknown to professionals and the support system (Chang, 2009).

This situation in which parents with lower income levels tend to have fewer resources is similar to the challenges faced by parents of children with special needs around the world, as suggested by McConkey (2016). These parents often experience poverty due to social exclusion, limited or absent societal support, and vast sums spent on medical services and other expenses for their children. Poverty is one of the most critical challenges faced by the parents around the world (McConkey, 2016). Therefore, it is not surprising that Taiwanese parents may have also experienced similar struggles when raising their children.

Even when receiving support services, parents often feel that they are not being included, involved, or consulted with respect by the professionals (Chang & McConkey, 2008; Wu, 2014). Parents have also mentioned the struggle of needing to constantly fight for more support and attention from the support system and to negotiate for better help and resources from professionals (Hsu et al., 2017). These negative experiences with services, poor relationship with professionals, and the fear of losing Face also hinder parents from searching for information for their families (Chang, 2009). Some parents have even shared the experience of being 'looked down (on)' (McConkey et al., 2008, p.71) by professional when accessing services due to their identity as parents of children with special needs (McConkey et al., 2008).

Although some researchers have stated that mutual or informal support may provide an alternative means of parent support when access to formal support services is not possible (Chang, 2009; McConkey & Samadi, 2013), problems regarding insufficient support for parents still remain unresolved. Feng (2011) has pointed out that overreliance on informal support may delay the development of formal support services. Feng (2011) has stated that most local governments in Taiwan are overly dependent on informal support and have thus neglected the provision of formal and professional support and resources. Besides the potential issue of overly dependent on informal support, seeking for informal support may somehow be challenging for some of the parents. Due to the traditional culture of Face in Taiwan, Taiwanese parents, especially mothers, are more likely avoid seeking support from their family and friends (Hsu et al., 2017). As mentioned before in Section 2.2.4, most of the Taiwanese parents hope to avoid the situations which they may lose Face. Therefore, encouraging parents to look for informal support may not solve the issue of lacking support for Taiwanese parents.

## **2.4 Using the internet for support**

With limited resources provided in traditional settings and under the pressure of losing Face, Taiwanese parents have been found to turn to the internet to search for help and support (Tsai, Tsai & Shyu, 2008). Several studies have mentioned that Taiwanese parents have begun using the internet to seek out information, resources, and emotional support (Hsieh & Van Puymbroeck, 2013; Juan, Wu, & Yang, 2014; Lin, Tsai, & Chang, 2008; Tsai, Tsai & Shyu, 2008). For example, in Tsai, Tsai, and Shyu's (2008, p. 1802) study on Taiwanese parents of children with autism, parents used the internet to search for 'possible treatment methods or training programmes to improve their child's behaviours and autism symptoms'. Taiwanese parents were also found to use virtual communities to collect information and seek mutual support from each other (Hsieh & Van Puymbroeck, 2013). Private organisations have also started to set up Web pages and virtual communities in order to reach out to parents who may need help or support services (Qiu & Zhuang, 2013).

These studies have mentioned that the internet could potentially provide support for parents and mitigate the lack of sufficient resources and information (Lin, Tsai, & Chang, 2008; Tsai, Tsai & Shyu, 2008), and mutual support (Hsieh & Van Puymbroeck, 2013) that these Taiwanese parents face in their local communities when raising their children. However, only few works have focused on how information, emotional support, and resources were actually identified and shared by parents using the internet, nor have many studies considered how these parents interacted with each other to offer support. Most of these studies only mentioned the internet as part of a more general discussion of potential solutions for the challenges parents may face when raising their children. Therefore, even though there may be a growing body of research indicating that the internet may be beneficial for Taiwanese parents in rearing their children, there may still be a limited understanding of how that information was identified and provided through that medium. Therefore, it is essential for more research to be conducted to better understand parents' experiences of using the internet as a tool for support and to examine their interactions in the virtual setting in terms of their search for support.

## **2.5 Summary**

In this chapter, I have introduced the Taiwanese contextual background of this research. By briefly describing the history and geography of Taiwan, I have indicated how Taiwan developed its complex culture of Face as various ruling governments brought multiple cultures to Taiwan. This chapter also discussed the culture of Face and its influence on every aspect of life for the Taiwanese. I then outlined how parents of children with special needs face substantial challenges and pressure within this culture of Face.

After introducing the concept of Face, to shed light on the experience of being a Taiwanese parent, I presented Taiwan's support system for parents and their children, including the healthcare, education system and the support services provided by the Taiwanese government and the private organisations. I discussed parents' struggles due to the insufficient resources delivered by the government and described how those challenges have prompted some parents to turn to the internet in search of support. The chapter then briefly noted that current studies have suggested that Taiwanese

parents are using the internet for support and resources, and it went on to point out the significant lack of studies on how these parents seek help and support through that medium. That gap indicates the need for research on how support is provided through the internet.

With this contextual background in mind, the next chapter outlines current understandings of online support for parents of children with special needs. It also introduces the concept of support in more detail.



## Chapter 3. Literature review

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This chapter reviews the international literature in relation to parent support and virtual communities. There are five main sections of this chapter: **Section 3.1** introduces the influence of virtual communities and social network sites on parent support and outlines the increasing importance of online parent support for parents of children with special needs. The categorisation of the three types of parent support—namely, informational support, emotional support, and advocacy—is also presented. **Section 3.2** describes how information is shared among, and accessed by, parents in virtual communities. The limitations of searching for information through virtual communities are also discussed in this section. **Section 3.3** presents the current literature on online emotional support for parents of children with special needs, along with how it can be helpful and beneficial for those individuals in their parenting journeys. Similar to Section 3.2, the limitations of online emotional support are also pointed out at the end of the part. **Section 3.4** illustrates the power of using virtual communities to advocate for the needs of parents. It demonstrates how the platforms in virtual communities are giving parents more opportunities to advocate for their rights and needs. Again, at the end of this section, the limitations of using virtual communities for advocacy are discussed. Finally, in **Section 3.5**, the gaps in the current literature on online parent support are considered.

It is important to note that even though this chapter aims to provide an international discussion of online parent support, the majority of the literature is, however, limited to the North American and Western European context. This factor is due to the current literature on online parent support being dominated by studies conducted in those settings (Doty & Dworkin, 2014; Nieuwboer, Fukkink, & Hermanns, 2013; Plantin & Daneback, 2009). This indicates a current gap in the literature, namely, the needs for more research based in the global South and East. Even though the literature is dominated by the research based in the US, this review still provides readers with a useful outline of how online parent support is portrayed and understood in current

studies. Moreover, this review helps to define the concept of support used in this study.

### *Terminology*

- Parent support

In this study, the term ‘parent support’ refers to both formal and informal support for parents. Formal support consists of support services provided by professionals within local governments in Taiwan, and informal support comprises mutual support offered by other parents, friends, or family members who are non-professionals. The reason I included both formal and informal support is that both types play a critical role in the wellbeing of parents and their families and improve quality of life for all family members (McConkey & Samadi, 2013; Wolfendale, 1992).

- Professionals

As for the term ‘professionals’, this refers to people who have been trained by a particular professional body, such as the Taiwan Association of Social Workers, and who are qualified and hold an official licence to offer support services. This category includes social workers, teachers in public and private schools, doctors, and family psychologists. The list is potentially endless. I did not include paraprofessionals, such as experienced parents or volunteers, as professionals in this study.

- Parental knowledge and parental information

The concept of information is closely related to ‘knowledge’. Both terms frequently appear together in many studies of parent support and are often used interchangeably in reference to the same or similar definitions. However, certain studies on parent support have suggested that information is a different concept than knowledge.

Dichtelmiller et al. (1992, p.212) have posited that parental knowledge is an ‘aspect of adult social cognition that comprises his or her understanding of the child development process, caregiving and childrearing skills, and developmental norms’. The term has also been defined as a process of seeking and understanding different information that relates to a child’s behaviours to perform critical actions to enable that child to achieve the best life possible (Dishion & McMahon, 1998). However,

unlike knowledge, information may only refer to facts and experiences (Baldick, 2008; Dichtelmiller et al., 1992).

The act of understating information is identified to be more important than simply receiving the information. Turning information into personal parental knowledge suggested to be important for good parenting outcomes (Dichtelmiller et al., 1992; Zand et al., 2014). Zand et al. (2014) examined the influence of parental knowledge on children with special healthcare needs and found that parents who were 'knowledgeable' responded better to the needs of their children, while the other parents tended to have the incorrect expectations or low expectations regarding their children's development (Zand et al., 2014).

As mentioned previously, the term 'information' is often used interchangeably with 'knowledge'. For example, in Plantin and Daneback's (2009) research on the relationship between the development of parenthood and the internet, the term parental knowledge was not mentioned. Instead, more specific types of learned information, such as healthcare and parenting experience, were cited as keys for parents to develop their parenting skill (Plantin & Daneback, 2009). In this study, both terms were used interchangeably to refer to facts and experience shared in a virtual community, along with information and experience that parents obtained to provide better care for their children.

### *Literature search process*

I conducted my literature search by finding similar and related terms within three databases, namely, Education Resources Information Centre (ERIC), Scopus, and Google Scholar. This search strategy is similar to Marchionini's (1995) 'building block' approach (Marchionini, 1995). I used the terms 'support' and 'social support' as the first block; the terms 'parents of children with special needs', 'parent', 'father', and 'mother' constituted the second block; and finally, 'virtual community(ies)', 'social network(ing) sites', and 'the internet' formed the third block in the search.

In addition to the systematic search based on Marchionini's (1995) building block approach, I also used the citation searching method (Wright, Golder, & Rodriguez-

Lopez, 2014) throughout the literature review process. I reviewed the list of references given by each paper using the three databases, including ERIC, Scopus, and Google Scholar, to check for references related to the theme of online parent support using the three above-mentioned search blocks.

I repeated this search process until the lists of reference exhibited similar, or even the same, lists of literature or irrelevant works. Most of the literature stopped being relevant or started providing the same references after the third citation search. Using citation searching helped me to 'identify papers already retrieved by the searches but missed at the screening process due to an absence of immediate relevance indicated in the bibliographic records' (Wright, Golder, & Rodriguez-Lopez, 2014, p.73).

As regards the criteria for inclusion, the articles had to focus on parents of children with special needs using virtual communities and social networking-related internet platforms as a tool for support, such as to seek support regarding parenting issues, health information pertaining to babies/children, or pregnancy. Articles were excluded if they only contained an abstract, were editorials, or did not focus on the previously mentioned definition of internet usage for parent support. In addition to including articles published in peer-reviewed journals, the relevant grey literature, specifically government documentation and internet statistics, was also searched using Google.

### **3.1 Virtual communities and parent support**

A virtual community is, as Porter (2004) roughly defines it:

an aggregation of individuals, who interact around a shared interest, where the interaction is at least partially supported and/or mediated by technology and guided by some protocols or norms. (Porter, 2004, p. 3).

Due to the fast development of internet accessibility and technology around the world, the impact of virtual communities has also increased and affects different areas of life, such as the social sphere, the economy, and education (Chiu, Hsu, & Wang, 2006). The past decade has also seen a growing body of research on virtual communities (Adedoyin, 2016). Despite becoming more and more influential and the focus of a

growing research stream, the concept of a virtual community is not new. This idea became popular in the late 1990s and has frequently been mentioned since that time, as the business world became more interested in using online groups and communities as a potential marketing tool (Blanchard, 2008). Virtual communities are frequently compared with physical communities, since they share many similarities; however, virtual communities are actually very different (Blanchard, 2008; Wellman, 2002). Wellman (2002) has argued that in a virtual community:

people remain connected, but as individuals rather than being rooted in the home bases of the work unit and household. Individuals switch rapidly between their social networks. Each person separately operates his networks to obtain information, collaboration, orders, support, sociability, and a sense of belonging (Wellman, 2002, p16).

A virtual community's lack of physical and geographical limitations allows individuals to have more control over their connections with others and even to create multiple networks and swap connections from network to network much more easily than in the traditional social setting (Adedoyin, 2016). This unique aspect of the virtual environment allows individuals to collect information, support, and other resources efficiently and rapidly, with fewer limitations and more flexibility regarding networking approaches than would be possible in offline communities (Wellman, 2002).

As more studies have considered the virtual community as the main subject of, or platform for, research, the concept has become more complicated. Some studies have emphasised the relationships among the members of the group (Etzioni, 2004), while others have placed their attention on the community's value and motivation and on the final result of the interactions among members (Ridings, Gefen, & Arinze, 2006). Blanchard (2008) has argued that these different definitions of the virtual community may stem from the complex concept of community itself. As suggests by Kendall (2011):

Even prior to research on Internet communities, the concept of 'community' posed a problem for scholars. [...] Community evokes empathy, affection, support, interdependence, consensus, shared values, and proximity. [...] This contradiction has had several effects on the study of communities, especially the study of online

communities and other communities that intersect the Internet.  
(Kendall, 2011, p.309).

Therefore, definitions of the virtual community may change depending on not only the theoretical background in question but also the structures of the social network, the members of the community, and the virtual environment of the community (Kendall, 2011). Within all virtual environments, social network sites are one of the most popular and powerful platforms for establishing virtual communities (Chiu, Hsu, & Wang, 2006).

In the 2000s, social network sites gradually became one of the most popular environments for virtual communities around the world (boyd & Ellison, 2007). Different virtual communities, including those for parents, were formed on multiple such sites. A social network site provides efficient functions and user-friendly platforms for its users to communicate, build relationship, and exchange information (boyd & Ellison, 2007; Nieuwboer, Fukkink, & Hermanns, 2013)

‘Social network’ is an umbrella term for a person’s interactions or practices that connect people with whom he or she shares, or potentially shares, a social relationship (Huberman, Romero and Wu, 2008). However, in the context of the web, the term refers to a more specific social relationship between internet users who connect with each other through an online platform (Huberman, Romero and Wu, 2008). A social network could be a newly explored web-based social circle consisting of strangers or an old, web-based social circle based on the real-life social ties of a person (boyd & Ellison, 2007). Websites that provide these social connection functions are thus called social network sites. Therefore, in accordance with the purpose of social network sites, virtual communities on those platforms naturally focus on building relationships, social networking, and creating quick connections from user to user.

Over the past decade, an increasing number of studies have indicated that through joining communities on social network sites, different groups of people who have few resources and a limited voice in society are able to advocate for their rights, make changes, and influence society (Mitra, 2005; Zickuhr & Smith, 2012). Mitra states that these virtual communities and platforms allow:

[these groups of people] to find a new voice with which to produce the new discursive places where the silenced identity narratives can be articulated again (Mitra, 2005, p.377).

One of the most famous examples is the Arab Spring social movement, which happened in the Middle East (Salamey, 2015). Different social network sites, such as YouTube and Twitter, were the key players that enabled citizens from multiple countries in the Middle East to state and realise their revolutionary agenda (Salamey, 2015). The citizens shared instant news and information, advocated, reported and gave updates on the protest situation, and created a network through these social network sites (Salamey, 2015).

Parents of children with special needs are also among those who have been influenced by virtual communities on social network sites (Nieuwboer, Fukkink, & Hermanns, 2013; Scharer, 2005). In their systematic review of 75 empirical international studies on online peer and professional support for parents, Nieuwboer, Fukkink, and Hermanns (2013) suggests that 41% of the studies specified that the research focus was on providing healthcare information to parents of children with special needs. Moreover, of these support services, 31.5% were based in group forums, which are an important platform of virtual communities. In addition, 61.3% of the services provided information pages, which are also another vital virtual space within a virtual community (Nieuwboer, Fukkink, and Hermanns, 2013). Several studies have also suggested positive impacts of virtual support communities on specific parent groups, such as parents of children with very low birth weight infants (Gabbert et al., 2013) and parents of children with rare illnesses (Gundersen, 2011). Parents use virtual communities to search for useful parenting information and develop social connections with other users for emotional support (Brosch, 2016; Scharer, 2005).

Across all studies on the benefits of online parent support, having sufficient access to information and providing timely emotional support that is not limited by space and time are two frequently mentioned benefits of using the internet or joining virtual communities for such purpose (Doty & Dworkin, 2014; Nieuwboer, Fukkink & Hermanns, 2013; Plantin & Daneback, 2009; Scharer, 2005). These two categories,

information and emotional support, have even been suggested as the main reasons that parents access the internet in the first place (Plantin & Daneback, 2009).

Moreover, in terms of the theoretical aspects of parent support, informational support and emotional support are frequently named as the main types of support for parents in both the virtual and offline environment. For example, Evans, Donelle, and Hume-Loveland (2012) included both informational support and emotional support in their typology of support as part of their research on virtual support communities for mothers experiencing postpartum depression. Evans, Donelle, and Hume-Loveland (2012, p.73) defined information support as actions that ‘involve advice giving, information sharing’, and emotional support as ‘consist[ing] of concern, affection, comforting, and encouragement resulting in sense of belonging and self-worth’ (p.73). That typology of support was used to understand and categorise mothers’ supportive interactions within virtual communities (Evans, Donelle, & Hume-Loveland, 2012).

In Beresford’s (1994) study on how parents cope with caring for children with special needs, both emotional support and informational support were also considered the foundation of the coping strategies within their model of stress and coping. Oakley (1992) also included the two types of support in order to characterise different types of support in her research on motherhood and social support. Ammari and Schonenebeck’s (2015) research on American parents who search for empowerment through Facebook also treated these two aspects as key types of support.

In addition to these two types of support, studies have included several other categories of support. For example, instrumental support ‘reflects tangible assistance such as practical help with daily living’ (Evans, Donelle, & Hume-Loveland, 2012, p.73), and financial support was mentioned in a study by Beresford (1994). However, since most of these types of support require physical contact or actions, they are less likely to be practiced or examined in a virtual environment. Even though some researchers have argued that these types of support may still be applicable in virtual settings if provided in the form of suggestions and information, such as childcare recommendations (Evans, Donelle, & Hume-Loveland, 2012), they are still somewhat limited and less beneficial to parents. As Barling, MacEwen, and Pratt (1988) argued in their review of typologies of social support, categorising suggestions and opinions



as a type of support may be confusing, since such elements significantly overlap with and may fall into the category of informational support. Therefore, to avoid confusion and to explore the most effective elements of interactions of support, these other types of support are not further discussed in this paper.

However, when reviewing the literature on online support for parents, the concept of advocacy stood out from all forms of support other than information and emotional support. Advocacy is:

largely about drawing attention to an issue that is important, directing decision makers to a solution, influencing decision makers at various levels and mobilising members of the community for a cause (Malinga & Gumbo, 2016, p.54)

Advocacy is considered an important function of virtual communities among parental users and one of their main benefits (Ammari & Schonenebeck, 2015; Duquette et al., 2012; Gundersen, 2011). Studies have found that parents, who are considered by others as powerless in society, are more likely to advocate for their needs in the virtual setting than in natural, face-to-face settings, due to the former environment's advantage of providing parents with anonymity, which allows them to avoid judgement (Ammari & Schonenebeck, 2015; Duquette et al., 2012; Gundersen, 2011). In her study on Norwegian parents of children with rare genetic disorders, Gundersen (2011) also stated that these parents turn to the internet to search for opportunities to advocate for the needs of their children, because traditional settings do not give them enough occasions and resources to do so. The virtual platform has even been considered as an important medium that permits professionals to gather information and advocate for parents and their children (Ferguson, Hanreddy, & Ferguson, 2013).

Therefore, using three essential concepts of support—namely, information, emotional support, and advocacy—this study set out to learn more about the how support is provided in virtual communities and why parents are motivated to seek these types of support in that setting. In the following sections, the three types of parent support are discussed, along with how parents in the virtual environment represent and approach such support. However, the concept of support is highly complex, making it difficult to distinguish supportive actions as belonging to a certain category of support.

Moreover, it is possible that ‘when individuals receive one type of support they perceive that they are receiving other types as well’ (Barling, MacEwen, & Pratt, 1988, p.141). Thus, it is also important to note that these categories may overlap, and an absolute definition of each type of support is not feasible. For example, information about child development is essential for parenting, but it may also provide parents with a sense of affirmation when they learn that their children are having healthy development.

### 3.2 Accessing information in virtual communities

Parents of disabled children face the difficulty of balancing the normal tasks of parenting with treatment programmes, additional physical duties, and the need to adjust emotionally to their child's difference from the parents' expectation.

Information is acknowledged as a vital component in understanding the practical implications of the disability and in facilitating adjustment to it. (Pain, 1999, p.299)

Parents need adequate access to relevant and accurate information to both care for their children and maintain their physical and mental wellbeing (Herman et al., 2005; Plantin & Daneback, 2009). Wolfendale (2013) has suggested that parents' need for information has been a frequently recurring theme within reports on special education, such as the Warnock Report (Warnock, 1978). Moreover, the authors state that 'parents want and need easy availability of information about service provision and straightforward access to it' (Wolfendale, 2013, p.51).

The importance of satisfactory access to sufficient information has also been frequently recognised by researchers and policy-makers in a range of countries (McConkey, 2003). Different policies state the importance of providing adequate information to parents and of taking actions to ensure that information is fully delivered. For example, the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (United Nation, UN, 1994) state that:

States should ensure that responsible authorities distribute up-to-date information on available programmes and services to people with disabilities, their families, professionals in the field, and the general public. (UN, 1994, Rule 13)

Accessing information through the internet has been reported to be widely beneficial for parents (Doty & Dworkin, 2014; Plantin & Daneback, 2009). For example, the absence of restrictions regarding time and space is a substantial advantage of searching for information via the internet (Plantin & Daneback, 2009). Griffiths et al.'s (2006) systematic review of online health interventions found that prompt communication, which the nature of online support community's makes possible, is

one of the most important traits of online support. The flexibility of location also helps parents who have children with rare disease to access information and resources that are not available at the local healthcare centre (Gundersen, 2011). Moreover, parents whose intensive childcare duties restrict their ability to leave home may also be able to receive sufficient support through virtual communities (Plantin & Daneback, 2009). Studies by both Herman et al. (2005) and Hudson et al. (2008) have also suggested that parents in the US with lower incomes, lower education levels, or a lower social status are more likely to search for parenting information through virtual communities. Searching for support in the traditional setting may be difficult for these individuals, as their identities may lead to judgements (Herman et al., 2005).

According to research on parent support in traditional settings, indirect access to information is one of the main reasons parents do not receive sufficient support (Chadwick et al., 2013). Chadwick et al. (2013) found that some parents gave up searching for information due to the complicated process of accessing it. Simply knowing where to begin the search for information was ‘already an initial hurdle for families’ (Petriwskyj, Franz, & Adkins, 2016, p.1087). Chadwick et al. (2013) also pointed out that some parents only received sufficient information for support when the family had reached the ‘breaking point’ (Chadwick et al., 2013, p.125). As McConkey (2003) explains, the majority of parents prefer direct access to information from familiar professionals, such as social workers with whom they have already built a relationship. Parents need trusted relationships with professionals and a relatively lengthy period of time of receiving services to obtain enough information (McConkey, 2003; Todd, 2003). Furthermore, parents hope to receive person-centred service that ‘gave their family member choice and control over their lives but that also balanced their rights and responsibilities appropriately’ (Chadwick et al., 2013, p.124).

The information provided in virtual communities is, as several researchers have suggested, more straightforward than that offered by traditional support services (Duquette et al., 2012; Scharer, 2005). For example, Duquette et al. (2012) have noted that some Canadian parents of children with foetal alcohol spectrum disorder found it hard—or even failed—to access information about medical and educational support for their children due to the complicated procedure required or the discrimination they faced. However, through searching and sharing information via virtual communities,

these parents, even those individuals who were new parents, shortened the time needed to search for information for their children and also ‘stay[ed] on top of what others were doing with their children’ (Duquette et al., 2012, p. 1212).

Studies have also suggested that some support services provided through virtual communities, such as online counselling sessions, is more cost-effective than from traditional settings, since the former approach reduces travelling expenses and time (Finfgeld, 2000; Hudson et al., 2008; Scharer, 2005). As Hudson et al. (2008) have argued, information and resources are more readily accessible and quickly updated in a virtual community than via the traditional process. Wong et al.’s (2015) Hong Kong-based study suggested that more and more parents are searching for additional information before and after they receive advice from healthcare professionals. Parents mentioned that the supplemental information improved their ability to judge suggestions from medical professionals and to efficiently negotiate for desired medical resources (Wong et al., 2015). Those parents also implied that their dependency on searching for information online was due to the fact that the materials were free and easily accessible (Wong et al., 2015). Wong et al. (2015) even suggest that this free internet resource had influenced and improved the parenting situations of lower-income individuals (Wong et al., 2015). As Pinkett and O’Bryant (2003) stated:

By providing access to large amounts of information, the Web is described as providing a ‘psychologically empowering role in assisting with the efficient and effective means by which information can be accessed’ (Pinkett & O’Bryant, cited in Siddiquee, & Kagan, 2006, p.5)

The process of accessing sufficient information via the internet is empowering for parents. Tsai, Tsai, and Shyu (2008) have also suggested that adequate information allowed parents to provide better childcare for their children and that seeing their children as healthy empowered parents to feel confident about their parenting identities. This empowerment that parents experience in their virtual communities is similar to what parents experience in parental support groups in traditional settings (Ammari & Schonenebeck, 2015; Scharer, 2005). As Wolfendale (1992) has noted, parents become powerful through obtaining adequate information and a working understanding of the system of support services, children’s healthcare, and education.

Through possessing this information, parents become more confident in their ability to influence the system (Wolfendale, 1992).

### **3.2.1 Searching for information together**

In addition to searching for information and resources on the internet as individuals, parents join virtual communities to realise even more efficient access to information. Ammari and Schonenebeck's (2015) study of 43 American parents using Facebook argued that parents constantly collaborate with other parents whose children have similar needs and conditions. Through virtual communities, parents of children with special needs build an efficient and powerful networking system that enables them to map out information, both formal and informal, from different sources and to easily navigate a range of services for their children (Ammari & Schonenebeck, 2015).

Ammari and Schonenebeck (2015) stated that:

Social media sites help parents to find other parents, overcome power imbalances between parents and service providers, and mobilise resources to support the special needs cause. Unlike with offline groups, parents are now able to do this through almost real-time access to other parents on Facebook. (Ammari & Schonenebeck, 2015, p.8)

Some parents join virtual communities to exchange update-to-date medical information and valuable experiences with other parents with similar parenting experiences (Gabbert et al., 2013; Janvier, Farlow & Wilfond, 2012). Gundersen (2011) also found that through the internet and virtual communities, a group of Norwegian parents formed platforms to discuss and collect more information about specific rare genetic disorder symptoms. These parents of children with the rare genetic disorder also efficiently access information about their children's condition through these virtual communities and gain knowledge (Gundersen, 2011). Some parents even became more knowledgeable about their child's condition than any professional in their region of Norway (Gundersen, 2011).

Moreover, anonymity also encourages discussions of sensitive issues among parents. Due to the anonymity of virtual communities, sensitive topics are more likely to be raised and discussed (Finfgeld, 2000). These sensitive issues are then also more likely

to be addressed by the professionals who are monitoring or managing the virtual communities. Timely support by the professionals through either the internet or services in natural settings are then more likely to be delivered to the person in need due to this reason (Finfgeld, 2000). Moreover, when using the internet, parents are also more likely to ask questions that they might consider as too ‘embarrassing or unimportant’ (Madge & O’Connor, 2006, p.209) to raise in the traditional setting. Through asking these questions, parents therefore gain information that they would be less likely to receive in the traditional setting (Madge & O’Connor, 2006). Moreover, parents who face societal discrimination, such as young, low-income African Americans (Hudson et al., 2008), feel more confident when searching for information or asking questions about parenting, since the anonymity on social network sites helps to remove the fear of such prejudices (Hudson et al., 2008).

### **3.2.2 Online professional support services**

Several studies have also suggested that by utilising the internet, and especially virtual communities and social network platforms, professionals can provide more efficient support and timely information for parents. The flexibility of time and location also allows professionals to efficiently reach out to more parents without the need to consider travel expenses or time limits (Nieuwboer, Fukkink, & Hermanns, 2013). For example, Meadan and Daczewitz (2015) suggest in their study on early intervention services that training and coaching parents from a distance through internet technologies helps the professionals to overcome the challenges of limited time and long distance in providing home-based early intervention for parents and their children with special needs.

Moreover, virtual communities also permit professionals to receive the latest updates regarding their fields; this possibility thereby helps professionals to keep their support services up to date and efficient (Nieuwboer, Fukkink, & Hermanns, 2013). Ferguson, Hanreddy, and Ferguson (2013) have also suggested that through online web logs, including parents’ posts on social network pages, professionals gain opportunities to learn about their experience of parenting a child with special needs. These narratives written by parents have led to parents’ voices being incorporated in the support

services process and have helped professionals to better understand those individuals (Ferguson, Hanreddy, & Ferguson, 2013).

However, even though there are several studies which suggested the use of virtual community is beneficial for professionals in developing professional skills and providing their services, there is still limited literature and research which focus on virtual professional services and development (Davis, 2015; Owen and Dunmill, 2014). Davis (2015) states that even though more and more professionals, such as teachers, have been using the internet, information and communications technologies (ICT) and social network sites to support students with special needs, there is still limited training and understanding of how these tools were and can be used. Owen and Dunmill (2014) also stated their concern-about how further training and development of these internet skills are lacking among the professional. Thus, more research on virtual professional service and development needs to be carried out in the future.

### **3.2.3 The limitations of searching for information through the internet**

Even though information is easily accessible through the internet and virtual communities, there are still several limitations associated with accessing information through virtual communities. Nieuwboer, Fukkink, and Hermanns (2013) have argued that due to the influence of their socioeconomic background, gender, age, and education, certain groups of parents are less likely to be able to use the internet and social network sites. Most studies have also found that older parents are less likely to use the internet as a supportive resource and instead mainly depend on face-to-face support services (Doty & Dworkin, 2014; McConkey, 2003; Zickuhr and Smith, 2012). Certain groups of parents' lack of knowledge and skills regarding using the internet and digital technology may constitute a critical barrier when providing online parental support (Nieuwboer, Fukkink, & Hermanns, 2013; Plantin & Daneback, 2009).

In addition to the ability to use the internet and digital devices, such as a smart phone or computer, owning the devices is another limitation of online parent support



(Plantin & Daneback, 2009). Computers or other internet-enabled digital devices may not be available to certain parents, especially those who have low incomes or who live in a rural area (Wickenden & Elphickp, 2016). Even though the internet has become increasingly popular and has gradually become a necessity in modern-day life, some parents may still have limited access to it (Plantin & Daneback, 2009). Due to their restricted internet access, these parents may face a larger challenge in accessing online parent support than other parents with more resources (Plantin & Daneback, 2009; Scharer, 2005).

This lack of internet access, however, could be solved by providing public community information technology (IT) services and resources, such as public-use computers and WiFi (a system of accessing the internet through the wireless connection) in the community library (Hudson et al., 2008). Parents could then connect with virtual support services through the community IT resource. Even though this solution may improve the access to internet, the internet's advantage of being not restricted by time and location may be minimised, since parents without home internet access would need to travel to a certain place to use it (Hudson et al., 2008).

The sharing aspect of virtual communities may also be another limitation. Even though the internet makes it much easier for users to share information, there is also a higher risk of incorrect or false information being disseminated (Doty & Dworkin, 2014; Finfgeld, 2000). For example, the judgement of the validity and reliability of information shared in these virtual spaces may not mainly be based on the source and accuracy of the information itself, but how popular it is among other users.

As Eranti and Lonkila (2015) suggest, the number of Likes here became a 'source of valuation for Web Page(s)' (2015:1) among the internet users. The Like is a virtual action in which a user clicks an icon shaped like a positive gesture or image, such as a thumbs-up sign or a heart. In clicking the icon, the user sends a notification to the other user that he or she approves of, or agrees with, the information that has been shared (Facebook, 2017b). The users were found to be more likely to believe and agree with the information which received more Likes than that with fewer Likes (Eranti & Lonkila, 2015). Gerlitz and Helmond (2013) claim that this pattern of behaviour gives birth to the 'Like economy' (2013:1349), which, in general, is the

economic value of the chain effect that generates more attention and engagement among users who may be potential customers through the actions of clicking Like. However, Allcott and Gentzkow (2017) argue that this generates attention through a high number of Likes may lead to false but popular information being shared, instinctually or unintentionally, among the virtual communities.

One of the most famous and recent incidents raising questions about the credibility of information shared on social network sites was the fake news shared on Facebook that impacted the US presidential election (Allcott & Gentzkow, 2017). Allcott and Gentzkow (2017) have suggested that even though a vast amount of information is shared on that social network site each day, finding a solution to ensure that all information is valid and trustworthy remains a difficult mission for both users and the site developers. Wong et al. (2015) also pointed out that when collecting information through virtual communities, some parents lacked the required healthcare background or other professional knowledge to search for suitable information. Therefore, the risk of online parenting information having low credibility may constitute a limitation when using the internet as the main tool for support.

### 3.3 Emotional support in virtual communities

At the point of diagnosis of a child's disability, a parent's first question is hardly likely to be about the local early childhood intervention services. These families are frightened, disturbed, upset, grieving, and constantly vulnerable. The role of the professionals involved with them is to catch them when they fall, listen to their sorrow, dry their tears of pain and anguish, and, when the time is right, plan the pathway forward. (Carpenter, 2005, p. 181)

Emotional support is important for parents to overcome fear and sorrow, and to have the strength to pick up their parenting role to take care of their children (Carpenter, 2005; Rogers, 2007). Such support comes from a wide variety of sources, such as family members and friends (Carpenter et al., 2004; Chiu, 2013), professionals in collaboration with parents (Carpenter, 2005; Chiu, 2013; Wolfendale, 1992), and internet users who are also parents (Scharer, 2005). Moreover, a diverse range of emotional support is possible. As Doty and Dworkin (2014) mentioned in their literature review on online parent support, individuals differ widely in how they define emotional support and a consensus definition of the term is missing:

Emotional support was presented in a variety of ways in these studies: overcoming isolation, sharing experiences, building self-esteem, and empathising. However, what was missing from the literature was a consistent, clear definition of emotional support. Each study described different aspects of emotional support. (Doty & Dworkin, 2014, p.185)

Since a multitude of definitions of emotional support exist, it is important to clarify what emotional support means in the context of this paper. Emotional support has frequently been defined as actions that help individuals to cultivate positive emotions, such as a sense of belonging and security, through 'offering care or sympathy, listening to someone, or just being available' (Scharer, 2005, p.28). The greater solidarity helps them to overcome the feeling of being alone (McConkey, 2016). Emotional support exhibits 'concern, affection, comfort, and encouragement' (Evans, Donelle & Hume-Loveland, 2012, p.406). In some studies, the concept of emotional support is connected to the relationship or social environment that provides parents with positive emotions. Examples include the feeling of being hopeful and relieved

when participating in a support group (Samadi, McConkey, & Bunting, 2014), the confidence felt in sharing opinions in a safe environment (Chang, 2009), and the sense of humour, relaxation, and joy from leisure activities that soothe the tensions of parenthood (Eriksson & Salzmänn-Erikson, 2012). These positive emotions can also be a sense of pride in one's children experienced upon joining a group of parents who have undergone similar experiences (McConkey, 2016).

Since the family structure is rapidly changing due to globalisation and modernisation, emotional support, which was once provided by close family members, may now be limited by the increasing geographic space between them (Nieuwboer, Fukkink, & Hermanns, 2013). With the internet and digital technology becoming increasingly common and easier to access, Nieuwboer, Fukkink, and Hermanns (2013) have argued that the internet has become emotionally essential for today's parents, who are far from the traditional support network formed by the biological family. Several studies have also illustrated the positive impact of this internet-based emotional support and have underscored that it may help improve parents' mental health and also fill the gap created through missing connections with, or insufficient emotional support from, close family (Doty & Dworkin, 2014; Plantin & Daneback, 2009; Scharer, 2005).

### **3.3.1 Overcoming isolation**

According to McConkey (2016):

The heart-ache that comes from feeling alone with a problem can be assuaged by meeting others who have been through or who are going through similar experiences. Equally it is easier to join others to challenge prevailing attitudes and practices in society rather than to take action single-handedly. Membership can also boost self-confidence and help to create a sense of pride in having a child with disabilities (McConkey, 2016, p. 238)

Kerr and McIntosh (2000) suggest in their study on face-to-face parent support groups that parents overcame this sense of feeling alone through sympathised and relate to other parents' parenting experiences. They also develop a sense of comfort and relief when recognising that others are also facing similar challenges.

By joining a virtual community and using the group chat function on social network sites, parents, especially mothers, of children with rare illness, foetal alcohol spectrum disorder) found comfort and encouragement through meeting other parental users who shared similar experiences (Duquette et al., 2012). Hall and Irvine (2009) have claimed that social network sites create more opportunities for these parents to find each other and share their backgrounds. Parents facing changes or a new stage of life, such as giving birth, also tend to join virtual communities to overcome the fear of being alone (Herman et al., 2005; Madge & O'Connor, 2006). Parents also network with each other, including new parents, in virtual communities in overcoming hardships and challenges associated with caring of their children, facing pressures from professionals (Duquette et al., 2012). Herman et al. (2005) suggest that these virtual networks and communities help these parents to build strong connection with each other based on their shared experiences and identities. Likewise, networking, searching for information, and navigating resources and support services together in virtual communities empowers parents and leaves them feeling more confident about their children and their role as parents (Ammari & Schonenebeck, 2015).

In addition to offering access to other parents who have similar experiences, the internet also makes mutual support possible and consistently available for parents limited to a certain location due to childcare responsibilities and the severity of the child's needs (Scharer, 2005). This mutual support in the online environment has been suggested as an essential element of long-term support for parents who are the main caregiver for their children (Scharer, 2005).

### **3.3.2 Building self-esteem**

Research on online empowerment among mothers of children with special needs has underscored that mothers feel free to express their feelings, disagreements, and opinions through the internet, since they are not limited by their 'seen' identity as mothers in society (Ammari & Schonenebeck, 2015). These mothers were more willing to advocate for their rights under the protection of anonymity (Ammari & Schonenebeck, 2015). Madge and O'Connor (2006) have also indicated that parents in the UK, especially new parents, take the advantage of the anonymity in virtual communities to try out their identity as new parents and to learn about their new sense

of self without worrying about making a mistake and feeling embarrassed. This allows parents to be more confident about who they are and their role as parents (Madge & O'Connor, 2006). Moreover, through trying out the new role as parents and asking questions in the virtual communities, parents also learn parenting experiences from parents who have older children. Hearing stories about older children's development can help parents to be more confident to face their current challenges, and most importantly, to know what to expect for their children's future (Whittingham et al., 2014).

Seeking information about leisure is considered as another important type of emotional support, which also overlaps with informational support, for parents. Planning for leisure and looking for holiday locations and opportunities are one of the most frequent search patterns and information needed among parents of different age groups in Ireland (McConkey, 2003). Parents have also been found to use virtual communities for entertainment, such as by sharing jokes, entertaining stories, and other pieces of amusing information (Eriksson & Salzmänn-Erikson, 2012). Eriksson and Salzmänn-Erikson (2012) pointed out that sharing and reading entertaining information help parents to relax and de-stress. Those actions might also be important for maintaining parenting in a health way (Eriksson & Salzmänn-Erikson, 2012). Enebrink et al. (2012) have suggested that receiving online parent management training, including sufficient information about being aware of self-emotions, is beneficial for parents in developing positive parenting practices and relationships with their children.

### **3.3.3 The limitations of online emotional support**

Even though joining a virtual community could be beneficial for parents in search for emotional support and connections with other parental users, that approach has several limitations. Brady and Guerin (2010) have argued that since the virtual world is composed of textual information, certain emotions or intentions are hard to detect when providing support services through social network sites. In the natural setting of social interaction, individuals can recognise hidden emotions or intentions through body language and the person's tone of voice. On the contrary, it is much more difficult to recognise these hidden emotions and intentions in the virtual world, since

interactions primarily rely on the exchange of text-based information (Brady & Guerin, 2010; Finfgeld, 2000). Therefore, a person providing support through the virtual space may miss important emotions of the parents, especially when those individuals do not know how to express their feelings through text (Brady & Guerin, 2010).

Besides the limitation of hidden emotion and intention, the missing of non-verbal cues in computer-mediated communication (CMC) may also cause misunderstanding between the users (Walther, 2007; 2010). Without the non-verbal cues, the understanding of the text-based information in the virtual environment is mainly based on the person's interpretation of the text. This personal interpretation is, however, highly influenced by the person's social background and his/her relationship with the user who shared the information (Edward et al., 2017; Walther, 2007). Thus, users who shared similar cultural and social background, or users who have known each other in the face-to-face environment, are more likely to understand the intended meaning of the text. On the contrary, new members, or members who do not have the shared social background, are more likely to misunderstand some of the information (Edward et al., 2017; Walther, 2011; Zukhi, Hussain, & Husni, 2017). Without non-verbal cues or shared identity and background, these users are more likely to feel frustrated and even eventually leave the virtual community (Brady & Guerin, 2010; Edward et al., 2017).

Therefore, even though Plantin and Daneback (2009) have argued that emotional support provided through the internet is gradually replacing traditional emotional support from mothers or other close family members and friends among the new generation, it still cannot replace face-to-face support in offline setting. Scharer (2005) has also stated that although an increasing number of parents are turning to the internet to obtain parenting and healthcare information and to form their emotional support networks during different stages of parenthood, there are still several situations and needs that only face-to-face support can address. Doty and Dworkin (2014) also shared a similar conclusion in their critical review, indicating that face-to-face support services are still essential and should not be replaced. They argue that virtual support should only enhance, and not replace, the support system in the offline environment (Doty & Dworkin, 2014).

Another limitation and danger of online emotional support is the unique function that allows the action of providing support to become too easy, as well as unpredictable. One example is clicking the 'Like' button. Liking is a unique and important function of virtual communities on social network sites. This action of clicking Like on a person's comment permits internet users to quickly express their approval, support, agreement, and recognition to other users and their posts and comments (Facebook, 2017b).

However, multiple studies have pointed out that the motivation for clicking the Like button, along with such factors that influence it, may be much more complex than the desire to signify approval or agreement. Even though the action of clicking Like seems neutral and harmless, for some users, the act of giving and receiving Likes influences their mental health and level of wellbeing. Brandes and Levin (2014) researched the impact of Like interactions on the wellbeing of teenage girls in Israel. The teenage users became anxious when they did not receive any Likes from other users and felt more secure in their identity and the information that they shared when they received Likes. Blease (2015) also suggests a similar reaction on the part of American college students. Those individuals became depressed when their expectations of being Liked on their Facebook spaces were not fulfilled.



### 3.4 Advocating through virtual communities

For some children and young people, expressing their own views will always be difficult and so, particularly for those with communication difficulties, parents and caregivers are usually, naturally, and necessarily their proxies and closest allies. The voices of disabled children's caregivers therefore need to be heard and amplified. (Wickenden & Elphickp, 2016, p.169)

In many situations, parents, and especially mothers, are the main caregiver for children with special needs (Wang, 2012; Wickenden & Elphickp, 2016). And often, these parents retain their role as the main carers when their children reach adulthood (Wickenden & Elphickp, 2016). These parents become an essential part of their children's life by speaking and taking actions on those individuals' behalf (Wickenden & Elphickp, 2016). Therefore, being able to advocate for their children's needs is one of the most important elements for these parents (Hess, Molina & Kozleski, 2006). According to the United Nations Children's Fund (UNICEF), the term 'advocacy' is defined as follows:

The deliberate process to, directly and indirectly, influence decision makers, stakeholders and relevant audiences to support and implement actions that contribute to the fulfilment of the right of children with special needs. (UNICEF, 2010, p.3)

Through advocacy, parents are more likely to receive adequate support that responds to their own needs and those of their children. This strategy is even more powerful when parents are allied with other groups of people who share similar interests and concerns (McConkey, 2016). For example, the Parents' Association for Persons with Intellectual Disability in Taiwan (PAPID, Taiwan) joined Inclusion International and became an affiliated member. This gives Taiwanese parents the chance to advocate for their needs not only nationwide but also globally, such via the 15<sup>th</sup> World Congress of Inclusion International.

Advocacy has also been reported to reduce parents' stress levels and increase their self-esteem (Gupta & Singhal, 2004). It also provides parents with a new sense of self that gives them confidence and courage to take pride in their family and children (Runswick-Cole, 2007). Ryan and Runswick-Cole (2009) have suggested that when

given a voice and becoming empowered, parents are prepared to 'fight' (Ryan & Runswick-Cole, 2009, p.50) against the system or professionals until services are improved and are responsive to their needs. According to a study by Featherstone and Fraser (2012), advocacy was beneficial not only to parents but also to the professionals who worked with them. It enabled those professionals to understand what their services had to do to fulfil the needs of parents. This support also made communication easier for parents when explaining their needs and influenced the outcome of the service they received (Featherstone & Fraser, 2012). In some of the cases, it also helped the professionals to 'ensure' (Featherstone & Fraser, 2012, p.246) that the parents had confidence in their ability to provide the right support service.

According to research based on parents in Ireland, Chadwick et al. (2013) have suggested that another goal of advocacy is to influence members of local communities by improving their attitudes and raising awareness of supporting families of children with special needs. Monitoring local services and the government as they seek to provide adequate and quality support for families is another important way to advocate for the rights of families of children with special needs (Chadwick et al., 2013).

Since the internet is becoming more and more available to parents, it has become one of the most essential tools that enable parents to advocate for their needs. Black and Baker (2011) have claimed that when virtual communities supply parents with sufficient information, emotional support, and social ties, parents are empowered to share their parenting experiences and to publicly advocate for their rights in front of other users in the virtual space. For example, a group of parents in the Netherlands used virtual communities to collect needed information and utilised chat rooms to communicate with each other before they advocated for their children with physical disabilities (Alsem et al., 2017). These parents also used the internet platform to bring awareness to their needs and educate people around them about this physical condition (Alsem et al., 2017). As Mitra (2005) has posited:

the Internet makes that empowerment particularly significant, since many such traditionally powerless voices can now connect with each other to empower each other. (Mitra, 2005, p.379)

In addition to providing resources that allow parents to advocate for themselves, virtual communities help individuals to reach out to larger and more powerful internet networks to advocate alongside them (Mittler, 2016). For example, 27 million global members of Avaaz, a worldwide virtual community for social movement, advocated with Malala Yousafzai, a Pakistani activist, for out-of-school children in Pakistan through an online petition. Their efforts forced the Pakistani president to respond by signing an order to fund schooling for three million out-of-school children in the nation (Mittler, 2016). Through virtual communities, parents are therefore also, with high possibilities, reaching out to larger audiences internationally.

Moreover, compared to traditional ways of advocating, doing so through the internet does not require a vast amount of financial capital (Mitra, 2005). Moreover, online advocacy arguably requires only minimal digital literacy, since social network sites and other online networking platforms are designed to be simple and straightforward for their users (boyd & Ellison, 2007; Mitra, 2005). That is, virtual community makes advocacy more feasible and affordable for parents comparing to the traditional ways of advocating for their and their children's rights.

### **3.4.1 The limitations of advocating through the internet**

However, Sabatello (2014) voiced her concern that even though the medium of the internet enables and empowers people around the world to join together to negotiate for the best outcomes for parents and their children, some groups of parents may be excluded from this internet advocacy movement, and their voices may thus be missing. For example, even though the process of advocating through the internet is relatively cost-effective compared to more traditional strategies, there may still be groups of parents who do not have sufficient access to the internet or who are not successful in explaining their needs through such medium.

Since most online communication is text-based and written in certain dominant languages, such as English, parents who are not fluent in the language, who are illiterate, or who simply struggle to express their needs via online communication may be ignored in this process of advocacy. In addition, those who are fluent in these ways of communicating may dominate platforms. For instance, persons who are

fluent in English are more likely to explain themselves in an articulate and effective manner than are individuals who only speak more localised languages (Sabatello, 2014).

Therefore, even though advocacy is made relatively easy for parents through virtual communities, potential issues such as parents' language and level of digital literacy, which are often influenced by their social class, wealth, and educational background, still exist and influence the outcome of advocacy actions (Koltay, 2011). It is therefore critical to be cautious that despite the prevalence of highly positive reviews of online advocacy in the current literature, limitations still exist, and certain parents' voices may be missing or silenced within this online advocacy movement.

### **3.5 The gap in the current literature**

Even though there is a growing body of research on online parent support, gaps within the current literature were still identified. The existing literature has barely mentioned interactions for support and the relationships among parents in virtual communities, with power relationship receiving a particularly limited amount of attention. In most cases, studies have focused on how the internet empowers parents and thus enables them to overcome the challenges they face in society (Ammari & Schonenebeck, 2015; Doty & Dworkin, 2014; Duquette et al., 2012). However, there is only a limited understanding of how parents collaborate, and scant research has examined their relationships with each other and also the professionals within their virtual communities. Therefore, it is essential to fill this gap by investigating the interactions and relationships among parental members and the professionals of such communities.

Secondly, as Nieuwboer, Fukkink, and Hermanns (2013) have argued, most current research on support for parents through the internet has focused on examining text-based data within virtual platforms, and a vast volume of research has relied on context analysis. However, since the technologies of internet communication are rapidly changing and improving, more and more ways of interacting are becoming available in virtual communities, and these options include using videos or virtual interactions, such as Likes and Shares (Nieuwboer, Fukkink, & Hermanns, 2013). Even though text-based data still remain essential for understanding interactions of support, and especially for shedding light on the content of parents' communication, they may, however, be insufficient. Therefore, it is vital for future research to investigate combinations of online interactions and to examine multi-layer virtual interactions, such as how parents use both text-based comments and interactive icons, such as Likes, to communicate in their virtual communities.

Finally, there is a lack of research based on non-Western contexts due to the current literature being dominated by studies based in Western settings. According to the majority of current, Western-focused studies, the internet gives parents significant benefits when searching for information and emotional support and when advocating for their rights (Ammari & Schonenebeck, 2015; Doty & Dworkin, 2014; Duquette et al., 2012; Scharer, 2005). However, the danger of generalising findings on these

positive aspects of using the internet and social network sites for parent support is that most of the studies have been conducted in a North American or Western context. In most cases within those environments, the internet is highly accessible, and it is mostly not strictly controlled and restricted by the government (Plantin & Daneback, 2009). The literature lacks perspectives from other global contexts, such as the global South and East Asian ones.

This absence of other contexts, including the East Asian point of view, is found not only in the literature on online parent support but also in the literature on supports for parents and families of children with special needs in general. As Wickenden and Elphick (2016) states in their study on the global South, up until the present, a critical lack of perspectives and analyses based on non-Western contexts has existed. There is an urgent need for more research to address this absence of studies on supporting persons with special needs. As Chen (2010) argues in his book of *Asia as method*, conducting research on Asian culture or more specifically East Asian culture, could be beneficial to not only Asian countries but also the West and all regions of the globe.

### **3.6 Summary**

This review of the literature has served a number of purposes. First of all, the three main concepts of support for parents—namely, information, emotional support, and advocacy—were identified and explored at the beginning of the chapter. Secondly, this literature review described how virtual communities influence how each type of support is provided to parents. According to this review, essential information for parenting can be easily accessed through virtual communities; parents build and find social networks via the internet, and virtual communities likewise empower parents to advocate for their needs and rights and those of their children. Even though searching for support through virtual communities has a number of limitations, such as the large amount of information lacking in validity on the internet, online parent support is arguably beneficial for parents in general. Finally, this review pointed out the gaps in the current body of literature on online parent support. It suggested a lack of focus on actual interactions of support among parents and pointed out that studies have yet to investigate communication that is not text-based, such as multi-layered interactions,

among parents in virtual communities. Moreover, the review addressed the lack of diversity regarding studies based in non-Western contexts.

This thesis seeks to understand the role that virtual communities play in providing parent support and to examine the interactions and motivations of parents who are searching for support in this way. Distinguishing it from the current, dominant stream of research, this study was based on the Taiwanese context. Therefore, its goal was to provide an East Asian cultural perspective for the current body of literature on online parent support. The following chapter offers specifics on how I conducted my research and how the conceptual framework guided the data analysis process.

## Chapter 4. Methodology

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The purpose of this chapter is to describe the qualitative paradigm underpinning my chosen research methods, explain the case study design and the selection of cases, present the procedure used in collecting the data, explain my ethical awareness, and outline the systematic procedure used to analyse the data. I begin this chapter with a brief explanation of the qualitative research paradigm that I used in this study (**Section 4.1**). I then introduce my pilot study and describe how it prepared me for implementing the case study design that I employed. In **Section 4.2**, I present the rationale and design of my case study of three virtual communities. Following the introduction of the research design, in **Sections 4.3, 4.4, and 4.5**, I explain the data collection methods, namely, web-based observations, semi-structured interviews, and a research diary. The selection of cases, recruitment procedure, inclusion criteria, and data collection process are explored in detail in these sections. In **Section 4.6**, I discuss ethical considerations and how I addressed different ethical issues. Finally, in **Section 4.7**, I present my data analysis strategy and process.



### *The aim of the study*

**The main focus** of this study was on understanding the role that virtual communities play in providing support for parents of children with special needs in Taiwan. This study examined how parents shared resources and information among themselves and other users of virtual communities. This study aimed to give voice to the parents and to explore their motivations and reasons for searching for support in virtual communities. Thus, methods that collect data on the parents' experiences were used in this research, including web-based observations of three virtual communities, semi-structured interviews with parents and other users, and a research diary that helped me to reflect on the data collection and analysis process. In addition, the study investigated the influence of virtual communities on the relationship between parents and professionals. Based on these aims, my research questions were:

- How do virtual communities provide support for parents of children with special needs in Taiwan?
- What motivates Taiwanese parents of children with special needs to search for support through virtual communities?
- How does support provided through virtual communities impact the relationship between Taiwanese parents of children with special needs and professionals?

### **4.1 Theoretical stance: A qualitative research paradigm**

Based on the focus of this study, a qualitative research paradigm was considered as the most appropriate choice, as it provided insights into issues, purposes, motivations, and meanings (Robson, 2011). In this section, I clarify my personal philosophical perspective and assumptions. Firstly, as Mason (2002) has stated, even though a wide variety of definitions of the qualitative paradigm exist, they all have several points in common:

- Being grounded in an interpretivist' position i.e. they are concerned with how the phenomena of interest are interpreted, understood, experienced, produced or constituted
- Based on research methods which are flexible and sensitive to social context

- Based on analytic methods which take account of complexity, detail and context. (Mason, 2002, p.3)

A qualitative paradigm assumes that there are multiple versions of reality or knowledge (Braun & Clarke, 2006), and that this knowledge is personal, subjective, and unique (Cohen et al., 2013) and closely linked to the context in which it occurs (Braun & Clarke, 2006). A qualitative research paradigm hopes to examine lived experiences in their natural environments (Creswell, 2013). That is, qualitative research aims to understand how participants see the world and gives them voices (Cohen, Manion, & Morrison, 2007; Robson, 2011).

I assumed that realities were multiple, constructed, and holistic. I likewise assumed that there was no single reality, but rather complex and multiple realities constructed by the research participants and me in my role as the researcher. I wanted to:

understand the world from your [the participants'] point of view. I want[ed] to know what you [the participant] know in the way you [they] know it. I want[ed] to understand the meaning of your [their] experience, to walk in your [their] shoes, to feel things as you [the participants] feel them, to explain things as you [they] explain them. (Spradley, 1979, p.34)

Therefore, based on the aims of this study, I gave voice to the parents during my research process and explored their experiences and motivations in seeking parent support in virtual environments, rather than trying to figure out 'firm facts' (Robson, 2011, p.24) about online parent support. Using qualitative approaches, I realised a more holistic overview of parent support in the three virtual communities through examining the experiences of their parental members (Robson, 2011).

## **4.2 The research design**

In order to fully examine and understand the influence of virtual communities on parent support, a case study design using three virtual communities as cases was adopted. Before I explain why I selected the case study approach, I explore the definitions and characteristics of a case study.

Following Yin (2003), Robson (2011, p. 179) defined a case study as:

a strategy for doing research which involves an empirical investigation of a particular contemporary phenomenon with its real life context using multiple sources of evidence. (Robson 2011, p178)

Through a case study, researchers can investigate and explore a phenomenon or case in depth and within a real-life context, especially when the case is closely related and deeply rooted to the context so that the boundaries between the two are not clear (Yin, 2009). Similarly, Stake (2005) has suggested that a case study focuses on examining what is unique and complex and explores the sociocultural, political, and ethical context of the case.

To investigate a case in its context, obtaining multiple sources of evidence and triangulating the collected evidence/data are essential to explore the various variables of interest (Yin, 2009). Creswell (2013) has also indicated that the case study approach uses in-depth data collection methods that involve multiple sources of information. Furthermore, for each case, specific sampling, data collection, and analysis strategies are used to explore these sources of information and understand the case (Creswell, 2013).

It is also important to note that as Robson (2011) stresses, a 'case study is not a flawed experimental design; it is a fundamentally different research strategy with its own designs'. Each case study is unique, and the case study method allows the researchers to understand the intricacies of a phenomenon (Stake, 2005) and provides a holistic understanding of the unique case in its real-life context (Yin, 2009). It allows researchers to answer questions of 'how' and 'why' during their investigation of the case (Stake, 2005; Yin, 2003).

According to the aim of this research, which was to understand the role that virtual communities play in providing support for parents, using a case study approach helped me to ask how and why support is offered in virtual communities and to explore the virtual community in the Taiwanese context. This study aimed to capture the real-life experiences and motivations of parents joining virtual communities in search of support. In addition, through the case study approach, I was able to carry out 'an empirical investigation' of Taiwanese virtual communities for supporting

Taiwanese parents of children with special needs, and those elements comprised the particular contemporary phenomenon within the real-life context. Selecting a case study approach helped me to realise that virtual communities in Taiwan are unique, but that strategy simultaneously yielded useful experience and information of relevance for virtual communities in a global context.

Furthermore, reviewing the current literature on online parent support around the world revealed that only a limited number of studies have investigated virtual communities and parents' experiences with online support as unique cases (Nieuwboer, Fukkink, & Hermanns, 2013). As Nieuwboer, Fukkink, and Hermanns (2013) pointed out in their systematic review of online parent support, most works of this kind have used content analysis or experimental study designs.

Following Creswell (2013), Boblin et al. (2013) have suggested that 'the type of case study is determined by the size of the bounded case or the intent of the analysis'. The case study units—here, individual virtual communities—are hard to differentiate, since unlike in the offline world, members within the communities remain connected and may have multiple links and ties with other communities (Wellman, 2002). In other words, it was impossible to identify a single, clear-cut case. Thus, investigating Taiwanese virtual communities as a holistic case, using embedded units of analysis of various cases of parents' virtual communities, was identified as the most appropriate strategy. (see Figure 3. for the case study design of this study.)

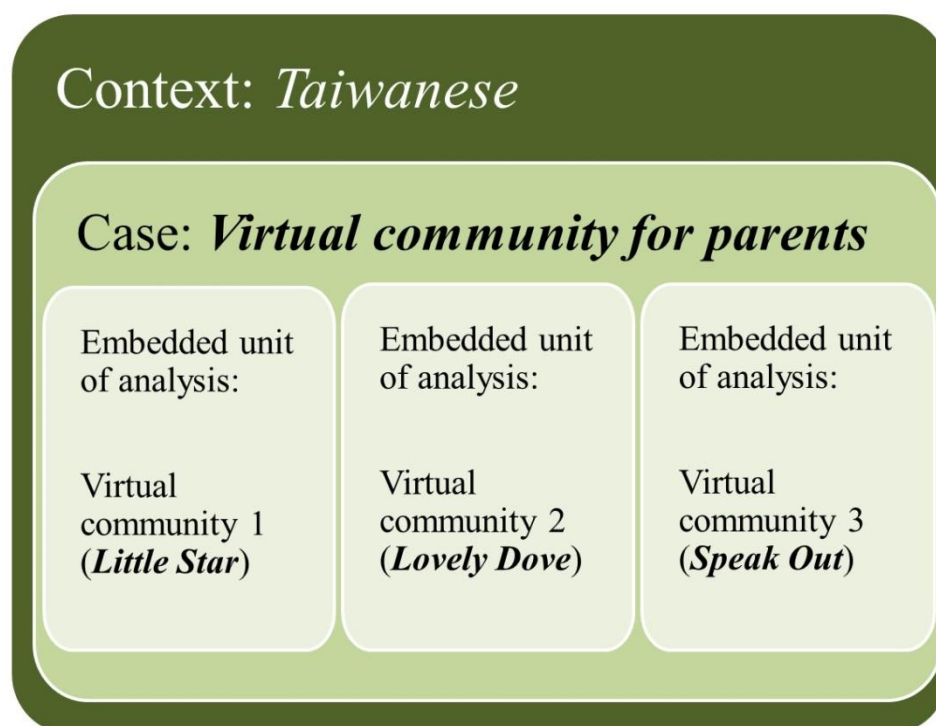


Figure 3. Case study design with three virtual communities as embedded cases (Adopted from Yin, 2009)

The case study design treated the three virtual communities as cases and allowed me to identify patterns, details, and even reasons regarding why and how virtual communities are essential for these parents in their search for parent support. Through an in-depth examination of each case, I gained a clearer understanding of how a virtual community functions in providing support for parents. By making a horizontal comparison across the cases, I then identified themes and patterns of interaction that were not common to all the cases. Through examining the cases individually, and by comparing individual cases, I explored the environment and culture of the virtual communities, the content of parent support, and the relationships among the community members. In the same way, I examined parents' experiences with, and motivations for, interactions of support in these communities.

For the above-mentioned reasons, a case study design with three virtual communities as embedded cases was thus used in this study. For the three embedded units, three active virtual communities for Taiwanese parents of children with special needs were selected. Details on the selected units are introduced in the following section.

### 4.2.1 Identifying the cases in this study

#### *Platform selection: Facebook*

In this research, a social network site, Facebook, was selected as the main environment, since it is the most common setting for all types of virtual communities (Sekar, & Sudhira, 2017). Facebook is also one of the most popular sites for forming virtual communities in Taiwan (Zong, 2016). According to *The Epoch Times* (Zong, 2016), there were more than 18 million Facebook users in Taiwan in 2016. This number indicated an approximately 85% penetration rate of Facebook within the Taiwanese population. Moreover, according to Berry (2014), Taiwan ranks 19<sup>th</sup> worldwide in terms of the number of Facebook accounts. Moreover, the number of Facebook users in Taiwan continues to grow (Zong, 2016). This growth could indicate that Facebook is an important social network site that is popular among Taiwanese people, including parents of children with special needs.

In addition to being one of the most popular social network sites in Taiwan (Zong, 2016), Facebook is also one of the largest social network sites worldwide (DeLegge, & Wangler, 2017; Sekar, & Sudhira, 2017). In 2017, the population of Facebook users reached two billion (more than one-quarter of the world's population in 2017), and that site has remained the most popular social network site around the world since 2009 (BBC, 2017; DeLegge, & Wangler, 2017). Therefore, examining parents' experiences with using Facebook may potentially benefit not only parents in Taiwan but also parents who use Facebook in another context, since the platform is popular globally.

Moreover, Facebook's platforms and settings are suggested to be widely representative of those of other social network sites (boyd & Ellison, 2007; Wilson, Gosling, & Graham, 2012). Therefore, even though social network sites may differ in terms of focus, the basic functions and platforms are still similar to those of Facebook. For example, YouTube, another popular social network site, has platforms that allow users to easily share videos and music. However, in terms of the basic structure, YouTube is the same as Facebook. It offers a Profile allowing users to share their videos, a list of other users who have subscribed/followed (similar to the concept of a Friend on Facebook) that Profile to watch posted videos, and a platform permitting

users to communicate with each other. Therefore, this study's findings on experiences with parent support in Facebook's virtual communities are very likely to also apply to other virtual communities on different social network sites.

### *Case selection*

This section lists the inclusion criteria and the reasons for selecting the three virtual communities.

#### **1. Virtual communities that were used by groups of parents, an organisation, or individuals for providing different types of parent support**

With this criterion in mind, I used Google to identify the Facebook-based virtual communities that I hoped to recruit as cases for the study. My search terms included: 'online parent support group', 'social network site for Taiwanese parents of children with special needs', and 'virtual communities for parents of children with special needs in Taiwan'. After my first round of searching, the results identified seven Facebook Pages formed by different organisations for parents or families of children with special needs. All seven Pages were created by organisations that provide support for families of children with special needs in Taiwan. Moreover, they all provided me with a decent context for understanding what parental users were receiving and sharing via Pages, the basic unit of their virtual communities.

Identifying virtual communities that provide support for parents of children with special needs helped me to select cases that yielded useful data. Ultimately, this strategy allowed me to closely examine interactions among parental users offering and receiving supports.

#### **2. Virtual communities with both a Page and Groups**

A virtual community in Facebook contains two main platforms, including Page and Group (see Figure 4.). A Page is the basic and also the biggest unit of a Facebook virtual community. The settings of a Page are similar to a personal Profile, which presents the public presence of the person in the virtual environments. However different from a Profile, instead of being owned by a single user, a Page is owned by an organisation, company or a public figure. Through following the Page, users could

keep up on the latest information shared by the organisation. They could also comment and raise discussion about the information shared in these Page. (see Appendix 3 for more introduction of Page). A Group is a unit that the administrators or members create to discuss specific topics in more detail or within a small subset of members, such as parents within the same local community. In order to gain a full understanding of the impact of virtual communities, it was essential to collect data from both virtual community platforms.

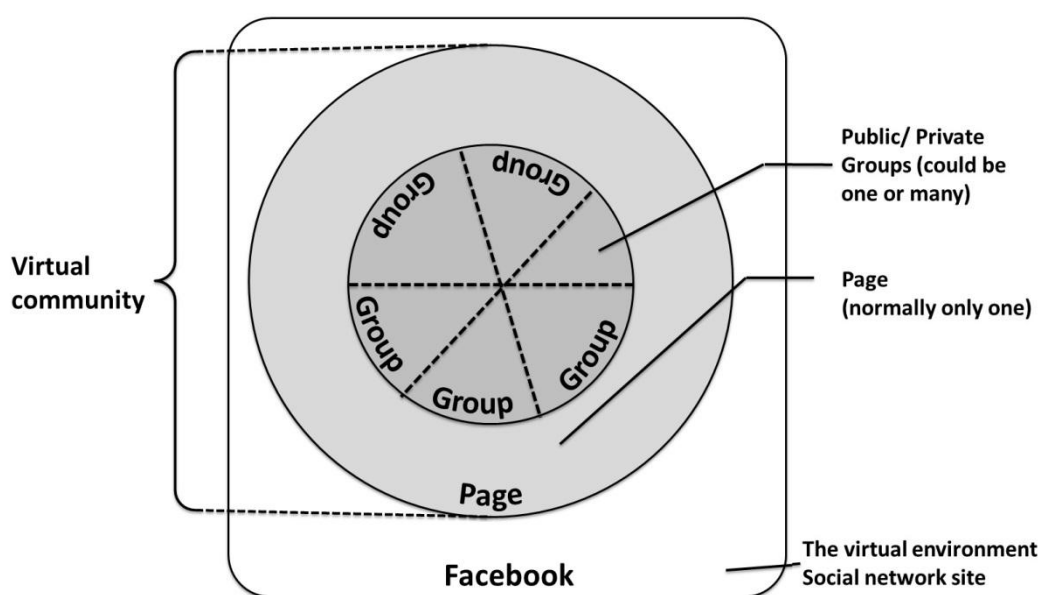


Figure 4. The basic structure of the three virtual communities in this study

Therefore, it was important for the selected cases to have both a Page and Group as platforms for providing parent support. Moreover, including both platforms also helped in comparing parents' interactions regarding their search for support in different platforms of a virtual community. It likewise provided opportunities to examine how parents interacted when Groups gave them more opportunities to share information, as the Pages were mostly controlled by the administrators.

Three virtual communities, Little Star (pseudonym), Lovely Dove (pseudonym), and Speak Out (pseudonym), stood out from the others. Little Star, a virtual community for parents of children with autism (the pseudonym Little Star was chosen, since in Taiwan, children with autism are also called children from the star), had one Page and six private Groups based on parents' locations and the age groups of their children.



Lovely Dove, a virtual community formed by a Christian couple for supporting parents of children with special needs in general, comprised a Page and three public Groups. (It was given the pseudonym Lovely Dove, because in Chinese, that term denotes a Christian organisation or charity). These Groups were based on different locations in Taiwan, similar to Little Star. Finally, Speak Out, a parent advocacy virtual community that also provides parent support for parents of children with intellectual disabilities. Speak Out supervised or supported more than two private Groups formed by parents. The reason why all Groups were managed by parents rather than professionals or workers in Speak Out was mainly because Speak Out encourages its parental members to set up Groups themselves. Even though Speak Out did not officially own these private Groups, it still had great influence on them, since most members of the Groups were also members of Speak Out.

### **3. A virtual community that was functioning and actively managed**

Finally, the virtual community needed to be actively used by members and administrators for parent support. When a virtual community is actively updated by the administrators, it is more likely to provide sufficient support for parents and to keep its members contributing and exchanging resources and information through the virtual platforms (boyd & Ellison, 2007). Therefore, to collect rich and sufficient data, the virtual communities needed to update the posts on their Page and Groups at least once a week during the data collection period. Parental users also needed to be participating in interacting with each other in the virtual community by clicking Like, Share, or leaving comment on updated posts. Little Star, Lovely Dove, and Speak Out added more than two posts per week. All three virtual communities were actively managed by the administrators. Little Star and Lovely Dove were two of the largest and most active virtual communities for supporting families of children with special needs in Taiwan.

In addition to meeting all three inclusion criteria, Lovely Dove and Speak Out were previously examined in my pilot study and proved to be highly relevant to my research aims. In addition, Little Star was highly recommended by one of the participants in the pilot study. As a result, Little Star, Lovely Dove, and Speak Out

stood out from the other virtual communities and were selected as the three cases for this study.

### **4.2.2 Characteristics of the three cases**

Basic information and the virtual environments of the three cases are introduced in the following sections. To provide directly comparable data, essential information about each case is presented in Table 1.

#### *Little Star*

Little Star is a private non-profit organisation formed by Shin, a mother of a 23-year-old son with autism. Shin is also a famous internet personality, a school teacher, and a well-known author of books on parenting. The main purpose of Little Star is to provide support for children with autism and their families, and more importantly, to advocate for people with autism. Little Star does not charge parents membership fees. However, parents need to pay fees to join most of the activities and to access services from the organisation. Since Little Star is not funded by the government, it depends on donations from different companies and the fees paid by parents to keep functioning.

Little Star had the largest virtual community among the three selected cases, with 101,275 members, 1 Page, and 6 Groups. Shin updated one post almost every day during the period from October 2014 to November 2015. Each post was around 200-400 words. Members also actively commented on most of the posts.

- **Platform Descriptions**

A clear title stating ‘Little Star: Helping the person with autism’ is visible at the top of the Page. The Page’s cover photo introduces Shin’s book about parenting and children with autism. The Profile photo of Little Star is a blurry photo of her son using the computer. According to Shin, that image represents how Little Star started from her motivation to help her son and others children with autism.

The About section, which introduces Little Star, shares a video giving a clear introduction to the topic of children with autism. Users who visit Little Star

immediately see the video at the top of the Page. In the About section, Shin also briefly introduces herself and the purpose of forming Little Star. After the introduction of Shin information follows a list of the awards that Shin has received due to her career and her role as a mother who advocates for autistic children. Clear contact information, including phone numbers and emails for Shin and the other administrators, is also shared in the About section. I used this contact information to recruit Shin to this study. After I contacted her, she replied the next day and agreed to participate.

Links to the six private Groups for parents are given in the About section of the Page. The private Groups are carefully classified according to the location of the parents and the age group of their children. Users can choose the Group that they hope to join by clicking the links. After clicking one such link, a short introduction of the Group is displayed. All the Group introductions state that any user who intends to join these parent Groups needs to be a parent of a child with autism or a professional, such as a social worker or family consultant. All users who hope to join the Groups also need to send a short introduction about their children and themselves to Shin and the other administrators. The Group members and Shin then decide whether the person is allowed to join the Group. This method of selecting members employed by Little Star's private Groups was the strictest among the three virtual communities.

### *Lovely Dove*

Lovely Dove is a virtual community that was formed by a private organisation for parents of children with special needs. The primary goal of Lovely Dove is to support parents of children with all types of disabilities and to provide support services not only for parents but also for their children and other family members, such as siblings. Lovely Dove offers individual support services for both parents and children, including individual and family counselling sessions, peer support groups, game/art therapy, and services related to personal document and resource management for children. However, parents need to pay for most of these services. Since it is only partially funded by the government, most of Lovely Dove's income is from donations and fees for support services.

The organisation was formed by a Christian couple with two daughters with severe developmental delays. Therefore, religious terms, such as 'God's grace', are used in some Lovely Dove posts. However, most of the posts do not make references to Christianity.

Lovely Dove had 1 Page and 3 public Groups, along with 31,078 members. The Page was update twice a week and the 3 Groups were updated around three times per week from October 2014 to November 2015. However, the Page and the Groups were mostly updated with the same or similar posts. That is, the platforms of the virtual community shared the same or similar information with members.

- Platforms descriptions

The name of the organisation is the title at the top of the Page. Lovely Dove's cover photo is an advertisement for a charity event that it held. It depicts a man in a wheelchair being pushed and supported by three other men. At the top of the photo is written 'The melody of love', and the time and location of the charity event are also given in the cover photo. Lovely Dove's Profile picture is the logo of the organisation, which is an angel hugging a young girl.

On the About page, the address and contact numbers for the head office and another branch official are given. After the contact information, the section states:

All children with special needs are angels of God, and parents of these angels are called humans with the heart of an angel. This group of parents may face difficulties on earth, so they need to support each other on this difficult journey.

In the About section, a brief summary of the story of the founding couple's daughters is provided. After that introduction, the About section contains web links to the three Groups.

All five Lovely Dove Groups have a similar layout: a cover photo of the charity event, the Profile photo featuring the Lovely Dove logo, and the same organisational introduction in the About section. The only difference between the layouts of the Page and the Groups is that the Group titles which is explicitly named after a location, such as the South Taiwan Lovely Dove Group. All these Groups are public platforms that all users can join. However, Group members and administrators can exclude users who are not parents or who do not fit the Group membership criteria.

### *Speak Out*

Speak Out is an advocacy non-profit organisation for parents of children with intellectual disabilities. The organisation focuses on supporting parents of children with intellectual disabilities and advocates for them. Speak Out also advocates for all children with other types of special needs and their families. It also pressures the local government to improve support services for families of children with special needs on behalf of these parent groups.

This organisation provides free consultancy sessions for parents, such as consultant services regarding education provision for their children. No member fee or service fee is charged for new members, since Speak Out is mainly funded by the government. In addition, since it is one of the oldest and largest parent organisations in Taiwan, Speak Out also receives sufficient levels of donations from companies and other organisations.

Speak Out's virtual community, however, was the smallest of the three cases. It had 3,476 members, along with 1 Page, and more than 2 private Groups. The administrator explained that the organisation hopes that parents can take the initiative

to form their own Groups and advocate for themselves. Speak Out provides these parent Groups with support if needed but will not interfere with them. I also discovered that Speak Out was the least structured virtual community of the three. Thus, it is possible that parents could have formed more private Groups of which the administrator of Speak Out was not aware. The Page was updated approximately twice per week on average from October 2014 to November 2015. Speak Out's Page was also the least active of the three. However, participants were quite active on their personal Pages and in their private Groups.

- Platforms descriptions

The cover photo of Speak Out is a photograph of a parent holding hands with his child. The title of the photo reads: "Deep Love of Parents, Never Gives Up". No introduction to the photo is given. Speak Out's Profile picture is a young girl with a smile on her face. On the About page, the address and contact number of the organisation's head office are provided. The introduction to Speak Out repeats the slogan 'Deep Love of Parents, Never Gives Up' and mentions that the organisation was formed by a group of parents with profound love for their children. Under this description is the following text:

The focus of Speak Out is always on advocating for a better welfare system, support services, and laws for people with intellectual disabilities and their families. We hope to take care of them throughout their lives and nail down all potential difficulties they might face in their lives. We hope to develop a great support system for the carer as well in order to fulfil this purpose.

After this short introduction, areas that Speak Out hopes to improve are listed. Direct links to the private Groups are not offered, but next to the Page is a list of suggested parent Groups for users to consider joining. When I interviewed Pu, the administrator of Speak Out, she mentioned that the organisation encourages parents to take the initiative to form private or public Groups. She introduced me to two private Groups formed by mothers of children with Down syndrome. The two Groups were also indirectly supported by Speak Out.

Table 1. The three virtual communities

Name	Pages and Groups	Description	Focus of the virtual community
Little Star	<ul style="list-style-type: none"> <li>1 Page</li> <li>6 private Groups</li> </ul>	<ul style="list-style-type: none"> <li>Non-profit private organisation</li> <li>Formed by Shin, a mother of children with autism</li> <li>Largest of the three virtual communities, with 101,275 members</li> <li>Most active virtual community of the three</li> <li>Little Star is managed by Shin, who treats the duty as a full-time job</li> </ul>	<ul style="list-style-type: none"> <li>Providing information related to children with autism</li> <li>Providing parent support for parents of children with autism</li> <li>Providing support services (need to pay for services)</li> <li>Advocating for people with autism</li> </ul>
Lovely Dove	<ul style="list-style-type: none"> <li>1 Page</li> <li>3 public Groups</li> </ul>	<ul style="list-style-type: none"> <li>Social welfare foundation, non-profit private organisation</li> <li>Formed by a Christian couple with two daughters with severe developmental delays</li> <li>Virtual community with 31,078 members</li> <li>Lovely Dove is managed by Yeh, a full-time administrator and social worker for Lovely Dove</li> </ul>	<ul style="list-style-type: none"> <li>Providing information related to children with all types of special needs</li> <li>Providing parent support for parents of children with special needs</li> <li>Providing support services (need to pay for services)</li> <li>Building friendships and social networks for parents</li> <li>Advocating for a friendly environment and supportive society for children with special needs and their families</li> </ul>
Speak Out	<ul style="list-style-type: none"> <li>1 Page</li> <li>2+ unofficial private Groups*</li> </ul>	<ul style="list-style-type: none"> <li>Non-profit, government-funded organisation</li> <li>Formed by a group of parents of children with intellectual disabilities</li> <li>One of the oldest and largest parent organisations in Taiwan</li> <li>Smallest virtual community of the three, with 3,476 members</li> <li>Least active of the three virtual communities</li> <li>Speak Out is managed by Pu, a Speak Out social worker who serves as a part-time administrator</li> </ul>	<ul style="list-style-type: none"> <li>Providing information related to children with all types of special needs</li> <li>Focusing on building parents' abilities to advocate for themselves</li> <li>Providing free support services and parent support</li> <li>Advocating for all children and others with special needs and their families</li> </ul>
* Speak Out encouraged parents to form private parents' Groups. For example, Ming, a participant who was a mother of an 18-year-old son with Down syndrome, formed a private Group for parents of children with Down syndrome with the support of Speak Out.			

### 4.3 The research methods

For each case, web-based observations, semi-structured interviews, and a research diary were used as the data collection methods (See Figure 5.). The **web-based observations** helped me to gather data presenting interactions related to support within virtual communities. They also enabled me collect the content of conversations among members in the virtual communities. The **semi-structured interviews** allowed me to develop an in-depth understanding of the context of each theme and interaction initially identified during the observation process. They also allowed me to further understand the social networks within the virtual communities. And finally, the **research diary** helped me to reflect on the observation and interview processes. These methods yielded valuable data from each case reflecting various aspects of support and different perspectives on the role of virtual communities.

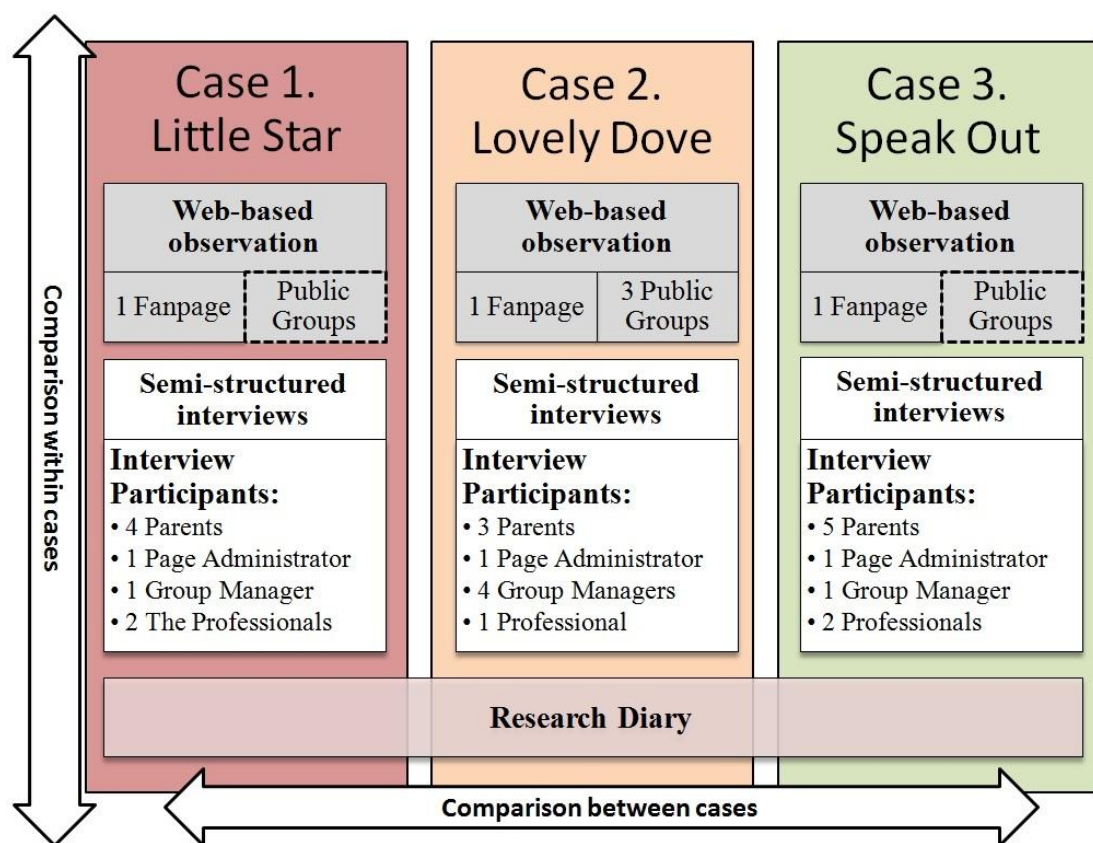


Figure 5. Research Methods



### *Pilot study*

I carried out the pilot study between August 2014 and October 2014. I identified two virtual communities formed by parent organisations in Taiwan. During that three-month period, I made web-based observations after collecting archived data from the platforms of the two communities. All main posts that were shared in the two communities during that period were collected. I also conducted three semi-structured interviews with parental members of the two communities. The data were examined through the conceptual framework of the matrix of sub-questions based on the research questions and the three concepts of support.

This pilot study indicated that web-based observations, semi-structure interviews, and the research diary were efficient ways to collect rich data reflecting the interactions among the parental users in the virtual communities. Based on my experience with the pilot study, I also decided that images, photographs, and videos shared in these virtual communities would not be collected during the web-based observation process in the main study. I made that choice after realising that videos and photographs were less relevant to the interactions of support between parents during my pilot study.

Moreover, I was also aware that attempting to include those types of data could have resulted in an overwhelming amount of data, which could have been challenging to analyse. Even though these types of data were not collected, I realised that analysing virtual interactions and text-based content still provided me with sufficiently rich and useful information to understand parent support in the virtual communities. Thus, after the pilot study, my goal was to avoid collecting an unnecessarily large amount of data but to gather as wide a variety of parents' interactions and experiences as possible. Thus, I decided to lengthen the main study's web-based observation period to a year (according to the school time table) in the main study and to only collect virtual interactions, including Likes and Shares, and text-based content.

#### **4.3.1 Data collection: Web-based observation**

Unlike other online platforms, social network sites allow users to interact with each other in virtual communities with more complex virtual actions, such as Liking, Sharing, and Tagging (see Appendix 3 for a more detailed explanation of different virtual interactions). In other words, communication among users in these virtual

communities is not limited to text-based data, and interactions in these virtual communities are much more similar to actual face-to-face interactions, in which multiple types of interactions also co-exist (boyd & Ellison, 2007). Therefore, to gather these actions, observation, which records actions, incidents, and times, was considered an appropriate data collection method.

Cohen, Manion, and Morrison (2007) have suggested that observations help to collect 'life' (2007:396) data that provide a closer view of patterns of interaction within the natural environment. Similar to traditional observation, web-based observation is the systematic collection of different forms of online data that exist in an online environment, such as a social network site (Kraut et al., 2004; Schroeder & Bailenson, 2008). In this study, the observation processes entailed the systematic recording of archived online data. I amassed both the text-based content of discussions and the virtual actions in the virtual communities. The main reason that archived data were collected was that I hoped to avoid potentially influencing the participants in my role as the researcher. This approach also allowed me to reconstruct participant interactions that were naturally practiced in the virtual environment (Kraut et al., 2004; Wakeford & Cohen, 2008).

This web-based observation process also recorded the frequency of the actions, such as the numbers of **Likes**, and the timing of the interactions among users in these virtual communities. This action of clicking Like is common used by the members of most virtual communities, and especially those based on a social network site. Liking is also commonly used as a verb in reference to the action of clicking the Like icon (boyd & Ellison, 2007). This function of Like recorded the parents' information preferences and the types of information that solicited their agreement and approval in the virtual communities. That data also potentially illustrated why the members of the virtual communities, including the administrators, parents and the professionals, shared this information.

The **Share** is another virtual action in which a user copies a piece of information and reposts it on his or her personal virtual platform or on another virtual platform (Facebook, 2017a). It records a user's attempt to collect information. Through

examining and collecting the data on this action, I explored how information was obtained and shared among the parents within their virtual communities.

These archived data were collected within the platforms of the three virtual communities, including their Page and the Groups. Gathering observations from both platforms helped me to examine the interactions among parents and other users within these virtual environments (see Figure 4 for the basic structure of the three virtual communities).

Similar to the offline world, the virtual world features different landscapes and venues (Blanchard, 2008). There are different layers of the virtual environment and a range of privacy settings that users can customise and employ to select their audience within the virtual space (boyd & Ellison, 2007). In this research, all the virtual communities had two main layers: The first layer was the Page, and the second was the Groups. These virtual communities welcomed all users, regardless of their interest in parent support, to join their basic platforms. For specific groups of users who were parents or professionals, these virtual communities provided smaller platforms, either private or public Groups, that these individuals could join and use to initiate further discussions and interactions with each other. Each member of the virtual communities also had an individual Profile as his or her personal platform for sharing information with other members. Detailed information on Facebook's online settings and platforms, including the Profiles, Pages, Groups, and Messages, is introduced in Appendix 3.

The basic unit of observation was a 'post', which is the information that a user shares on a virtual community's platform. Other users can leave comments on that information (see Appendix 3 for more details). I collected the content of the comments and posts that the members shared within the three virtual communities. This material included the content of the main body of the post and the content of the comments. I also recorded all interaction data, such as the number of Likes, replies, and Shares. This recording process was initially carried out using printouts so that I could make sense of the general interactions happening within a post (see Figure 6).

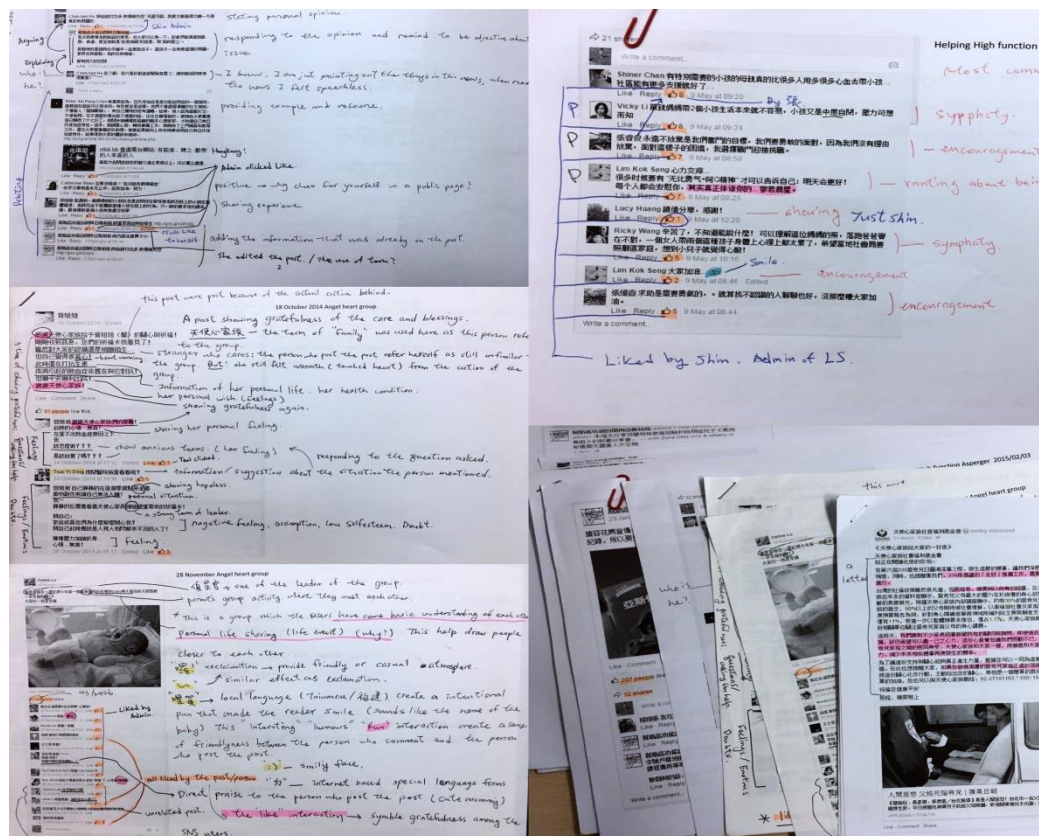


Figure 6. Process of recording web-based observations

All data were then recorded and coded through R based qualitative data analysis, which is commonly called RQDA (Huang, 2014). R is ‘a free software environment for statistical computing and graphics’ (<https://www.r-project.org>), and RQDA is a qualitative software package of R that helps organise text-based qualitative research data. This software helped me to systematically organise the observation data into categories of dates, cases, and codes (see Appendix 4).

Through web-based observations, I aimed to identify patterns of interactions and networks of relationships. I also hoped to examine the content of the information that parents shared and discussed in the virtual communities.

The web-based observation process collected archived data posted to all Pages and Groups of the three virtual communities between 1 October 2014 and 31 November 2015. This 13-month period was based on school semesters and summer and winter vacations, since there was a high probability of support information for parents being strongly related to their children’s education timetable.

I was aware of the potential volume of the data when I decided to collect data for 13 months. Based on the pilot study, which collected web-based observation data from 2 virtual communities for 3 months, the 13-month data collection period was expected to be feasible for my main study. This was due to the fact that each virtual community only updated the information on its Page and Groups around two to three times per week in average. Moreover, each post was less than 200 words long, except for posts about critical incidents, which were sometimes longer. And that not all posts were commented by the members of the virtual communities and the parental users. Therefore, based on my experience with the pilot study, the collected data were expected to be manageable. The actual web-based observation process met those expectations.

The analysis of the web-based observation data became saturated when I reached the sixth month of data collection; at that point, I had collected ‘enough information to replicate the study’ (Fusch & Ness, 2015, p.1408) and no further coding was feasible. Therefore, after May 2015, I reduced the frequency at which I collected data and obtained the archived data during the first and third week of every month until December 2015 to check whether new patterns or themes would emerge. However, similar findings were identified. Therefore, it was possible that my data were sufficient for my research purposes after Six months of collection.

I conducted web-based observations of three Page and three public Groups from Lovely Dove. I did not conduct web-based observations in the private Groups of Little Star and Speak Out due to the restricted access to these private Groups (which is explained in the following sections). Overall, 447 posts were recorded, including 173 posts from Little Star, 218 posts from Love Dove (including posts from the 3 Groups), and 56 posts from Speak Out. Even though web-based observations were not carried out in the private Groups of the two virtual communities, I collected the parents’ interactions and the content of their discussions in these private Groups by asking them about their experiences during the in-depth interview process. I also asked them to provide an example of the posts and information that they shared in the private Groups.

### *Limitations of access and ethical issues*

In this section, I explain why I did not conduct web-based observations in the private Groups of Little Star and Speak Out. While selecting samples for the web-based observations, six private Groups from Little Star, three public Groups from Lovely Dove, and two private Groups from Speak Out were identified. I contacted the administrators of each Group to recruit the Groups into my web-based observation samples and asked for authorisation to access archived data. The administrators of the three public Groups for Lovely Dove immediately agreed to participate in the study and gave me permission to access the data in their public Groups.

However, when I contacted the administrators of Little Star and Speak Out, I encountered several restrictions in the process of recruiting those organisations' private Groups. Shin, the page administrator of Little Star, raised concerns about me accessing information and conducting observations in the private Groups, since those Groups' privacy settings should allow parental users to feel 'safe' and 'free' to share anything, even sensitive personal topics. Therefore, giving access to other users who are not parents of children with autism, such as myself, might damage this 'trust relationship' that Shin has built in these private Groups. Even though there were other users who were not parents in these private Groups, they were mainly professionals with whom the parents were familiar through Little Star's face-to-face events and services. Therefore, as a researcher with whom the parents were not familiar, I was not allowed to access their private Groups. According to my research diary, Shin was quite protective of Little Star and was cautious during the interview process.

Ming, the administrator of one of Speak Out's private Groups, gave similar reasons when I attempted to recruit the Group. In contrast to the case of Little Star, Ming suggested that she would permit me to collect data in the private Group if its other parental members agreed. She also suggested that I attend some of their social events to become familiar with the parents so that I might successfully recruit the Group. However, when I contacted Ming again, she suggested that due to the high level of private and sensitive information within the Group, not every member was comfortable sharing that material.

Fortunately, the administrators of these private Groups agreed to impart their experiences of sharing information and providing parent support via these private Groups. They also gave me clear examples of how they interacted with parental users in these Groups. In addition to the Group administrators, I also interviewed other members, including parents and other professionals, such as a social worker, in these private Groups during the semi-structured interview phase. I asked them to share their experiences with accessing parent support in these Groups. Therefore, without directly accessing private Group materials, I collected rich data that helped me to understand the interaction patterns in these private Groups.

On the contrary, observing the Pages and Lovely Dove's public Groups—which were coded as Group 1, Group 2, and Group 3—presented fewer ethical issues. This was because in public spaces on the internet, users should be aware of the transparency of information before posting any personal material (Eynon, Fry & Schroeder, 2008; Kollock, & Smith, 1996). Moreover, warnings or reminders related to the privacy settings are shown at the top of all the platforms; thus, all users see that reminder before posting a comment or starting a discussion. That is, in my study, all information collected from the public platform, such as the Page and public Groups, was posted by users who were aware of that their content would be accessible to all other users. Therefore, unlike with the private Groups, data generation within public spaces, such as the Pages, requires less of a demonstration of consent from the participants, and most of the time, obtaining consent to use the data for research purposes is not necessary (Eynon, Fry & Schroeder, 2008). However, even though collecting archived data in public spaces does not require consent from internet users, I still informed each administrator about my web-based observation and that I would be employing the data for my research. When informed, all of these administrators were content for me to collect any information from the public spaces of their virtual communities. Moreover, I also replaced all Page, Group, and member names with pseudonyms.

### **4.3.2 Data collection: Semi-structured interviews**

Semi-structured interviews are essential for understanding parents' motivations for, and experiences with using a virtual community for parent support. Semi-structured interviews, which are more flexible than other types of interviews in terms of their

structure, allowed me to explore a ‘much broader range of factors: the thoughts and feelings of study participants’ (Wasserman & Faust, 1994, p.80). Fylan (2005) has also suggested that semi-structured interviews allow the researcher to explore complex research questions and to obtain an in-depth understanding of the research aims. Therefore, according to my research aim, which was to understand parents’ motivations for using a virtual community as a tool for parent support, the semi-structured interview was selected as the second data collection method.

Overall, I conducted 25 one-to-one semi-structured interviews – including interviews of 14 parents, 7 professionals, and 6 administrators (two are also parents). Each interview lasted approximately an hour. I used a systematically designed interview schedule (see Appendix 1) to guide me through each interview and explore all topics and questions that were essential for this study. I also allowed the participant to direct the interview to collect in-depth data. All participants were asked to share their experience of interacting in private Groups on Facebook and to provide examples of those experiences. I conducted longer interviews with the private Group administrators from Little Star and Speak Out and asked them to provide more detailed information regarding their experience of interacting with parents in these private Groups. These interviews yielded important data that made up for the limited access to the private Groups of Little Star and Speak Out.

All interviews were recorded using my smartphone, and verbatim transcriptions were made so that my records would be as faithful to the original as possible. All the interviews were transcribed and recorded using the qualitative software RQDA.

### *The inclusion criteria for the interviewees and the sampling strategies*

I recruited three types of members from the three virtual communities to participate in the semi-structured interviews, namely, administrators, parental users, and professionals. These three types of members were recruited to collect different perspectives on how support was shared in the virtual communities for parent support. In the following sections, I introduce the inclusion criteria and the sampling strategies for recruiting each group of participants.



- Administrators

First of all, I used a purposeful sampling strategy to recruit the administrators managing the three Pages and the organisations' Groups during the data collection period. I contacted these administrators through Facebook private messages and telephone calls, since their contact information had been shared on the three Pages. All three Page administrators, Shin, Yeh, and Pu, agreed and were pleased to participate in a semi-structure interview. Apart from Shin, the administrator of Little Star and the mother of a boy with autism, the two other administrators, Yeh and Pu, were social workers. However, it is important to mention that Shin is also a famous author and information technology (IT) teacher.

As for the recruitment of the Group administrators of each virtual community, I likewise identified and contacted some of these individuals through Facebook private messages and telephone calls. Again, these individuals' contact information had been posted publicly in the About sections of their respective Pages. The administrator of the private Group of Speak Out, however, was introduced to me by Pu, since she was managing private Groups for which contact information was not shared.

Overall, three Page administrators and six Group administrators were interviewed, including one Page administrator from each virtual community, one Group administrator from Little Star, four Group administrators from Lovely Dove, and one from Speak Out.

- Parents

As for the parental users, all of the participants needed to meet the following selection criteria:

1. Parent who had at least one child with special needs
2. Parent who had been using a social network site for parent support at least five times per week
3. Parent who was a member of at least one of the three selected virtual communities

The 'parent' category included fathers, mothers, step-parents, and other primary guardians of the child. In addition, the criterion of using a social network site for

parent support meant using such a site at least five times per week to check, read, share, or search for information related to one's parenting role. For example, a parent might read about other parents' parenting experiences or sharing his or her own experience.

Before I recruited the parental participants, I identified them through the list of member names or 'Fans' in each Page and Group. This list of names gave the identities of the social network site users who were the members of the Page or Group. The list of names also provided links to that person's Profile, and I could also send individual private messages to those users. Therefore, after purposefully selecting a number of contacts from the list of names according to the above criteria, I used Facebook private messages to directly contact these selected parental users and invite them to participate in the study. In addition to direct contact with via a Facebook message, the snowballing strategy was also used in the recruitment process. Some parents who agreed to participate in the research introduced me to other parents who might be interested in participating. Shin and Pu also introduced me some parental users with a potential interest in participating in the study.

Overall, 14 parental Facebook users were recruited. Of the 14 parent participants (including 1 Page administrator and 2 Group administrator), only two were fathers. That is, the majority of the participants were mothers. Samples comprised primarily of mothers are common within studies of families of children with special needs (Ryan & Runswick-Cole, 2009; Traustadottir, 1991). This situation may be due to the fact that mothers of children with special needs are more likely than anyone else to be the primary carer in the family (Ryan & Runswick-Cole, 2009; Joseph Rowntree Foundation 2001; Cole 2004). It is possible that this research was biased due to the female-dominated sample. However, this composition was also a rather accurate reflection of current Taiwanese family/societal norms, in which mothers are the main family caregiver for all children, including those with special needs (Hsu et al., 2017). Therefore, I argue that even though the sample consisted primarily of female participants, it was a reliable and trustworthy group of participants who shared rich experiences. Half of the parents were aged between 40 and 50 years old (7 of 14 parents, 50%), with 36% aged between 30 and 40 years old (5 of 14, 36%), and 8% (2 of 14) over 50 years old. Five of the children were of primary school age (under 12

years old), 5 were in secondary school (12 to 18 years old), 2 had graduated from the educational system, and 1 was in university (over 18 years old). See Table 2, Table 3, and Table 4 for the participants in each case, as introduced in this section.

Table 2. Little Star semi-structured interview participants

Type		Name	Age	Age of Children	Type of Special Needs	Notes
Administrator	Page	<b>Shin</b>	40-50	23	Autism	Famous author, speaker advocating for the rights of children with autism, and mother
	Group	<b>Shung*</b>	30-40	NA	NA	Special education teacher who was also interviewed in her role as a professional who uses social network sites to provide support
Professional	Special education Teacher	<b>Winni</b>	20-30	NA	NA	Teacher of Nini
	Speech therapist	<b>Mei</b>	20-30	NA	NA	
Parent	Mother	<b>Kuai</b>	30-40	10	Autism	Member of Little Star parent's group
	Mother	<b>Jade</b>	40-50	15	Autism	Math teacher of Cheng's son
	Mother	<b>Cheng</b>	30-40	10	Autism	
	Mother	<b>Nini</b>	40-50	17	Learning difficulties	

\*: This participant was also interviewed in her role as a professional.

Table 3. Lovely Dove semi-structured interview participants

Type		Name	Age	Age of Children	Type of Special Needs	Notes
Administrator	Page	<b>Yeh</b>	20-30	NA	NA	Full-time Page administrator for Lovely Dove
	Group	<b>Su</b>	30-40	NA	NA	Part-time Group Administrator/family counsellor
		<b>Tung</b>	20-30	NA	NA	Part-time Group administrator/social worker
		<b>Lee</b>	40-50	NA	NA	Full-time Group administrator
Professional	Social worker	<b>Ann</b>	30-40	NA	NA	
Parent	Mother	<b>Dee</b>	40-50	10	Autism	
	Father	<b>Fu</b>	40-50	6	Intellectual disabilities	Spouse of Chi
	Mother	<b>Chi</b>	30-40	6	Intellectual disabilities	Spouse of Fu, member of Lovely Dove Group
	Mother	<b>Wa</b>	30-40	18	Autism	Part-time Group administrator

Table 4. Speak Out semi-structured interview participants

Type		Name	Age	Age of Children	Type of Special Needs	Notes
Administrator	Page	<b>Pu</b>	30-40	NA	NA	Part-time Page administrator who also worked as the human resource manager for Speak Out
	Group	<b>Ming**</b>	40-50	18	Down syndrome	Also interviewed as parental user
Professional	Social worker	<b>Tian</b>	20-30	NA	NA	
	Teaching assistant	<b>Tim</b>	20-30	NA	NA	Caretaker of Quini's son
Parent	Mother	<b>Quini</b>	30-40	6	Down Syndrome	Member of Speak Out private parent's Group
	Mother	<b>Diana (Da)</b>	50-60	20	Intellectual disabilities	Member of Speak Out private parent's Group
	Father	<b>Zen (Ren-Yi)</b>	40-50	15	Cerebral Palsy	Author
	Mother	<b>A-lin</b>	50-60	17	Down syndrome	Member of Speak Out private parent's Group

\*\* : This participant was also interviewed in her role as a parental participant.

- Professionals

Finally, the inclusion criteria for the professional participants in this research were as follows

1. Professional who was a social worker, special education teacher, teaching assistant, speech therapist, psychologist, physiatrist, doctor, or any member of any other occupation related to providing professional support for children with special needs and their families
2. Professional who used Facebook at least once per week for interacting with parental users, providing support, or even collecting useful information for helping parents of children with special needs
3. Professional who was a member one of the three virtual communities

The category of ‘professionals’ encompassed people whose occupations were related to providing healthcare services, consultation, and education for children with special needs and their families. For example, social workers are broadly recognised as professionals who help to arrange appropriate healthcare resource and benefits for the families of children with special needs. Moreover, the professional category referred to individuals who had an official licence or certificate to carry out their work and who had undergone formal professional training. In Taiwan, most staff and other professionals, such as social workers, who support families of children with special needs, have licences from the government. Likewise, most organisations, both private and governmental, hire people with licences. Therefore, I did not include parents or experienced volunteers who had been recognised as paraprofessionals within the professional category.

The professionals needed to have experience or to have been participating in virtual communities to interact and to support parents during the recruitment period. They also needed to be members of the three virtual communities in this research for at least a month.

Similar to the sampling strategy for the parental participants, I identified these professionals through the lists of names on each Facebook page, since those lists also

gave the occupation of the person. After I identified these candidates, I contacted them through a Facebook message, as I could access the public information section of their Profiles. I contacted 10 users, but only 3 replied and agreed to participate in the semi-structured interview process. In addition, two professionals were introduced to me by the administrators of Little Star and Lovely Dove, and one professional was introduced to me by a parental participant who was a member of Speak Out. Overall, I recruited six professionals, including two special education teachers, two social workers, one speech therapist, and one teaching assistant (See Table 2, Table 3, and Table 4. for the participants in each case, as introduced in this section).

Since Shin met two sets of criteria for both parent and page administrator, and as Ming and Wa also met the inclusion criteria for both parents and Group administrators, I conducted a longer interview in those instances to collect information on both aspects. These semi-structured interviews were mostly conducted face to face, although telephone calls were used in certain cases, from July 2015 to December 2015.

### **4.3.3 Research diary**

I kept a research diary, which helped me to reflect on the data collection and analysis process, during the research period. It helped me to ensure consistency and reliability within the collected data. As suggested by Nadin and Cassell (2006):

Any reflexive researcher needs an understanding of their own epistemological assumptions in relation to reflexivity. [...], the decision to use a research diary was grounded in the first author's own epistemological position of social constructionism, and a commitment to render as transparent as possible the subjectivities inherent to the researcher and the research process which influence the interpretations generated. [...] this process of reflection is aided by the use of a diary as it enables the researcher to continuously think about their own research practices and assumptions, by recording those thoughts in a systematic way. (Nadin & Cassell, 2006, p.210)

My research diary was used in two ways: (1) to record the incidents that happened during the interviews and observations and (2) to record my reflections on the data collection methods and data analysis process. For example, I recorded several incidents that happened during the interview with Shin, the administrator of Little Star.



I noted the general atmosphere during the meeting, and the occurrences that took place, such as that I stopped recording the interview for a short period of time due to Shin's request. I wrote down the reasons that she asked me to stop recording and my reflection on the incident. Table 5 illustrates how I documented these incidents in my research diary.

Table 5. An example from my research diary: Interview notes (transcribed from an A5 lined notebook)

<b>Date:</b> 10/07/2015 <b>Who?</b> Shin, Little Star's administrator
<ol style="list-style-type: none"> <li>Where: Taiwan, at the cafeteria of the organisation of Little Star</li> <li>Time: morning, around 10am 10/07/2015</li> <li>The interview (the atmosphere and incidents that happened during the interview): <p>Shin was quite tense in the beginning of the interview. Since I had sent her the information sheet before the interview, she mentioned that she understood what the study is about. But, <b>she also asked me who I would be interviewing in the future. I did not tell her about it due to ethical issues. She nodded and said that I did a good job in handling ethical issue.</b> She did not ask further questions about my research. In the beginning, she did not look at me during the interview, but after about 10 minutes into the interview, she started looking at me, and the atmosphere became less tense.</p> <p>In the middle of the interview (the recording time showing 23:27), <b>Shin started to become very upset and complained about her negative experience with a parent in Little Star's Page sharing information about medication with other members in the virtual community.</b> She explained how this incident had caused a lot of problems for her. <b>She asked me to turn off the recording</b> and then mentioned several other incidents which involved her in conflicts with parents or professionals who used to be members of Little Stars. She explained that since some of the people she mentioned were famous in Taiwan, especially famous among the parents' group, she would not want me to record these incidents in my research. Shin gave me the impression that she did not like how medical information was shared in Little Star, especially by parents. She also explained the reasons why she considered sharing medical information in Little Star to be problematic. She showed a strong sense of control over what should be shared in Little Star.</p> <p>There were also several situations when Shin burst out laughing when she shared about her past experiences interacting with the parents in Little Star.</p> <p>During the interview, she also showed me the main platforms of the private Groups she was managing through her smartphone. However, she did not give me access to these private groups, but she said that I could mention what I saw in the research.</p> </li> </ol>

The main platforms of **these private Groups** mainly contained information and **posts Shin shared**. This may suggest that Shin was controlling most of the information in these Groups.

After the interview, Shin thanked me and mentioned that she had a good time.

All reflections were written in a lined, A5 notebook in both English and Chinese (see Figure 7), since using both languages helped me to reflect in a more complete manner that considered the influence of language and culture. That approach was a suitable fit, as I am a bilingual researcher who use both languages in daily life (see p.107 for more details on of how I managed langue, interpretation, and translation during this research project).

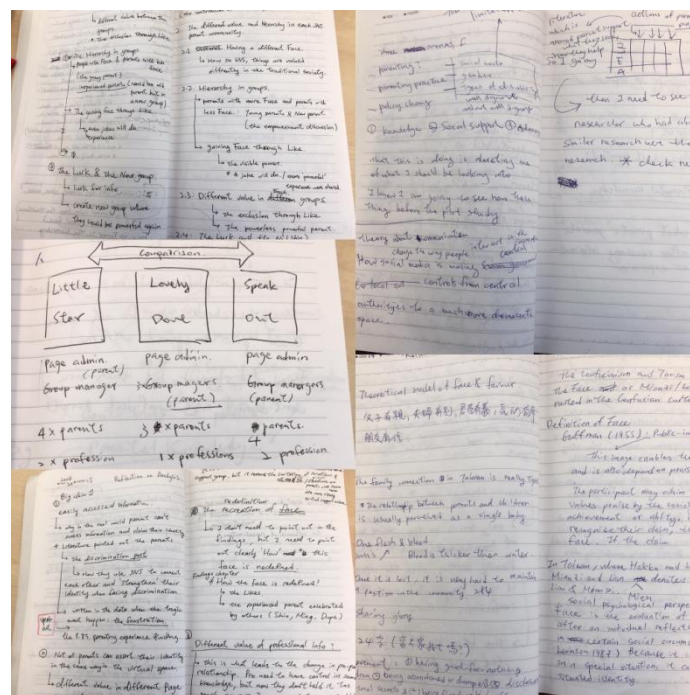


Figure 7. Research diary

## 4.4 Establishing trustworthiness

Robson (2011, p.77) asks: ‘How do you persuade your audience, including yourself, that the findings of your research are worth taking account of? What is it that makes the study believable and trustworthy?’. In answer to these questions, I justified and enhanced the trustworthiness of this research through the criteria for reliability and validity, as outlined in the following sections. I also present how language and the

translation process were carefully managed in this research, along with how I addressed ethical issues. Finally, I present my researcher positionality.

#### 4.4.1 Validity and reliability

When conducting a case study, Yin (2003) has argued that besides internal validity, design tests for construct validity, external validity, and reliability are essential for a quality case study design. In order to guarantee the validity and reliability of this research, I adopted Kilroy's (2013) chart of case study tactics and three design tests (see Table 6).

Table 6. Case study tactics and three case study design tests (adopted from Kilroy, 2013)

Case study design test	Case study tactic	Phase of research in which the tactic occurs
<b>Construct validity</b>	<ul style="list-style-type: none"> <li>• Use multiple sources of evidence</li> <li>• Establish chain of evidence</li> <li>• Have key informants review draft case study report</li> </ul>	Data collection Data collection Data collection
<b>External validity</b>	<ul style="list-style-type: none"> <li>• Use replication logic in case study between the cases</li> </ul>	Research design
<b>Reliability</b>	<ul style="list-style-type: none"> <li>• Use systematic data collection methods</li> <li>• Use systematic data analysis strategies</li> </ul>	Data collection Data analysis

For construct validity, I collected multiple data from multiple sources, including web-based observations and interviews, and I also kept a reflective diary. Comparison and triangulation of data collected through different methods were also undertaken. As for maintaining a 'chain of evidence' and having key informants review my draft case study report, I have presented my analytical findings at different academic conferences and have also published my pilot study in a peer-reviewed conference proceeding. I also presented my draft case study to my supervisors throughout the research process. That supervision contributed to achieve construct validity.

For external validity, as Yin (2003) suggests, the replication logic was identified through either literal or theoretical replication. Literal replication illustrates similar findings across cases, while theoretical reapplication points to contrasting results across cases. According to my findings, similar themes and findings were identified across these cases. That is, the literal replication among these cases was achieved in this study. The analysis of the data was also saturated in all three cases, suggesting the validity of the pattern of replication.

Finally, for reliability, I followed my research design (see p.73) and created systematic ways of collecting both web-based observation data and interview data. I also kept a research diary, which helped me to reflect on the data collection process to ensure the consistency and reliability of the data. Both following my research design throughout the research process and using systematic data collection methods allowed me to achieve reliability in this research.

#### **4.4.2 Language and translation**

Within the qualitative research paradigm, I saw myself as the ‘analytical instrument’ (Barrett, 2007) who translated and interpreted the data not only through the selected paradigms and conceptual framework but also through the lens of my Taiwanese culture and background. In this section, I explain how I addressed and embraced my multilingual engagement with the research process.

First of all, I am aware of, and have investigated, the influence of Taiwanese culture on my research (see Chapter 2, p.26). As Stelma, Fay, and Zhou (2013) have suggested, language is an ‘emergent property of communities and cultures’ (Stelma, Fay, & Zhou, 2013, p.302) that influences and structures research participants’ experiences and identities. As a Taiwanese person and a special education teacher with experience interacting with parents of children with special needs in Taiwan, I am aware of the influence of culture and identified these factors in the process of analysis. Secondly, I conducted the interviews in Mandarin and transcribed them in that same language. This helped me to collect data close to the participants’ culture (the Taiwanese culture). After each theme had been identified, it was translated into English. The selected datasets were then translated into English as well. While

translating the datasets, I discussed them with both native English speakers and Mandarin speakers who were familiar with the concept of special needs and Facebook to ensure the accuracy of the language and the context of the data following translation. As Stelma, Fay, and Zhou (2013) have suggested, the ‘multiple perspectives of the authors, interacting with each other and with the data to generate understandings of researching multilingually, may be described as an ecological process in itself’ (Stelma, Fay, & Zhou, 2013, p.304). This process helped me as the researcher to precisely and faithfully illustrate the contextual background and the research findings according to the culture and language of the researcher, research participants, and readers. Moreover, due to my translation experience for the Enabling Education Network (EENET), a global information-sharing network, and for Visualising Opportunities In Character and English (VOICE), a leadership, character-building, and English-language learning organisation based in the US and Taiwan, I am positive that I had rich resources, both human and material, and abilities that helped to enhance the accuracy of the translations.

## 4.5 Ethical considerations

### *Interview*

Due to the high potential of private and sensitive information emerging within the data collection process, significant attention was paid to clarification and consent to ensure that ethical issues were addressed. All participants were given clear and complete information on the study via an information sheet (see Appendix 2), and they provided written consent before they shared their personal experiences of participating virtual communities, including in private spaces, in the interviews (see Appendix 3 for an example of the participant information sheet and consent form). In addition, during the interview process, the participants were informed and reminded of their rights before and after the conversation took place (Cohen, Manion & Morrison, 2007; Kraut et al., 2004; Lea & Spears, 1992; Riordan, Markman, & Stewart, 2013). Strategies for managing research ethics included the following:

- **Anonymity:** All the data collected remained anonymous, and all participants were given pseudonyms.

- **Member checks:** The accuracy of the meaning and interpretation of the data was checked by the participants during the interviews. I achieved this goal by restating and summarising the information that I received and questioning the participants regarding its accuracy. During the interview process, I made short summaries of the information that I obtained and asked the participant if my summary correctly captured what he or she had said in the interview. Furthermore, I used my research diary to keep track of the process of member checking during and after each interview.
- **High autonomy:** The participants were reminded of their right to withdraw their participation and their data anytime during the research.
- **Self-selected data:** In addition to being given the option to agree to give me full access to review and collect data, participants were given an alternative in which they could select the data they were willing to provide for my research use from within their private spaces. Sensitive issues that the participant did not want share were thus avoided through this process. For example, I asked the parents to provide me with examples of the information that they had posted in their private space. They could decide which post or information they were comfortable passing to me.

During the process of inquiry, the participants had the right to withdraw from the research at any time, as well as the right to refuse to give permission for their collected data to be used. Moreover, the participants who provided access to their private space for research purposes were also reminded of their rights as participants and of their right to exclude me from their private space at any time.

### *Web-based observations of public archived data*

As I mentioned in Section 4.3.1 (p.93), collecting public archived data from the public space/forum of the virtual communities created fewer ethical issues since participants themselves are—and should be—aware of the transparency of information before posting any personal material on a public website (Eynon, Fry & Schroeder, 2008; Kollock, & Smith, 1996). That approach is similar to conducting public document analysis of materials such as newspapers. Thus, unlike collecting data from private platforms, data generation within the public spaces of virtual communities requires

less demonstration of consent from the participants, and most of the time, consent to collect data for research purposes is not necessary.

Even though collecting this publicly posted archived data—which was posted without the influence of the researcher in the internet environment—requires less consent from internet users, as I explained in Section 4.3.1 (p.94) I still informed all Page and Group administrators that I would use the data from their public Pages or Groups. And all names of the Pages and Groups and the participants were replaced with pseudonyms, and so all the collected data remained anonymous

#### **4.5.1 Researcher positionality**

Within the research process, I observed the interactions among participants in virtual communities from a researcher's perspective. That is, throughout the data collection period, I collected data in my role as a researcher who did not influence the environment and behaviour of the members within these virtual communities.

Even though I am not a parent, I am a qualified special education teacher with four years of teacher training in National Taiwan Normal University, one year of teaching experience and one year of experience volunteering in a local development central in Taoyuan, Taiwan. I am sensitive to the setting and issue of supports for parents of children with special needs within the Taiwanese context due to my teaching and volunteering experience. Moreover, as a teacher, I am able to understand and relate to issues identified within the professional's point of view.

Most importantly, I am also a Facebook user, a member of various virtual communities, and even Friends with some of the parents I met in the development centre. I am sensitive to the virtual environment and the meaning of virtual interactions. This identity allowed me to carefully examine and interpret the online data in a manner that mimicked the parents' original intended meaning.

Being a Taiwanese person, a professional, a special education teacher, and a volunteer, I was able to relate to the parents' experiences. I was also sensitive and capable of identifying the influence of Taiwanese culture in the data. Finally, due to my experience of becoming Friends with the parents, I was also more aware of the pattern

of the interactions among parental users when searching for support through Facebook.

## 4.6 Data analysis

The process of data analysis started with the data collection phase and was ongoing. As Robson (2011) has emphasised, data analysis involves collected data being continuously categorised and organised into datasets according to the conceptual framework of the research. This analysis process gives meaning, structure, and order to data, and this process is not fixed but is elastic (Tesch, 1990). A systematic approach guiding the analysis process is essential for ensuring trustworthiness. Therefore, I adopted Miles and Huberman's (1994) process of qualitative analysis as the systematic strategy governing my data analysis (see Figure 8.).

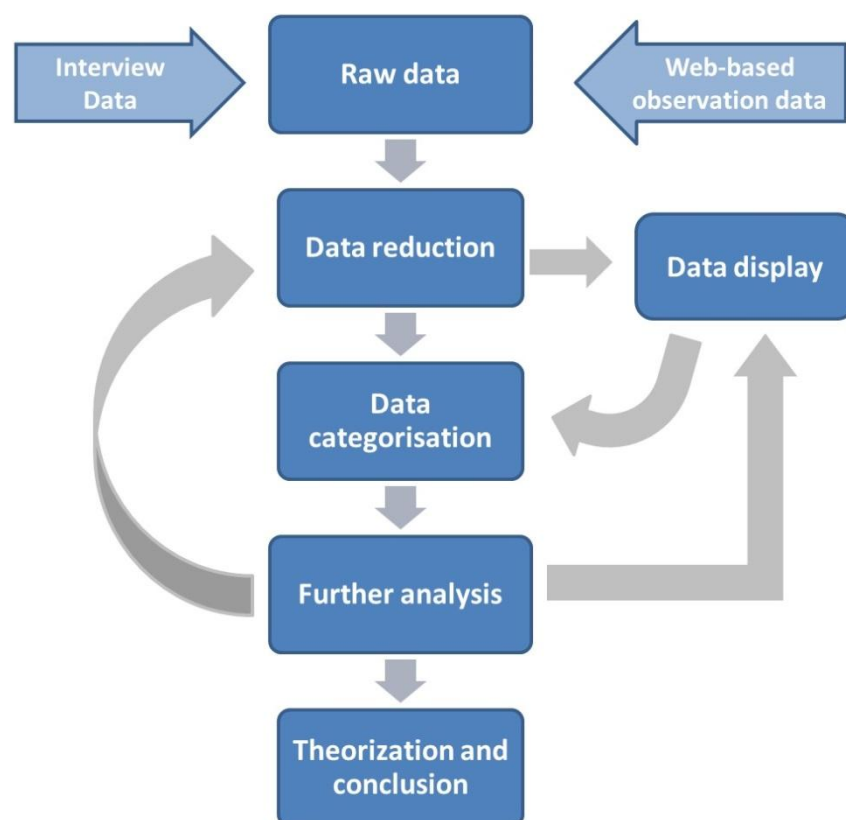


Figure 8. Qualitative data analysis process (adapted from Miles & Huberman, 1994)

Data gathered through both web-based observations and semi-structured interviews went through the first stage of data reduction. During this phase, I reduced data that were overly repetitive and organised them into units of files through RQDA (see Appendix 4).



The data were then displayed through the files in RQDA. This display strategy helped me to make sense of my data and identify potential threads within the basic datasets. I then categorised the datasets according to the themes identified during the analysis process. I conducted thematic analysis (Braun & Clarke, 2006; Bryman, 2012), which Braun and Clarke (2006) have described as:

a method for identifying, analysing, and reporting patterns (themes) within the data. (Clarke, 2006, p.83).

The thematic analysis was based on my analytical framework, which was a chart incorporating concepts of support and the research questions (see Table 7.). The conceptual framework is mentioned in more detail in the next section of this chapter.

I used my research diary to record the process of how themes were identified to help me reflect to on my decisions throughout the analysis process. After the categorisation, I then conducted further analysis, such as comparing a category between cases. The next step was to again display the data to see if any new theme emerged. The data were also exhibited in a number of meetings with my supervisors. This process also helped me to reflect critically on my categorisations and allowed new themes to be considered and identified. Finally, I drew conclusions regarding the analysis process in the shape of carefully considered themes.

#### **4.6.1 Analytical framework**

As Miles and Huberman (1994) define it, an analytical framework is:

a visual or written product that explains, either graphically or in narrative form, the main things to be studied—the key factors, concepts, or variables—and the presumed relationships among them (p. 18).

Therefore, according to my central focus on support for parent and virtual communities and based on the literature I reviewed and synthesised, I constructed an analytical framework, which consisted of a table with the three main concepts of support , including the information, emotional support, and advocacy, and the research questions (Table 7.).

While reviewing different strands of the literature on online parent support, I also realised that most current research on online support for parents has relied on social capital theory, which focuses on examining social interaction within the internet platform (Doty & Dworkin, 2014; Nieuwboer, Fukkink, & Hermanns, 2013; Plantin & Daneback, 2009). Although I could have used social capital theory as framework to guide my research, I still decided that it was less relevant and did not employ it as my analytical framework, since this study primarily aimed to explore parents' interactions and motivations and to examine the content of information shared as parent support. Thus, after reflecting on the purpose of my research and its focus on virtual communities and the internet, I adopted the three concepts of support as the main structure of my analytical framework.

In addition to these three categories, I added 'other' as the last category of parent support, and that group encompassed types of support that did fall into the above-mentioned categories. I also listed sub-questions, which were based on the research questions, to guide the analysis of the data:

- How do virtual communities provide support for parents of children with special needs in Taiwan?

**What** are the existing types and forms of parent support provided in the virtual community?

**Who** provides the support?

**How** do parents interact in their virtual community for support?

- What motivates Taiwanese parents of children with special needs to search for support through virtual communities?

What do parents **expect** to receive?

Does the support meet the **needs** of the parents, and if so, how?

- How does support provided through virtual communities **impact the relationship** between Taiwanese parents and professionals?

These questions helped me to identify themes in each category of support.

Based on the three categories of parent support and the research questions and sub-questions, a chart was constructed as the analytical framework of this inquiry. The complete analytical framework is depicted in Table 7.

**Table 7. Analytical framework**

<b>Categories of support</b>	<b>Emotional support</b>	<b>Information</b>	<b>Advocacy</b>	<b>Other</b>
<b>Research Questions</b>				
What are the existing types and forms of parent support provided in the virtual community?				
Who provides the support?				
What do parents expect to receive?				
Why do parents search for support?				
How does support provided through virtual communities impact the relationship between Taiwanese parents and professionals?				

This chart guided the design of the data analysis process and helped me to identify the concepts of parent support in my research data.

### 4.6.2 Analysis process

All web-based observations and interview data were transcribed and recorded using RQDA (Huang, 2014) and its coding system. All transcription, recording, and coding processes were executed in Mandarin to keep the data as close to the original meaning as possible, as I explained in the previous section (p.107). Information or posts that were overly repetitive in the virtual communities were reduced to only one post of such information. For example, in Lovely Dove, the same advertisement for a charity fundraising event was posted across all four virtual platforms, including the Page, Group 1, Group 2, and Group 3. Therefore, in order to avoid repetition, I only kept one post about the charity event for my data analysis process. Overall, I identified 13 repeated posts shared in these virtual communities between 18 March 2015 and 10 April 2015. After reading the content of the posts and making sure that the information was the same and no further discussions occurred in relation to these posts, I removed them from my datasets. However, I also created an extra RQDA document to store all the original data, including the observation data and the interview data. Storing all the original data in an extra RQDA document allowed me to extract them as needed later in the research process. The need to extract the reduced data, however, did not arise later in the study.

#### *The first stage of analysis: Within-case analysis*

Within each case, I first categorised the three sets of data—namely, the interview, observation data, and research diary—into broad categories based on the three concepts of parent support: information, emotional support, and advocacy. All data were examined several times to determine that all issues were uncovered. Newly emerging categories were also classified and grouped into the category of ‘other’. During this process of categorisation, I constantly reflected on the literature on parent support, as introduced in Chapter 3, to categorise the data in terms of the three concepts of support as accurately as possible. I was aware that the categorisation may be overlapping with each other. Therefore, during the process of categorisation, some data were placed into two classes of support, or even three. Table 8. contains an example of this first stage of categorisation.

Table 8. Stage 1.1: The categorisation of data into three categories of parent support

Data	Three categories of parent support
<p>Web-based observation data from Lovely Dove</p> <p><b>Post</b> [2 February 2015, 8:10 pm]:          Could I ask the parents in this Group how do you teach your kid to shower? I got a bathtub at home so I fill the bathtub with water. Then I teach my son to use the little bailer to shower himself. But he cannot lift the bailer up when it is filled with water. He is already using the smallest bailer in the shop.          We also tried to use the showerhead, but the water pressure is too strong. And, he does not like water in his eyes, so whenever he would use the showerhead, he would keep dropping it, because he wanted to wipe the water off his eyes. Please let me know if there is another solution.  <b>Action:</b> Received 15 Likes</p>	<p>Informational Support</p>
<p><b>Comment 1</b> [February 2015, 8:23 pm]:          You could try the showerhead that has different spray patterns, so you could change the water pressure through changing the pattern.  <b>Action:</b> <u>Received 1 Like from the user who asked the question</u> and 3 Likes from other users</p>	<p>Informational Support</p> <p>Emotional Support</p>
<p><b>Time:</b>  <b>Comment 2</b> [February 2015, 9:02 pm]:          If your son is worried about water getting into his eyes, you could consider bringing him to a swimming lesson. It is a good way to help children overcome their fear of water. This will help you and your family in the future when you travel. My daughter is the same, but now she can cope with water better. It might take awhile but the result is worth it.  <b>Action:</b> <u>Received 1 Like from the user who asked the question</u> and 4 Likes from other users</p>	<p>Informational Support</p> <p>Emotional Support</p>
<p><b>Interview Data: Chi</b>          Oh, I read her [Ming's] posts quite frequently. You know, her son is now working. I have known her and her son since he was just a little boy. And he used to be a little child with Down syndrome with low potential. But now he's got a <u>permanent job! And he can take care of himself! I really admire Ming. How she made all these things possible.</u></p>	<p>Informational Support</p> <p>Emotional Support</p>

- After this first step of categorisation, I then identified sub-categories that emerged from within the three sets of data by examining the sub-questions listed in the chart of the analytical framework. For instance, within the broad category of ‘Informational Support’ I identified sub-categories including: child development, raising children with special needs and their siblings, formal parenting instruction, formal and informal medical information, educational placement, school activities and school life of the children, communicating and cooperating with teacher or professionals such as doctors, welfare information and travelling leisure information. Within each broad category, data relating to particular subcategories were grouped together. . I compared data within these sub-categories in terms of differences and similarities regarding experiences of parent support among members of the same virtual community. The comparison allowed me to examine the experiences with parent support according to the type of support and to explore the realignment of parent support in each virtual community. Comparisons were also made of parents’ interactions pertaining to support within the private and public spaces of the virtual communities. These comparisons provided me with a better understanding of the forms of interactions for parent support that arose on the different virtual platforms of the three cases. In making these comparisons, I was therefore able to identify themes, emerging within and across the subcategories. Table 9 contains a sample from my work demonstrating how I identified informational support sub-categories and themes using data from Lovely Dove.

Table 9. Stage 1.2: Sub-categorisation and Themes

Informational support (Lovely Dove)	Sub-categories	Themes
<p>If your son is worried about water getting into his eyes, you could consider bringing him to a swimming lesson. It is a good way to help children overcome their <u>fear of water</u>. This will help you and your family in the future when you travel. [Comment 2. Shared in <b>Lovely Dove</b>, 2 February 2015]</p>	<p>Childcare</p> <p>Travelling tips</p>	<p>Parenting skills</p> <p>Leisure</p>
<p>You need to let the teacher know that you are on the same side with them. And if the teacher needs your help, please let him or her know that you are available to help. For example, you could help advocate for better working hours and pay for teachers, since teachers are still struggling to get better hours and pay. [Comment 2. Shared in <b>Lovely Dove Group 3</b>, 15 March 2015]</p>	<p>Teacher, communication with teachers, parent-professional relationship, experience-based information</p>	<p>Educational provision</p>
<p>All academic assessments are done by the homeschooling teacher. So no need to worry. So will her son return to school after the chemotherapy? [Comment 1. Shared in <b>Lovely Dove Group 3</b>, 28 August 2015)</p>	<p>Assessment, specific education programme</p>	<p>Educational provision</p>
<p>Not all treatments are good for your kid. And my kid has taken most of the treatments already, so I know what the treatments are like. I will leave my comments [replying to parents who ask questions about treatments] based on my son's experience. [Interview with <b>Dee</b>, mother and member of <b>Love Dove</b>]</p>	<p>Treatment, experience-based information.</p>	<p>Medical resource</p>

During this stage of the analysis, I also focused on understanding how the roles different users functioned in influencing the interactions of support and resources within the virtual communities. That is, in this stage, I also identify the members who were controlling the information, managing the resources and providing the resources. As Scott (2012) has suggested, social network analysis helps to identify the relationships among individuals and their patterns of relations. Such insights assist researchers in understanding the network relationships and system. Therefore, borrowing from social network analysis (Scott, 2017), I counted and compared the frequency of interactions, such as clicking Like or replying, among individuals who participated in each post of all three virtual communities. The higher the frequency of the interactions initiated by an individual or of the responses that person received from other members, the more in control or more influential was that user with respect to the discussion. For example, Shin was identified as frequently receiving Likes when she commented in the posts shared in Little Star, and she also received more attentions and responds from other parents in the majority of the discussions attached to these posts. Thus, in other words, she may have been more influential and powerful in the Little Star community than other parental users. Through this examination of the frequency of interactions, I identified the users who appeared the most likely to control the resources and information in each community.

After identifying the network and relationships, I displayed the data and repeated the first and second steps of this stage of analysis to analyse the contents of the discussions and to identify potential themes. This strategy helped me to identify differences in the contents of the shared information across the virtual platforms. These comparisons also helped me to pinpoint the diverse expectations held by the parents in the virtual communities regarding means of receiving parent support. This process ended when no new themes were identified.

### *The second stage of analysis: Between-case analysis*

In the second stage of the analysis, I reviewed and compared the data across all three cases within each category, sub-category and theme (see Table 10. for an example of this step of the analysis). I then reviewed each set of data repeatedly to develop an



interpretive relationship with it. This comparison across cases allowed me to identify potential connections and identify new themes and also helped me to avoid missing themes that were not identified in the previous analysis.

Table 8. Stage 2.1: Cross-case analysis

Little Star (Emotional)	Lovely Dove (Emotional)	Sub-categories
<p>Yes, <u>I understand</u>. And I almost gave up on myself and my son as well. I used to hope that there could be a way where I could die without hurting anyone in my family, but, thankfully, I pressed on with tears and blood [meaning perseverance in Chinese] and hard work during that period. So even though it is hurting and hard, I have overcome those difficult times in life. All us parents of children with autism shed our tears and said <u>We understand</u>. And yes, I understand. (Post shared in <b>Little Star</b>, 24 March 2015)</p> <p>When I read this news yesterday, my heart ached. <u>I understand</u> his pain. And I am also afraid that one day I will be like him. Well, I can only hope that I will keep <u>pressing on</u>, one day at a time. (Comment 9 shared in <b>Little Star</b>, 24 March 2015)</p>	<p>With this sad incident happening in our society, all of us felt sad and sorry for the family. [...] We as a family <u>can relate to</u> the father's struggle, and we hope to <u>press on</u> through this difficult situation together with all of you. We hope to prevent the tragedy from happening again. (Post shared in <b>Lovely Dove</b>, 23 March 2015)</p> <p>Not only the family members were tired, the boy with cerebral palsy was also tired. As a parent, I tried my best to help my daughter to grow up just like other children and help her to be positive in her life, but sometimes she would still try to hurt herself by madly hitting her head and feet. <u>She even tried to kill herself</u> several times. So I think even though the parents were tired, the person with disabilities was the one who suffered the most. (Comment 12 shared in <b>Lovely Dove</b>, 23 March 2015)</p>	<p><b>Sympathy:</b> Using the terms 'I/we understand' and 'I/we can relate'</p> <p><b>Sorrow/sympathy:</b> Expressing the feeling of sadness, feeling sorry, shedding tears</p> <p><b>Encouragement:</b> Using the term 'press on' to encourage other parents to keep going</p> <p><b>Self-harm/suicidal thoughts:</b> Expressing extreme feelings, potentially hoping to seek support from the members</p>

Overall, under the three categories of support, I identified 20 sub-categories, including 10 sub-categories of information, 7 sub-categories of emotional support, and 3 sub-categories of advocacy (see Table.11). Bring together data from multiple sub-categories I then identified five cross cutting themes, including developing parenting skill, searching for medical resource, educational provision for their children, welfare information and finally leisure, were identified (see Table 11). All themes are connected to the concept of Face. All categories, sub-categories and themes are shown in Table. 11.

**Table 11. Summary of the categories, sub-categories and themes**

Categories of parent support	Sub-categories	Themes
Information	<ul style="list-style-type: none"> <li>• Child development</li> <li>• Raising children with special needs and their siblings</li> <li>• Formal parenting instruction</li> <li>• Formal medical treatment/therapy/resource/medication</li> <li>• Informal medical information</li> <li>• Educational placement</li> <li>• School activities and school life</li> <li>• Communicating and cooperating with teacher or professionals such as doctors</li> <li>• Welfare information</li> <li>• Travelling tips/Holiday/Social gathering information</li> </ul>	
Emotional support	<ul style="list-style-type: none"> <li>• Sympathy</li> <li>• Sharing sorrow</li> <li>• Offering care/comfort</li> <li>• Encouragement</li> <li>• Showing solidarity</li> <li>• Finding solidarity through building social relations</li> <li>• Relaxed through having fun together with other parents</li> </ul>	
Advocacy	<ul style="list-style-type: none"> <li>• Educating the public/professional about their children's condition and their needs</li> <li>• Explaining/protesting about the lack of medical/educational resource for their children</li> <li>• Explaining/protesting about the lack of support parents faced in the society/school/hospital/family</li> </ul>	
Others	NA	

## 4.7 Summary

This chapter has outlined and justified the methodology employed to answer the research questions. A principle goal of the study was to understand how parents interacted in the virtual communities to obtain support, including by accessing information and emotional support, networking, and engaging in relationships with professionals.

A case study of three virtual communities and a qualitative paradigm were thought to be the best approach for gaining deep insight into the parents' experiences with interacting for support and their motivations of joining virtual communities for support. Web-based observations were conducted in each virtual community. Semi-structured interviews were held with parents, professionals, and administrators. The analytical framework was used to identify broad categories, sub-categories and themes in the data. A thematic analysis was employed to examine within and across the cases to identify new emerging themes, commonalities and differences. And, a systematic evaluation borrowing from social network analysis was used to map the interactions among the participants.

### *Presentation of the findings*

Chapter 5 presents the pilot analysis of the categories (as presented in Table 11), before proceeding to chapters 6, 7 and 8 for my presentation of my findings. All results are arranged according to the themes that emerged throughout the data collection process, rather than in a case-by-case manner. The reason that I discuss my findings in that way is to help the reader to see those themes across the three virtual communities to build a holistic picture of the parents' overall experiences with support in virtual communities.

It is also important to note that due to the large number of members in each virtual community, it was impossible to give each member a pseudonym. Therefore, in the findings chapters, only the interview participants are assigned pseudonyms (see Table 2, Table 3, and Table 4).

The interview data shows the name, the role, and the name of virtual community of the quotation. For example, the code used to signify a quotation from the interview with Jade was as follows:

Interview with **Jade**, mother and member of **Little Star**

And the code for Shin read as follows:

Interview with **Shin**, administrator of **Little Star**

As for the web-based data, they were coded according to the format of the information, the date, and the virtual community. For example, for a post shared in Little Star on 22 July 2015, the code was:

**Post** shared in **Little Star**, 22 July 2015

As for the comments on the post, all comments were coded in the order that they were made. For example, the first comment on the post shared in Little Star on 22 July 2015 was coded as:

**Comment 1** shared in **Little Star**, 22 July 2015

The second comment on the post is presented as:

**Comment 2** shared in **Little Star**, 22 July 2015

## Chapter 5. News about a father murdering his son: A critical incident

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Chapter 5 presents the pilot analysis of the categories and themes identified in this study, using a news story which was shared within all three virtual communities. The news story is about a father strangling and killing his son with cerebral palsy. All three communities posted and demonstrated their responses to this news on their Pages after the incident took place. All three virtual communities shared the original news story, and then the Page administrator commented on the incident on behalf of the respective organisation. Parental members of the communities also made comments and engaged in discussions with other users. There were three main reasons why this critical event was essential to this study: (1) It revealed clear patterns of interactions among the parents and professionals within the three cases. (2) It provided comparable data from the three cases. This helped me to identify the similarities and differences related to the interactions among the users from the three virtual communities. (3) It provided useful data to explore the concept of Face and categories of parent support.

This chapter is divided into two main sections. In **Section 5.1**, the content of the news is presented and discussed, along with how the Taiwanese culture of Face influenced the tone of the news content and the broadcasting style adopted by news corporations. In **Section 5.2** of this chapter, I presented how each virtual community responded to this critical incident. The categories and themes of the findings identified based on the analytical framework were shown in this section in order to present the pilot analysis of the categories and themes before proceeding to Chapter 6, 7, and 8. These will address the themes in greater detail.

### 5.1 The news

On 22 March 2015, an incident grabbed headlines across all news outlets in Taiwan. A father strangled his son with cerebral palsy to death after his son agreed to die for the family. The news article from *China Times*, the national news corporation in Taiwan, stated:

The worst Tragedy of Humankind...Father Killing His Son with Cerebral Palsy

Yet another tragedy! A 21-year-old young man with cerebral palsy was killed by his father Mr. Ho, 41. The tremendous amount of stress involved in taking care of his family, including his son with cerebral palsy, who had become suicidal and homicidal, and his two elderly parents. Feeling exhausted and desperate, Mr. Ho killed his son with cerebral palsy in his minivan and phoned 110 to turn himself in. 'I killed my son!' he told the police over the phone. When Mr. Ho was arrested, he cried and shouted, 'I should have gone with him [his son]! I don't want him to suffer!' (Hu, 2015)

A multitude of news articles and videos about this tragic incident were repeatedly shared within different social network sites and social media platforms. Discussions were held by different groups of people, such as parents' organisations for families of children with special needs. All three virtual communities considered in this study also posted the news article and held discussions about it. Little Star chose the news article from *The Liberty Times*, one of the largest news corporations in Taiwan, and posted it to the Little Star Page. Both Lovely Dove and Speak Out chose the same news article from *Apple Daily*, which is another of the largest news corporations in Taiwan, and both posted it to their Page. After the news was posted to each Page, parental users and other general users commented on it and discussed the event together.

The following sections illustrate the comments and discussions of the users of each virtual community. However, before I present how each page reacted to the incident, I discuss which news article was selected by each page administrator and how the reporting style of the selected news corporations shaped the context in which the incident was portrayed.

### **5.1.1 Content of the news articles**

Firstly, the news context that Little Star chose came from *The Liberty Times*. That publication's article covering the incident was titled as follows:

Tired of taking care of the son with cerebral palsy? A father strangled his son and cried in the police officer's arms. (The Liberty Time, 2015)

This title of the news story implied the hardship of taking care of a son with cerebral palsy being the main reason why the father killed his son. The title also stated that the



father was experiencing great grief when he ‘cried in the arms of the police officer’ and hinted that the father was reluctant to kill the son and that the challenges of taking care of his son might have been the main cause of this tragedy.

In the main body of the news article, the author frequently used the term ‘tragedy’ to describe the event. The text gave vivid descriptions of how the family had been suffering from taking care of their son before the incident happened. The story continued:

The son with cerebral palsy was cared for mostly by his grandmother, but, unfortunately, due to his violent tendency, he started to beat his grandmother. The father has been exhausted, mentally and physically, due to this difficult situation he faced. Under this stress for such a long time, the father decided to kill the son. [...] (The Liberty Time, 2015)

The news item again indirectly suggested that the father was not entirely at fault for committing this crime, but that the challenge of taking care of a child with severe cerebral palsy had led to this incident.

Apart from emphasising the stress of taking care of the son, in the sections describing the murder, the news story repeated the descriptions of the father ‘weeping constantly and bitterly’ and ‘crying and hugging the dead body of the son’. These descriptions could potentially have been intended to make the reader sympathise with the father’s struggle. This news article was short, with only two main paragraphs in total.

However, the article paints a very clear picture of the struggle of the father. Most of the text was dedicated to describing that individual’s grief and his difficulties in taking care of the son with cerebral palsy.

Secondly, as for the news article used by Lovely Dove and Speak Out, both selected the same story from *Apple Daily*. This news article was longer than the one that Little Star shared on its Page. However, similar to the news article posted by Little Star, *Apple Daily*’s description of the incident also mainly focused on the father’s struggle and frustration and on the challenges associated with caring for the son with cerebral palsy. The story was titled as follows:

The worst tragedy of our society—Father killing his son with cerebral palsy. (Apple Daily, 2015)

The news reporter emphasised the incident by using the term ‘worst tragedy’ in the title. As for the content of the news article, detailed descriptions of how and why the incident happened, such as the father’s reason for killing his son and means of carrying out this crime, were given.

When the father learned that his son hurt his grandmother this afternoon because of anger, he was heartbroken. He was worried about both the son’s illness [cerebral palsy] and the safety of his family members, especially the grandmother. He felt helpless. This morning, he took his son out in his car as usual. When the car he was driving reached the intersection of Fuyuan Street and Riverside Street, he stopped the car. He turned around and talked to the son in the back seat with tears: ‘Everyone in this family is exhausted because of you. So can I kill you?’ The son, who was already suicidal, then nodded and agreed. The father got out the car and went to the back seat, sitting right next to the son. He strangled the son, who had no strength and will to fight back, to death. (Apple Daily, 2015)

This article from *Apple Daily* also illustrated how the other family members reacted to this incident.

When the grandmother of the victim received the news, she rushed to the crime scene immediately. She cried and asked ‘Where is my grandson?’ ‘Let me see him!’ When the grandmother saw the body of her grandson, she collapsed, burst into tears, and shouted ‘My grandson!’ All of the people who were there also burst into tears when they saw the grandmother crying. (Apple Daily, 2015)

After the description of the incident, the news article then shared thoughts and recommendations obtained through an interview with a senior manager of a cerebral palsy advocacy group in Taiwan. The senior manager stated:

The reason why the son with cerebral palsy agreed to let his father kill him is that he understood that his father was struggling to take care of him. So the son repaid [‘Huìbào’, a Chinese term meaning to contribute, reward, or repay someone] the family through his death. But even so, this father shouldn’t have done such thing! No one has the power to take other people’s lives like that. (Apple Daily, 2015)

Here the term ‘repaid’ is referring to the traditional Taiwanese culture of ‘Xiào’ (as introduced in p.26) in which sons and daughters need to be devoted to the family and provide either financial support or physical support, such as taking care of elderly relatives, to thank their parents for raising them. Therefore, the manager of the cerebral palsy advocacy group was suggesting that the son, who understood his father’s struggle of raising the family, hoped to ‘repay’ the family through his death and to reduce his father’s burden related to taking care of him.

After this comment, the senior manager then mentioned that she also had a daughter with cerebral palsy and emphasised that her daughter was currently a postgraduate student and considered successful and have Face in society. She argued that there were plenty of resources for families of children with special needs in Taiwan. She said:

Even though it is hard, I survived, and now, my daughter is studying for a master degree. [...] even though they [children with cerebral palsy] learn slowly, they can still learn. [...] There are unlimited resources you could use, so don’t give up just because you think they [children with cerebral palsy] have no hope. (Apple Daily, 2015)

After the comments from the senior manager, the news article then presented medical facts about cerebral palsy by quoting a junior neurosurgeon from Lin Shin Hospital. The doctor suggested that the victim in this incident suffered from a ‘severe case’ of cerebral palsy. That quotation also explained other potential limitations of having cerebral palsy:

[...] these patients may also have problems such as slow development, learning difficulties, and emotional disorders. (Apple Daily, 2015)

This news article from *Apple Daily*, which was shared on the Page of both Lovely Dove and Speak Out, clearly suggested that this incident was pitiful and disturbing to society. The text also adopted the medical model of disability, which focused on the disability of the son and the challenges associated with disabilities in Taiwanese society.

### 5.1.2 The cultural influence on the reporting style

When considering the main reasons that both articles focused on blaming the disability and using dramatic descriptions, two potential explanations suggest themselves. The first one is the sensationalistic reporting style of the two news corporations, and the second one is the influence of Taiwanese culture.

Both *The Liberty Time* and *Apple Daily* are known for their sensational style of reporting (Wu, 2012). They use eye-catching photos and exaggerated descriptions of incidents, most of which are lurid, in their newspapers to capture the reader's attention (Wu, 2012). This scandalous style of thick description can be clearly seen in the two news articles, and examples include the references to the grandmother's tears or the father's conversation with the son before killing him.

Therefore, I compared the two news articles with another four news articles from other news corporations in Taiwan that Wu (2012) identified as less sensational than *Apple Daily* and *The Liberty Time*. The alternative articles came from the *Central News Agency*, *China Times*, *Formosa News*, and *Eastern Broadcasting Corporation*. However, after the comparison, I discovered that all of the descriptions were similar to those found in *Apple Daily* and *The Liberty Time*. All of the news articles focused on the challenge of raising a child with cerebral palsy and the struggle of the father and the family. All of the news stories suggested the incident was unfortunate and pitiful.

The following are the titles of the news articles published by each news corporation:

Could I Kill You? Mr. Ho Killed His Son with Cerebral Palsy After Being Exhausted of Taking Care of His Son. *Central News Agency* (Tsai, 2015),

The worst Tragedy of Humankind...Father Killing His Son with Cerebral Palsy. *China Times* (Hu, 2015),

'Everyone is Tired of You'—Father Killed His Son with Cerebral Palsy with Tears. *Formosa News* (Formosa News, 2015)

Person with Cerebral Palsy Beat His Grandmother Violently. Father Strangled Him and Cried Bitterly in Car. *Eastern Broadcasting Corporation* (Eastern Broadcasting Corporation, 2015)

The primary focal point of all of these news titles was the father's exhaustion, and the headers suggested that this incident was the 'worst tragedy'. As for the content of these articles, most of the news reports also laid the blame for the incident on either on the son or the father. Some articles took up an entire page of the newspaper to describe how the 21-year-old son with cerebral palsy was acting violently towards his grandmother by kicking her and to explain that the son had already caused significant hardships for the family despite the father's love and care. The mother of the family was only mentioned briefly in the *China Times* and *Formosa News*. These two articles stated that she was working and did not spend much time at home and fulfil her motherly duty. These pieces of evidence may suggest that these news articles were trying to indirectly advise readers to blame the mother for this tragic incident and to pity the father, who had no choice but to murder his son since he did not receive support from his spouse in caring for their child. This reflects the Taiwanese cultural norm that gives mothers most of the responsibility for taking care of the children in the family and for supporting their husbands.

Five out of the six news articles blamed the father for 'giving up' and being unable to fulfil 'Xiào'. That concept, which was introduced in Chapter 2 (p.26), refers to the virtue of respect and of demonstrating one's devotion to his or her parents, elders in the family, and the ancestors according to Confucian philosophy. In most instances, 'Xiào' is measured by the quality of life enjoyed by one's parents, and permitting the elderly to suffer in their old age is considered the worst example of a failure to fulfil 'Xiào'. Therefore, when the news articles pointed out that the father allowed his elderly mother to suffer as a result of caring for his son, they were possibly implying that he was bringing shame to the family for failing to act out 'Xiào'. Thus, the news items were indicating that the father was at fault for this tragedy and for failing to 'be the honourable man' in the family.

These common emphases on the misfortune and the negative image of the son and his family across all of the news articles might reveal a shared ideology rooted in traditional Taiwanese culture that people with special needs and their families have bad karma and may bring bad luck. As discussed in Chapter 2, Hsu et al. (2017) have stated that most parents of children with special needs in Taiwan continually face blame from the wider family community and society. Furthermore, this culturally

rooted blame is a common reason for the overwhelming stress experienced by parents of children with special needs in Taiwanese society. Chang and Wang (2016) researched how Taiwanese newspapers portray persons with disabilities and found that the majority of the public still views people with disabilities as ‘helpless’ (2016:23) and a ‘burden of the society’ (2016: 23). Wu’s (2014) study reviewing special education development in Taiwan indicated that the majority of people with special needs and their families still have a negative image in society and face discrimination. These news articles might suggest that this biased cultural influence regarding how society views persons with disabilities and their families was evident in their reporting on the father and the son. That cultural influence might have also played a role in the stories’ portrayals of these individuals as members of an unlucky and pitiful group of people who have lost Face in society.

## 5.2 The response to the news from each virtual community

### 5.2.1 The response of Little Star

Using the news article from *The Liberty Times*, Shin, the administrator of Little Star, showed her sympathy to the father and the son in her post. Shin wrote:

Yes, I understand. And I almost gave up on myself and my son as well. I used to hope that there could be a way where I could die without hurting anyone in my family, but, thankfully, I pressed on with tears and blood [‘Xiěhàn’, meaning perseverance in Chinese] and hard work during that period. So even though it is hurting and hard, I have overcome those difficult times in life. (**Post** shared in **Little Star**, 24 March 2015)

Shin expressing her sympathy by stating that as a mother of a son with autism, she could relate to, and understand, the struggles and difficulties facing the father. Shin shared the news through a first-person perspective as a mother who ‘had been there’ and who could understand the father’s struggles. She wrote:

[...] All the parents from Little Star shed our tears and said ‘We understand’. And, yes, I understand. (**Post** shared in **Little Star**, 24 March 2015)

Expressing sympathy is identified as a common sub-category under the category of emotional support. It is also identified to be a way these members show their support

in all five themes (see p.122) identified in this research. For example, Shin's comments frequently emphasised that she 'understood' and repeatedly introduced the idea of 'we' in reference to parents of children with special needs. She suggested indirectly that 'we', as parents, understood the struggle the father was facing. Other parental users echoed and supported Shin's idea in their comments through restating: 'Yes, we understand' and 'Yes, I could relate to that pain'. She explained to the users that she had been fortunate to be supported by different people around her during that difficult period of her life. Shin received more than 1,300 Likes on this post, and 359 users shared her post. This indicates that the parents in the Little Star community strongly agreed with the information that Shin shared and expressed their solid support for her. Jade explained:

The information Shin shared in the Groups was always good and helpful. And I really like reading her posts. So I click Like to them to show my support. (Interview with **Jade**, mother and member of **Little Star**)

Some parents also demonstrated their support directly by commenting on Shin's post after she shared her experience of being ready to give up and of facing hardships in taking care of her son. A mother's comment referred to Shin's struggles:

We will support you fully Shin! Keep pressing on! (**Comment 4** shared in **Little Star**, 24 March 2015)

In addition to echoing Shin's idea, one mother reminded all other parental users that they should not react to the news simply by reinforcing that they, as parents, could relate to the father and by expressing their sympathy. According to that mother, the users should also 'turn the grief into strength' and keep pressing on. She wrote:

I understand too how the father feel too, but we could only keep reminding ourselves to keep pressing on and turn this grief [feeling sorry for the family in the news] into strength to face the difficulty in our life [...] let us press on together! [received 8 Likes] (**Comment 5** shared in **Little Star**, 24 March 2015)

After this comment was posted, it received 8 Likes from other parental users. Shin also clicked Like on this post. This mother illustrated how Facebook provides opportunities for parents to encourage each other and to display their determination, and strength to each other.

This comment on Shin's response to the incident stimulated a handful of new discussions in which other parental users shared ideas for how to stay strong and press on together. The focus in this discussion shifted from giving sympathy to actively sharing ways to seek solutions and strength as a group.

Yes, even if our heart aches, we need to press on! [received 3 Likes]  
(**Comment 8** shared in **Little Star**, 24 March 2015)

A father wrote straightforwardly that they needed to receive more information about welfare support from the local government.

We received very, very little resources and information from the government. With such limited resources and information, I don't know how to carry on supporting my family. [received 2 Likes]  
(**Comment 11** shared in **Little Star**, 24 March 2015)

Some parent shared how they also needed emotional support to take care of their children, and a number of them even voiced their fears and worries in the comments.

When I read this news yesterday, my heart ached. I understand his pain. And I am also afraid that one day I will be like him. Well, I can only hope that I will keep pressing on, one day at a time. [received 7 Likes] (**Comment 9** shared in **Little Star**, 24 March 2015)

After reading Comment 9, several parents expressed their support, encouragement, and solidarity to the mother who had written it:

Let press on together! Don't give up! [received 2 Likes] (**Comment 10** shared in **Little Star**, 24 March 2015)

This is a tough journey, but we can press on together! Let's keep going! [received 5 Likes] (**Comment 12** shared in **Little Star**, 24 March 2015)

Cheng mentioned that these interactions among parents to demonstrate encouragement and solidarity were common in Little Star, even though she did not comment on this post. She said:

We clicked Like or comment to show each other that this information, the opinions or suggestions they shared, are good. We



understand what each other has been through, and that understanding becomes a powerful thing. A powerful thing that supports us to keep going and face the music. (Interview with **Cheng**, mother and a member of **Little Star**)

As can be seen in this example, this virtual community provided a platform where all users had the same authority to contribute their thoughts to a discussion. It allowed parents to share their thoughts and ideas and to stimulate discussions on topics that diverged from the news story's original focus on blaming the father and the son. The community provided a space where parents could speak their minds and voice their opinions that countered the dominant culture.

This critical event also illustrated that the identity of parents of children with special needs allowed those individuals to build strong connections with each other and helped them to freely share their opinions and emotions, this identity of being a parent also helped Shin, the administrator of Little Star, to gain trust from other parental users. In this situation, it was crucial for Shin to identify herself as a mother.

During the interview with Shin, I asked her directly about her identity, since she is a famous internet personality, a school teacher, and a well-known author of books giving parenting tips for parents of children with autism. She hesitated but then firmly refused to be seen as a professional. 'I am and always will only be a mother', she stated. When other parents mentioned her, they also referred to Shin as 'that amazing mum' or 'super mother'. This may demonstrate the importance of being a parent in the virtual communities. By emphasising this identity while introducing the news, Shin may possibly provided the parents with a strong idea that she was able to relate to their situation and also sense of solidarity. This sense of solidarity is also influenced by the Taiwanese culture of Face, in which a person's self-identity is given by the community the person belongs to. Through sharing the same identity and being approved by other parents in the virtual community, parents gain their Face which is lost in the Taiwanese society, as has been discussed in Chapter 2.

Interestingly, in Shin's response to the news, she also made claims representing all parents of children with autism. She asserted that 'living human beings', such as a group of professionals or friends, is the most important resource (social, educational

and medical) to help children with autism. She claimed that she had found these people and organised a team to provide help for parents who were facing similar challenges. Shin wrote:

Over the past few years, I realised that the best assistive equipment for a person with autism is actual living human beings. So we [Little Star] have a group of people who are devoted to serving the families of children with autism. We help each other to become the 'assistive equipment' for helping our children with autism. (**Post** shared in **Little Star**, 24 March 2015)

She then continued by suggesting that autism is different from all other types of disabilities and implying that it is useless to seek help from the government. She wrote:

Many people said that the welfare system is set to secure all citizens' benefit, but I think it is only suitable for other types of disability. People with other types of disabilities see the welfare system as some charity that gives them money and resources. But this could only provide limited help to those with autism. Because people with autism not only need a complete welfare system to support them, they also need a group of people who understand and support them. To be honest, I do not expect the government to do things that could help in the near future since this is a tough challenge for all countries around the world. So I believe, we need to start taking actions right now. (**Post** shared in **Little Star**, 24 March 2015)

Here, Shin stopped discussing the issues related to the news. Instead, she started to promote her organisation and to claim it alone could provide proper support for the parents and their children. She asserted that children with autism were different and government support services and the welfare system were only suitable for 'other types of difficulties'. This claim indirectly suggested that only her organisation, Little Star, could provide appropriate support for the parents and children and that the government could not help these parents. This change from commenting on the news to introducing workshops held by her organisation may possibly be business-directed since part of the main income for Little Star was from the fees parents pay for attending the workshop. Even so, many parental users still illustrated their agreement with Shin's idea by leaving comments affirming what Shin had said. For example, a mother wrote:

Thank you Shin for helping us and leading us. My son is still young, but he might need this information about vocational training in the future, so I hope to learn more about this training you hold. (**Comment** 17 shared in **Little Star**, 24 March 2015)

In the post, Shin also gave examples of how teenagers with mild autism faced a greater struggle than teenagers with Down syndrome in finding a job or in fitting into the work environment.

Unlike children with Down syndrome, teenagers with mild autism may become really unsteady in their emotion when facing even the slightest frustration in their workplace. Having these unstable emotions, these teenagers are seen as landmines in the company. (**Post** shared in **Little Star**, 24 March 2015)

After her explanation in the post, she invited parents to join a workshop providing vocational training for teenagers with autism. However, not all teenagers with autism were welcomed.

Our team of doctors and I will select teenagers with mild autism who are willing and also able to participate in our further vocational training sessions. The doctors will make the decision based on the evaluation of the level of the children's emotional stability. (**Post** shared in **Little Star**, 24 March 2015)

She specified that only teenagers with mild autism could join. She also explained how she and her team of doctors would select a few teenagers to continue with further vocational training after the workshop. Throughout this post, Shin demonstrated her confidence and power in the community by giving suggestions, making decisions, and even diagnosing, as she indicated whose children were more capable of accepting further support. Within the seemingly equal and supportive environment of Little Star, Shin may have been holding a relatively larger share of the power in the parents' community.

In short, in responding to the critical incident, the Little Star members engaged in a discussion in which parents expressed both their sympathy and their determination to keep 'pressing on' in raising their children. Parents who mentioned the needs for sufficient resources for their children, such as welfare and education, also shared their personal parenting experiences throughout the discussion to illustrate that they could

relate to the struggle of the father who killed his son. In this discussion, Shin, the administrator and also a mother, also shared her experience and displayed sympathy for the father in the news. However, Shin also used this opportunity to promote vocational training workshop, which is somehow least related to the news, in the Page of Little Star. It is possible to suggest that information shared in Little Star may also be influenced by the marketisation of support services in Taiwan as mentioned in Chapter 2. Shin also demonstrated her power in the community. She even altered the discussion and used the news to attract the parents' attention to promote her workshop. This finding demonstrates the potential for power differences among members within a virtual community.

### 5.2.2 The response of Lovely Dove

As for Lovely Dove, the administrator, Yeh, shared the news on the Page and attached a letter written by Mr. Chang, the founder of Lovely Dove. Mr. Chang is the father of two daughters with developmental delays and cerebral palsy. The letter employed a tone used to address a family member. It read:

Dear Family of Lovely Dove,

With this sad incident happening in our society, all of us felt sad and sorry for the family. This incident also reminds us that we need to keep on advocating for a 'friendly' society. Even though the social welfare system in Taiwan is great and up to date, according to me and my wife's parenting experience and the surveys Lovely Dove has done over the years, parents of the Angels [children with special needs] still face huge difficulties and stress when taking care of their children. This is mainly caused by the sapping of our physical strength and the unfriendly judgement we received. (**Post** shared in **Lovely Dove**, 23 March 2015)

In this letter, Mr. Chang also pointed out how he, as a parent, could relate to not only the boy and the family in the news, but also all other children with special needs and their families in Taiwan and the discrimination they were facing every day. He urged the parents to continue advocating for a friendly environment in Taiwanese society for children with special needs and their families.

After mentioning about the current situation in Taiwan through his experience as a father and a founder of Lovely Dove, Mr. Chang expressed his sympathy for the

father in the news. He also mentioned that all parents of children with special needs belong to a large family and that no member of that family has to face difficulties alone. Mr. Chang wrote:

We as a family can relate to the father's struggle, and we hope to press on through this difficult situation together with all of you. We hope to prevent the tragedy from happening again. (**Post** shared in **Lovely Dove**, 23 March 2015)

The letter also praised the members of Lovely Dove for responding to the news with words of care and love for the victim's family.

Over the past two days, we got so many phone calls from many of you [members of Lovely Dove]. These phone calls were all asking about how we can help the family in the news [the father killing the son with cerebral palsy]. Even though none of these parents knew the family, they still hope to help them and give them support. This kind-hearted action really touches my heart. (**Post** shared in **Lovely Dove**, 23 March 2015)

The founder again urged the parents to keep advocating for a friendly societal environment for their children with special needs. This emphasis on advocating for the rights of children and families is clear in the letter. Similar to Shin, the identity of being a parent of children with special needs was underscored. Chang presented how the parents were united to help the father in the news after they learn about it. He praised this action of solidarity among the parents in showing support for the family in the news even if they did not know them.

In the end of the letter, the telephone number of Lovely Dove was given, so that anyone who might need help or support could contact the organisation if needed. Yeh, the administrator, also posted a link to the government's healthcare resources website in a comment under the post.

After the news and the letter were posted in Lovely Dove, the community's members commented on the post enthusiastically. More than 10 parents and community members commented on the letter within an hour of it being posted. These parental users also emphasised the idea of 'we understand' and expressed their sympathy. They also shared their experiences in overcoming these struggles.

If you are tired, please do find help! [...] I have been through these challenges as well! Let's press on together! (**Comment 4** shared in **Lovely Dove**, 23 March 2015)

In addition to showing sympathy, a mother complained about the comment made by the senior manager of the cerebral palsy organisation in the *Apple Daily* news article suggesting that 'There are unlimited resources you [parents] could use' (see p.130).

The mother wrote:

Plenty of resources??? I have been calling the local healthcare centre several times to apply for rehabilitation services for my child, but they always give me really vague and useless answers = = [annoyed face emoticon] (**Comment 5** shared in **Lovely Dove**, 23 March 2015)

After these comments, some other parents also complained about being turned down by the government when they tried to apply for healthcare or welfare support. A mother wrote:

What did the government do for us? The social welfare system?? They just want money! Did they [the government] really want to help us? (**Comment 8** shared in **Lovely Dove**, 23 March 2015)

Another mother followed the comment and criticised the *Apple Daily* reporter for penning such a discriminatory report biased against families of children with special needs. She wrote:

This family [the victim in the news] has already suffered so much! The dad is definitely tired! He must hurt so much in doing such a thing to his son. [...] I can't believe the reporter asked that STUPID question: 'Why did you kill your son?' The dad was already so upset about what he did, can the reporter not tell?? That reporter is just STUPID!!! (**Comment 11** shared in **Lovely Dove**, 23 March 2015)

After a few comments criticising the government, one mother shared her sympathy by simply commenting 'Being a parent is really tiring'. A father who read this comment then argued with this mother soon after this comment was posted. He posited that according to his personal parenting experience, the son with cerebral palsy should be the one suffering, not the parent:

Not only the family members were tired, the boy with cerebral palsy was also tired. As a parent, I tried my best to help my daughter to

grow up just like other children and help her to be positive in her life, but sometimes she would still try to hurt herself by madly hitting her head and feet. She even tried to kill herself several times. So I think even though the parents were tired, the person with disabilities was the one who suffered the most. (**Comment 12** shared in **Lovely Dove**, 23 March 2015)

This father used a detailed description of how his daughter self-harmed as an example to argue with the mother and make his point that the children, and not the parents, are the victims. Two hours later, the mother responded to this father also by providing her personal experience with taking care of her own son. She wrote:

You are right. I have a child who was diagnosed with a severe injury in his brain when he was still in my belly. [...] Now he is eight, can't talk or walk. I have tried to kill myself and my child so many times before. But thankfully, we still tried to travel around, go to church, and bring my child to the hospital for early treatment. I just want us to be a normal family. [...] that is why, when I read this news, I commented that I know the father is tired. (**Comment 13** shared in **Lovely Dove**, 23 March 2015)

In this reply, the mother illustrated that she understood that the child was also suffering but that as a parent, she also knew how tired the father was. She even shared her sensitive personal experience to convince the father that she understood and could relate to the child as well. After receiving this reply from the mother, the father stopped the argument with the mother. After this dispute ended, other users started posting comments that were again focused on the news.

Most of the parents who commented on the news received several responses and Likes from different users. The discussion was lively, and many members of the virtual community joined. On the contrary, Yeh's comment, which shared information about the support services provided by the government and links to the website in question, was ignored. Yeh, the administrator, received no responses or Likes on her comment.

In addition to the interaction on the Page, Lovely Dove's three public Groups also shared the same news story and the letter from the director of Little Dove. However, since the main discussion happened on the Page, the responses in the Group were less

active. However, the parents in these Groups still engaged in conversations about this critical incident. For example, in Group 3, a mother commented on this incident and then expressed her suicidal thoughts:

When I saw this news, I felt really sad. I am happy that my daughter is growing up gradually. But to be honest, I don't know how long I can keep pressing on like this [taking care of her daughter] anymore. [...] (**Comment 2** shared in **Lovely Dove** Group 3, 23 March 2015)

Twelve minutes later, two mothers in the Group replied to encourage her:

Oh, let me give you a hug ~~ You are doing amazing already!  
(**Comment 3** shared in **Lovely Dove** Group 3, 23 March 2015)

Mother 2: We will always be here for you, love. Please let us know what you need anytime! Please don't suffer on your own. I understand your pain and struggle! (**Comment 4** shared in **Lovely Dove** Group 3, 23 March 2015)

The first mother responded by clicking Like on both comments. This incident might suggest that the virtual community provided opportunities for parents to receive timely feedback from others. This example may indicate that the parents used the virtual community to express their need for emotional support—which may be hard to articulate in face-to-face situations—in relation to sensitive issues, such as suicidal thoughts. The platform of the virtual community, which gave the parents anonymity (boyd & Ellison, 2007), may have allowed parents with hidden needs to receive help and support.

On the whole, most of the interactions in Lovely Dove were initiated by parents, and those parents strongly voiced their opinions to other users in the virtual community. However, only a few users who were not parents or professionals joined the discussion. Most of the discussions in Lovely Dove seemed to take place among parents.

### 5.2.3 The response of Speak Out

Speak Out shared two posts in response to the news. Similar to Lovely Dove, the first post was a letter from the director of the organisation, Mr. Wu, who also had a son



with Down syndrome. However, in contrast to the approaches of Little Star and Lovely Dove, he did not mention his son or his identity as a father in the letter. In addition, Mr. Wu did not express his sympathy by writing ‘I understand’, nor did he share his personal parenting experience. He only reminded the readers that taking care of children with special needs is not easy. Mr. Wu wrote:

The reason why family members of children with special needs are facing so many difficulties in Taiwan may be due to the following reasons: **1)** The limited resources and services in the current social support organisations. **2)** The huge amount of money the family needs to spend if the child is receiving long-term support service. Yes, families still need to pay for the service their children receive. **3)** There is no suitable service or organisation that meets the needs of the children. **4)** Parents are worried about the quality of service in the support centre, so they would rather choose to take care of their children themselves. **5)** Parents are tired of the judgement and bias they received from others, so they would rather stay at home than going out and searching for help. [...] (**Post** shared in **Speak Out**, 25 March 2015)

He then gave suggestions on how governments could build a better society for all.

The service we have now is not enough in terms of both quantity and variety. We need services which fulfil the needs of the children in their daily life. [...] Besides the long-term healthcare support, the professional services, financial support, and transportation support, we need to fight for [‘Zhēngqǔ’] a system which can organise and arrange all these resources. These support services also need to be family-centred, which allows everyone to be supported. [...] (**Post** shared in **Speak Out**, 25 March 2015)

Mr. Wu used the term ‘we’ to suggest that the parents will stand together when facing difficult situations in life. He also used the term ‘fight for’, or ‘Zhēngqǔ’ in Mandarin. The term also suggests negotiating and applying for things, rights, or resources. The director pointed out the reasons why this incident happened and asserted that society needs to take action and help these families facing challenges in life. He wrote:

Many parents have been through a tough period where they feel frustrated and helpless. [...] There are still many things we could improve in the future. Remember the deep love of parents never gives up. We will not neglect the fact that it is our children’s right to have a better life. Therefore, dear friends, who are now reading this letter, no matter if you are working for the government, working as managers in private companies, or just working as employees, please

let us work together for a better society that is friendly, and more supportive of these families [...] (Post shared in **Speak Out**, 25 March 2015)

This letter demonstrates that the Mr. Wu was aware of the wider audience on Facebook and how he could share information to advocate for parents' rights and needs.

Interestingly, however, this post received the least comments and Likes of the administrator responses within the three cases. Only one parental user commented under the post to express her agreement with the director. To generate more attention, Pu, the page administrator of **Speak Out**, created another post responding to this incident. It consisted of an article written by a 34-year-old man with cerebral palsy in response to the tragic incident. This article, as compared to the letter from the CEO of **Speak Out**, displayed more personal emotion, both anger and frustration, when discussing the challenges that a person with cerebral palsy might face in his or her daily life.

If I never move to the sanatorium [place for long-term care for children with special needs] from my home, I think I will be like the boy in the news. I will become really emotional and want to die. Because no one knows my pain at home, and there is no joy living there. [...] I also know that it is already hard for my family to take care of me 24/7, so how can I ask them to listen to me when I am upset? How can I show them my anger and emotion? That would be unfair for them.

In the post, he shared that he was not happy at home, since he was a 'burden' to the family. Due to this self-blame, the writer suggested that he struggled in developing connections with his family members or even in sharing his feelings with them. After describing the challenges he faced at home, he then continued by sharing his educational and occupational journey.

After I graduated from university, I found a job and worked for two years. But I had a car accident which made my body even weaker. Now I can't even find a job. I need my family to raise me. I don't have any dignity left, and my family is under loads of pressure. Eventually, I end up selling bubble gum on the street for a living. (Post shared in **Speak Out**, 27 March 2015)

He shared his deep frustration with no longer being considered by society as able to pursue a steady occupation. After sharing his experience, he then mentioned that the main purpose of his life is to advocate for others like him.

Because we people with disabilities can't be certain of our value in life. And others in this society will not think we are important. That's why we are suicidal [referring to the son who was suicidal in the news]. But I will keep on living, no matter how hard. I will also give most of my time to advocate for all of us with disabilities. I hope no one will ever need to commit suicide anymore. And no tragedy of family members killing their loved ones will ever happen. But, how long until this dream comes true? (**Post** shared in **Speak Out**, 27 March 2015)

This post received more responses from the parental users than the post containing the letter from the director of **Speak Out**. A mother wrote:

We need to call on our government to prevent such a thing from happening again. Taiwanese people are kind, we show our love. But the government, big companies, even the president, who is high up there, they rarely reach their hands out to help the ones with disabilities. (**Comment 1** shared in **Speak Out**, 27 March 2015)

A father then asked:

I know that they have an assistive device for people with cerebral palsy. Such as the one the main character used in the movie *The Theory of Everything*. I really hope that some big computer company can help the people with cerebral palsy to design one. Is there any way we can fight ['Zhēngqǔ'] for this? (**Comment 2** shared in **Speak Out**, 27 March 2015)

Parents in **Speak Out** expressed the necessity of advocating for their needs, and a father even specified the need for assistive devices in responding to the news. This example demonstrates that the virtual community provided opportunities for the parents to advocate and share their opinions with other users on the social network site. It gave them a space to articulate their opinions and suggestions on issues related to the rights of persons with special needs.

Even though the second post generated more discussion and attention from the parental users of Speak Out, this virtual community's conversation about this news event was still less active than those in Little Star and Lovely Dove.

In general, the information shared in Speaks Out implied a strong sense of advocacy, and the comments shared among the members of the community also focused on advocating for the needs of parents and their children. However, the parents tended to pay more attention to experience-based content, such as the letter in which someone with cerebral palsy described his experiences. Thus, informal information may be more interesting to parents.

### 5.3 Summary

In summary, this chapter has presented the critical incident and demonstrated how the Taiwanese media reflected the cultural attitude toward people with special needs and their families. It has indicated how the media and society were still biased against persons with special needs, regarded them as 'pitiful', and portrayed them in a negative light. This chapter has also highlighted that the critical event stimulated discussions among parents and that they rejected the idea of being seen as 'pitiful'. These parents commented on the insufficient resources provided by the welfare system and support services. They also used the public platform to address the challenges facing them. In addition to advocating for their needs and rights, these parents also expressed a strong sense of sympathy and solidarity, using terms such as 'we understand' to encourage each other. The comments and Likes revealed that the parents were providing each other with emotional support when discussing this incident. For example, several parents shared their suicidal thoughts, and other parents who saw the comments quickly expressed their sympathy and encouragement to the suicidal users.

This chapter has also pointed out that the three communities' members had different characteristics and perspectives on the incident. **Little Star** members expressed a strong reaction of sympathy and solidarity, and solid relationships were present among Shin and most of the parents. Shin also demonstrated her power in deciding who was capable of accepting support from Little Star. She also shared her strong

recommendations with the parents and urged them not to rely on the welfare system but to join her workshop and sessions. It is possible to suggest that Shin had strong control over Little Star as an administrator.

**Lovely Dove** members also expressed a strong sense of sympathy and solidarity in response to this incident. However, in contrast to Little Star, parents, instead of the administrator, led the conversation. The parents in Lovely Dove also displayed a strong tendency to advocate for their needs and a hope of improving or changing government policy. Some parents even shared detailed information about their children's conditions to demonstrate their opinions to other parents, and that children, not parents, are the ones who struggle the most (p.142).

Finally, unlike both Little Star and Lovely Dove, the parents in **Speak Out** strongly focused on advocating for the rights and needs of parents and children. Speak Out was also the only community that posted content from the point of view of a man with cerebral palsy and that allowed such an individual to speak on his own behalf. However, compared to the other two communities, Speak Out received the fewest responses from parents.

Through this chapter, I introduced a critical incident that provided an opportunity to identify the characteristics, similarities, and differences of the three virtual communities, and also the opportunity to present some of the categories, sub-categories and the emerging themes I identified in this study. Thus after presenting the pilot analysis, I now discuss the themes this illustrates in more detail in Chapters 6, 7 and 8. These themes include (as introduced in Table 11) developing parenting skills, searching for medical resources, negotiating for educational provision, searching for resources from the welfare system, and finally, leisure.

## Chapter 6. Developing parenting skills

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In this chapter, I define ‘parenting skills’ as parents’ ability to respond to children’s signals and needs and to manage their children’s behaviours (Tremblay, 2015).

Developing strong parenting skills is essential for children’s development and safety.

The focus of this chapter is on introducing how parents search for information related to their parenting skills. I explain that this type of information was the most popular content among members of all three virtual communities.

This chapter is divided into two main parts. **Section 6.1** discuss parenting information was shared among the parents in the three virtual communities. Information about parenting skills was divided into four sub-categories, child development, skills for raising children with special needs, formal parenting information, raising siblings of children with special needs. **Section 6.2** explains how the parents supported each other emotionally in raising their children, including showing their encouragement, affirmation and solidarity. **Section 6.3** illustrates the way parents advocate for their children through sharing their children’s daily life to the general users, the professionals and other parents.

### 6.1 Information

#### 6.1.1 Child development

In this study, ‘child development’ refers to all information related to the biological growth of children or adolescents and knowledge of both psychological and emotional changes in children and adolescents.

In all three virtual communities, knowledge about child development was frequently shared among the parents. Most of the information on child development shared in the virtual communities was informal information, such as parents’ personal experiences regarding their children’s development. For example, a mother from Speak Out wrote:

When my son was around three years old, I realised something different about him. He would concentrate on one toy and play with

it for a really long time. But when he communicated with us, he would not pay any attention to me and my husband and would not concentrate on interacting with us. I found it hard to communicate with him at that time [age of 4]. He couldn't tell the difference between 'you' and 'I'. But in my eyes, I choose to ignore his behaviour as 'weird' or 'abnormal' and explained to myself and others that 'It is just a different habit' [...] Two months after he attended primary school, we got a phone call from the teacher, she wanted to talk with us about our son. She told us that our son might be autistic and that he needed to go to the hospital to check up. Reluctantly, me and my husband finally bring him to the hospital. [...] It feels like centuries had passed when we were waiting for the result. Three months later, we finally got the report paper from the hospital. 'Autism' was written nice and clear on the top of the report, forcing me and my husband to face the music. That is how I learned to accept my 'autistic' son. But you know what, I am glad I did so. [...] He [the son] has improved so much now. And yes, he is autistic. But yes, I am so proud of him. [received 112 Likes and 13 Shares] (Post shared in **Speak Out**, 26 May 2015)

The mother wrote about her journey of accepting that her son is autistic and also described her feelings throughout that period. She also shared the process of how she started to accept the 'Face' she then owned, which involved accepting the identity of being a mother of children with special needs in the eyes of the public. This experience of acceptance of one's Face is commonly seen in all three virtual communities when sharing about parenting experience.

In the final section of the post, she encouraged parents to accept their children's needs and shared that her son's behaviour had improved after he started to receive treatment from different therapists. In total, 112 users Liked the article, and 13 users shared it on their private spaces, such as their Profile. Similarly, posts about their journeys of acceptance were frequently shared among members of Little Star and Lovely Dove.

### **6.1.2 Parenting skills related to raising children with special needs**

In addition to information about child development, parents shared their parenting experiences with raising their children with special needs in the virtual communities. For example, a mother shared her detailed interactions with her autistic son to demonstrate to other parents that children with autism express their love for their

parents and to encourage those parents by telling them that their children do love them.

She wrote:

One day, I was hugging my daughter and was tickling her. She giggled and laughed so much that she started to kick me. So I got many dirty footprints all over my trousers because of her. And I said to her: 'Oh dear! Look at the dirty marks on my trousers!' All of a sudden, my son with autism, who was playing with his toys next to us in the room, turned over and walked toward us. He then started to pull the shoes off his sister's feet. Then, of course, his sister fought back and tried to kick my son. My son started to shout loudly: 'My sister's shoes need to be taken off, so my mum's trousers will not be dirty.' I was so moved by what he said. It felt like butterflies flying around me! But I told my son that he needed to ask his sister politely before taking her shoes off. Then he asked me: 'But if I waited and asked my sister, my mum's trousers will already become dirty.' I replied: 'That is really kind of you son, well done! But your sister doesn't want to take off her shoes. Let's figure out how to ask her politely, should we?' My son looked away and stopped pulling his sister's shoes. He seemed to understand what I meant. [...] [received 23 Likes] (**Post** shared in **Speak Out**, 30 October 2014)

Through her detailed descriptions, other users who were not parents could also obtain a degree of understanding of the characteristics of a child with autism and also learn how to interact with them. Similar posts which parents shared about detailed information about how to interact with their children were found in all three virtual communities. Suggestions were also found posted by other parents through the comments.

In addition to reading other parents' stories for parenting examples or suggestions, some parents directly asked for parenting suggestions. For example, a mother of a seven-year-old son with cerebral palsy asked the members of Group 3 for better showering ideas, since her son did not have a strong enough arm to hold the bucket they used for that purpose.

Could I ask the parents in this Group, how do you teach your kid to shower? I got a bathtub at home, so I fill the bathtub with water. Then I teach my son to use the little bailer to shower himself. But he cannot lift the bailer up when it is filled with water. He is already using the smallest bailer in the shop. [...] We also tried to use the showerhead, but the water pressure is too strong. And, he does not like water in his eyes, so whenever he would use the showerhead, he would keep dropping it, because he wanted to wipe the water off his



eyes. Please let me know if there is another solution. [received 15 Likes] (**Post** shared in **Lovely Dove Group 3**, 2 February 2015)

One parent provided an alternative suggestion for the showerhead. That father wrote:

You could try the showerhead that has different spray patterns, so you could change the water pressure through changing the pattern. [received 4 Likes] (**Comment 1** shared in **Lovely Dove Group 3**, 2 February 2015)

However, in addition to making a suggestion about the showerhead, the person who left that comment also had another idea for helping the son to overcome the fear of getting water in his eyes.

If your son is worried about water getting into his eyes, you could consider bringing him to a swimming lesson. It is a good way to help children overcome their fear of water. This will help you and your family in the future when you travel. My daughter is the same, but now she can cope with water better. It might take awhile but the result is worth it. [received 5 Likes] (**Comment 2** shared in **Lovely Dove Group 3**, 2 February 2015)

After the father gave the suggestion about the swimming lesson, the mother then demonstrated her interest in enrolling her son in that activity by asking a further question about it. The father replied to the mother, and the conversation ended. This exchange clearly demonstrates that asking about parenting experiences in a virtual community not only provides opportunities for parents to discuss the question at hand, but also creates chances to learn new things.

Some professionals also shared stories about parenting with these parents in the virtual communities and added their professional opinions regarding those narratives and provided suggestions to parents in similar situations. The following is an example of how the professionals shared parenting stories in these virtual communities. A speech therapist wrote in Lovely Dove Group 2:

I saw a mother praising her son when he was not behaving in public. The mother told her son: 'You are doing great, but could you do better next time?' I could tell that the mother tried really hard to encourage her son. But she did not realise that even though she was encouraging her son, she sounded very disappointed, disappointed with her son's behaviour. [...] The important skill of praising your

child is to say it with the right timing and say it with your heart. If you praise your child even when he or she was not behaving, it is meaningless to praise. [...] [received 17 Likes and 1 Share] (**Post** shared in **Lovely Dove Group 2**, 14 December 2015)

After publishing the post, the speech therapist also gave his suggestion to other parental users in a comment. However, the number of Likes and the amount of attention given to this post did not match those of other posts shared by parental members. In all three virtual communities, parents generally dominated the discussion about parenting skills.

Kuai also mentioned that some parents may even have very strong opinions when sharing their personal parenting experiences. Those individuals may even refuse other parents' opinions. She said:

Parents will sometimes attack each other online. For example, the topic of breastfeeding. Mothers who believe in breastfeeding will attack mothers who use milk powder. [...] I always feel annoyed by those who have a really strong opinion. They also like to interpret things in their ways. So, even if other users who were just trying to ask questions or give suggestions, the people who have strong opinions would criticise their comments. (Interview with **Kuai**, mother and member of **Little Star**)

A-lin had a seemingly similar experience when she tried to help some of the 'stubborn' parents in Speak Out. Eventually, she stopped commenting on Speak Out posts or replying to parental users in that community. Instead, she lurked, which is the action of reading information on a Page but did not comment on it or discuss about it with other users. She also added parents who she recognised to be 'positive like her' to her private Group to avoid conflict. She said:

Not all parents take your advice when you try to help them on Speak Out. Will these parents suddenly change and appreciate your help? No! That is impossible. So, I give up, I stop commenting or helping them. [...] so I just read what was posted on there [Speak Out]. And stop commenting or replying. But there are some parents who are more likely to take my suggestions. [...] So, in the end, I only add parents who are as positive as me and parents who share positive things to my private Groups. (Interview with **A-lin**, mother and member of **Speak Out**)

Zen also suggested that most parents preferred to remain silent in the majority of situations entailing a conflict in their virtual communities. They opted to deal with the situation ‘in a silent way’.

Most of the parents like us don’t like to argue with other users in the virtual community. [...] If they want to say something to the person, they will do it in a silent way. Either they will send the person a private message, or they will just ignore the person. (Interview with **Zen**, father and member of **Speak Out**)

Several other parents, such as Ming (see p.167), also suggested that they had similarly created Groups and only invited parents with comparable opinions or perspectives. Therefore, when facing other members with opposing opinions, to avoid conflict, a parent may leave the discussion or join or create a different Group primarily comprised of members with analogous perspectives on parenting. It is possible that parents also avoid this conflict in order to maintain their Face in the group, which is to maintain the identity which they have been accepted by others. Thus, when they own Face in the virtual community, they tend to maintain and keep it. Therefore, it is possible that this is also one of the main reasons parents avoid conflict with other members of the virtual community where their identities as parents of children with special needs are accepted.

### 6.1.3 Formal parenting instruction

In some Pages, such as Little Star and Lovely Dove, information was given on how parents should interact with their children with specific disabilities. For example, in Little Star, Shin listed several steps for parents to follow when helping their autistic children with their challenging behaviours. She wrote:

The four ways to defuse the bomb [challenging behaviour] of your child, you need to remind him/her:

1. You are amazing! Because you are listening to me. (obedience)
2. You are amazing! Because you can make it. (capability)
3. You are amazing! Because you did things that are beneficial to you. (ability to make the right choice)

4. You are amazing! Because you make yourself responsible for your own behaviour. (the child has done the best in this situation, being responsible for himself/herself)

(Post shared in **Little Star**, 25 December 2015)

She used the terms ‘bomb’ and ‘defusing’ as symbols to indicate how parents should deal with the challenging behaviour of their children with autism. She explained that parents should always be sensitive to their children’s behaviour and needs and that these steps might be difficult to implement in the beginning. She then mentioned that these steps had been shared by a special education teacher at a workshop held by Little Star. In response, 626 members clicked Like, and 405 members shared the post to their personal spaces in the virtual community. This suggested a strong acceptance of this ‘defusing the bomb’ strategy among the parental users. However, not all parents agreed with it.

A father expressed his disagreement with the post through a comment but did not receive any reply from the page administrator. In the comment, he wrote:

This is actually an awful way to respond to a meltdown. Most autistic children have a high or normal IQ, so they do understand what they are doing. Being grumpy may just be a way he is showing his emotion. Why grumpy? Because he felt no one understands him. [...] So this ‘defusing bomb’ method is pathetic. Just treat him like a grown up and try to understand him. All we need to do is just help the children to respond more maturely in the future, and let him feel that we understand his feelings.[received 1 Like] (**Comment 3** shared in **Little Star**, 25 December 2015)

One other parent agreed with this father by clicking the Like icon attached to his comment. However, Shin and majority of the parents ignored this comment and did not reply or click Like on it. Kuai also mentioned the conflict she experiences with other parents in Little Star when she did not share the same value with the majority of the parents.

I got into an argument with the other parents in Little Star. And it was not good for me. But I learned my lesson and I tried to avoid it now. For example, I stop sharing any sensitive information with them now. To be honest, I even stop replying questions in Little Star and hide. [...] But I still read what they are discussing in the Little Star. (Interview with **Kuai**, mother and member of **Little Star**)

Kuai suggested that in order to avoid conflict with other members in Little Star, she stop contributing to the discussion on Little Star but ‘hide’ behind her computer and read about the discussion in order to keep updated with the information shared. It is possible that lurking might be one of the solutions for parents when facing conflict or challenges in their virtual communities. It is also possible that by lurking, Kuai collected the information she needed in the virtual community and also maintained her Face. She avoided conflict with others through observing the conversation from a safe virtual space.

Other than sharing this information in Little Star, Shin also published the same post in Group 3 of Lovely Dove. However, she received little attention from the parents in Lovely Dove. She received only 5 Likes from that community’s members, and none of the members shared the post or commented on it. When I examined other posts that Shin had shared in Group 3, the members’ responses to her content were similar. As previously mentioned (p.29), it is possible that Shin became less influential when sharing information in other virtual communities, such as Lovely Dove.

Besides formal parenting instructions, short pieces of information and invitations to workshops and face-to-face support services for formal information about child development were also shared. These workshops covered different child development topics, depending on the stage of development, including issues related to teenagers and puberty. For example, post about a Lovely Dove workshop where parents could discuss sexual maturity in relation to children with special needs with other parents and professionals were clicked with a high number of Like and shared among the members of Lovely Dove.

This workshop will be discussing the sexual maturity of your child and the importance of sex education. Miss Wong, a special education teacher, will be leading the workshop. Visit [website address] for more information. [received 96 Likes and 15 Shares] (**Post** shared in **Lovely Dove**, 2 March 2015)

Parents shared these invitations to workshops and support service offerings to their personal spaces, including private Groups and Profiles. However, again, they were less likely to comment on this type of post in both the Groups and Pages.

#### 6.1.4 Raising the siblings of children with special needs

In addition to information about taking care of children with special needs, the ways in which parents care for the siblings of those children were also shared in the three virtual communities. For example, a mother of three children, two with special needs, shared the story of her youngest daughter. This girl struggled when her oldest sister, who had severe disabilities, passed away. She wrote:

Not long after my oldest daughter [with cerebral palsy, 13 years old] passed away, a friend who is a psychologist told me that something was wrong with my youngest daughter [6 years old] [...] It was not until then that I realised my youngest daughter was blaming herself for not taking good care of her older sister. Her reactions to her sister's death surprised me so much since she was only 6-year-old at that time. After that, I started to pay more attention to my youngest daughter. I realised that the siblings of children with special needs also need to be cared for and loved [received 34 Likes]. (**Post** shared in **Lovely Dove**, 5 November 2014)

In sum, 34 parents Liked the post, and 1 shared it to their personal Profile. In several different posts about caring for the siblings of children with special needs, parents offered short stories about how these siblings love their brothers and sisters with disabilities. In response, many users offered their support and encouragement to both the parents who had posted and to the siblings in the story. Responding to posts is a common way for parents to demonstrate their encouragement and to provide emotional support to other members of their virtual community.

Several posts about workshops or camps for siblings of children with special needs were also found within Little Heart, Speak Out, and the three Groups. These posts invited siblings to attend workshops exclusively for them. This information was also popular among the parental users. If the sibling was old enough to manage his or her own Profile, the parents shared the link or tagged him or her directly on the Page. This finding indicated that parents can also use social network sites to provide direct support to the siblings of children with special needs.

## 6.2 Emotional support

### 6.2.1 Encouragement and affirmation through positive parenting experience

Most of the parents suggested that reading stories about a child who shared similar difficulties with their own children but who had grown into a healthy adult with an independent life provided them with encouragement and hope for their own sons and daughters. Jade explained:

When I was frustrated about my son, I would not go to my friends or ask them for comfort. But I will seek for other parents' experience in the virtual communities, and read what they have also been through, how they have solved it, and what has happened next. I will feel better after reading that. And when I see my son, I think I still have hope. (Interview with **Jade**, mother and member of **Little Star**)

Reading about other parents' experiences provides not only important parenting information for parental users but also emotional support in the form of comfort and encouragement. Most of the parents in this study also suggested that knowing they are not alone reduces the feeling of loneliness.

I really like to read about things other parents shared, like their feelings, their experience, the Down syndrome kids' daily life. They also faced these [challenges], but they still live a positive life. I also feel positive because of this [other parents' experiences]. (Interview with **A-Lin**, mother and member of **Speak Out**)

I also identified that posts written by parents who had longer periods of parenting experience attracts more attention from the members of communities. Moreover, most of these parents' children were also considered as successful or have Face by the communities in general. Having children who exhibit outward signs of success, such as the ability to live independently, graduate from university, find a steady job, or even build a family on their own, is seen as an important parenting achievement for these parents. Therefore, they were more likely to read content from users who were already recognised as 'successful' parents. For example, Ming and Shin were considered as famous mothers with 'successful' sons. Both their sons had been actively participating in advocacy projects, had successfully graduated from high school and university, and had a permanent job after graduation. Several parents

mentioned Ming and Shin, referring to them as their role models. Chi is one of the parents who regarded Ming as her role model. She explained:

Oh, I read her [Ming's] posts quite frequently. You know, her son is now working. I have known her and her son since he was just a little boy. And he used to be a little child with Down syndrome with low potential. But now he's got a permanent job! And he can take care of himself! I really admire Ming. How she made all these things possible. (Interview with **Chi**, mother and member of **Lovely Dove**)

She also explained that if Ming's son with Down syndrome could work and take care of himself, her son with a mild intellectual disability could also be independent in the future. I identified a strong need to seek 'success' and affirmation through having a child who is considered 'able' in society. Admiring parents whose children were considered as able by society meant harbouring the hope of one's own child following the same path and of being indirectly accepted by society.

Parents also found affirmation through reading other types of information about children's strength or seeing improvements in their disabilities. Most of the parental users shared positive aspects related to their children's development, rather than sharing struggles or negative experiences regarding their children's development. For example, most of the parents often expressed their joy in learning that their children had similar abilities as those children who they regarded as successful. For example, after reading a post about a 10-year-old girl with autism helping out in a convenience store in the US, several members of Little Star commented on it, stating that their children also had similar skills. They wrote:

This job is perfect for my son ... (**Comment 2** shared in **Little Star**, 13 June 2015)

My son will also organise the packed milk according to the colour code of the package. (**Comment 3** shared in **Little Star**, 13 June 2015)

My son has OCD [obsessive compulsive disorder]; he will also do things like this! (**Comment 4**, shared in **Little Star**, 13 June 2015)

Moreover, most of the parents also demonstrated their sense of relief in the comments:



My child has recently behaved like this girl as well! Thank God! There will be a job that's suitable for her in the future! (**Comment 6**, shared in **Little Star**, 13 June 2015)

It is possible to suggest that these parents read about these experiences to justify their identities in relation to the acceptable and agreed-upon parental identity in Taiwanese society. Such perspective holds that children should be 'able' to contribute to society and live an independent life—in other words, they should be able to maintain Face for themselves and their family. Through this platform, parents also publicly shared with other readers that their children were as 'able' as other children in society.

In addition to sharing indirectly, some parents encouraged other parents to accept their identity, or their Face, as parents by directly sharing their own journey of acceptance. Diana wrote and shared after reading a post about parenting experiences on **Speak Out**:

My daughter taught me how to be brave, how to be 'myself', how to observe different situations. She is my daughter, my daughter with intellectual disabilities. [...] I learned to accept the fact of her disability. [...] Now I know, no matter what happens, it is not the end of the world. We will find the solution, and carry on. (**Comment 1** shared in **Speak Out**, 26 May 2015)

This shared encouragement, joy, and affirmation may be one important way for parents to provide emotional support for each other through virtual communities.

A potential issue related to providing emotional support for parents through virtual communities, however, is the limitations of text, as that medium cannot reveal the full intention of the writer. For example, Tung mentioned that she tried to comfort one of the parents by leaving a comment urging positive thinking. However, the parent misunderstood her and thought she was mocking her.

With the phone, I can at least hear her voice, know her emotion. But with text, you know, when people are down or really negative, whatever they read will be negative. [...] When the mother was emotional, well, she didn't care what I posted. I tried to post the positive quotes from famous people, positive stories. She just thought that I was mocking her. (**Tung**, administrator of **Lovely Dove** Group 2)

Even though text-based support may be efficient, according to the examples given above, it could still have limitations, such as the risk of being misunderstood. However, these examples still demonstrate that sharing a personal experience about a child's development through virtual communities provides parents with chances to encourage each other. The shared parenting experiences encouraged others parents who were also experiencing, or who had already experienced, a similar parenting stage.

### 6.2.2 Solidarity through sharing the experience of hardship as parents

Ming suggested that all parents who have 'come out' the struggles of accepting their identity as parents of children with special needs and those who have overcome the challenges of raising their child should share their experience with parents who are still struggling.

We have been there [...] When we slowly, slowly, slowly came out of that situation, when our kids were more in shape, we realised even though it is hard, it is still possible. We gave our very best to share these experiences and tell those parents who are facing this and let them know that it is not that difficult. (Interview with **Ming**, mother and member of **Speak Out**)

A virtual community provides important platforms for parents to interact with other parents facing a similar situation with their child to gain unique parenting skills, receive specific parenting information, and fulfil their parental role. Their identity as parents of children with special needs is, however, the main motivation prompting them to share this detailed information with other parents. Ming explained:

This is why we have this Group, because we [parents] are the same, our kids have the same disability, so we also have the same disability as well. We didn't know how to take care of them, worried about their future. This is our disability, worrying is our disability. (Interview with **Ming**, mother and member of **Speak Out**)

These virtual community members who are parents of children with special needs shared the same Face through experiencing the same, or similar, struggles of parenting. Through this shared experience, these parents encouraged each other and

showed their solidarity with each other. The emotional support these parents received is critical for the parents to develop better parenting skills and also to have Face again.

## 6.3 Advocacy

### 6.3.1 Sharing about their children's daily life to raise awareness

Seven out of the 14 parents, including Shin and Wa, said that they frequently recorded and shared their child's growth with other parents or social network site users in general through their personal websites. For most of these parents, the initial idea was to keep an electronic diary recording their parenting journey and the development of their children. Ming explained:

This is called my memory, memory of my parenthood, the memory of my child. How many things can we remember with our human brain? Facebook is my second brain. It is a place where I save my memories. I am already 45, almost 46 years old. And I can feel my brain is not functioning as well as before. I really need the internet to remember what happened before for me. (Interview with **Ming**, mother and member of **Speak Out**)

Dee also explained that her initial purpose of using Facebook was only to record her child's daily life, but then Facebook became a platform where she interact with other parents.

I was just recording how my child was doing on my Profile, and then I also shared many things. Well, so it turns out to be a platform for sharing my child's and my life with others. (Interview with **Dee**, mother and member of **Lovely Dove**)

These parents referred to this function of recording the growth of their children as a virtual diary they kept on Facebook. Such a virtual diary includes photographs and videos of the children, along with notes about events or incidents. Most importantly, a virtual diary not only records notes, pictures, and videos posted by parents but also permits the parents' Facebook Friends to review the content and comment on it. Useful advice or encouragement was also recorded. Ming said that initially, she just hoped to use Facebook to record what that had happened to her son and to share her parenting journey with others. However, she did not expect that keeping a virtual

diary would benefit her, a mother of children with special needs, in such a significant way.

At that time [when her son was still of preschool age], I had so many things in my brain about my son, I just hoped to record it. I tried a traditional diary, but it was boring, so it didn't work. Then this internet thing [Facebook] appears. You put photos and notes and different stuff on it. People then respond to it. This keeps this diary alive. [...] I wrote it wherever, on the bus or the metro [...]  
(Interview with **Ming**, mother and member of **Speak Out**)

She then carried on explaining that keeping a diary through Facebook helped her to remember her past parenting experiences and to develop a better role as a parent.

Like this morning, Facebook reminds me that three years ago today, I was training my son to do house chores. That was during his summer holidays. [...] This memory is significant to me. It reminds me how much my and son I have grown. (Interview with **Ming**, mother and member of **Speak Out**)

Quini and Zen even created a public Page just to share their children's life with more Facebook users. Quini said the Page that she created attracted many 'fans' to her son, and those readers follow the Page and his life events. Some of those Friends were even from countries that were far away from Taiwan, such as the US and Malaysia. She proudly showed me the website and shared her joy of managing the Page, and she also described sharing the 'funny moments' of her son's daily life. The website that she showed me contained detailed information about the daily life of her son, such as his meals and the new skills that he had learned over the past few months. For example, a few posts detailing how her son had learned to play with an iPad were shared in 2015. She said:

My purpose in forming this Page for my son was really simple. I want to show everyone how my son with Down syndrome grows up. How he is just a normal kid and happened to have Down syndrome. I want other families who also have children with disabilities to learn about the growth of these kids. I also want other Facebook users to know us better through this [sharing her son's daily life on Facebook]. (Interview with **Quini**, a mother and a member of **Speak Out**)

These parents advocated in the virtual communities for their Face – being respected as parents – and their children's Face – being respected as children – in the society.

Tim, who is also a Facebook user who follows the Page that Quini created, said that he enjoys reading these detailed life stories of children with special needs, because it helps him to learn more about them. That knowledge assists him in more effectively teaching other children with special needs at school. He even mentioned that this objective was his main reason for adding parents as Friends on Facebook.

The reason why I add parents [as Friends] on Facebook is that they will record their children's development on their Profiles. These records are just like diaries. There are photos of the children, stories of where they have been to on their Profiles. So, I could know what this kid learned, liked, hated, and cared about through reading these virtual diaries. It helps me to adjust my teaching in school. (Interview with **Tim**, teaching assistant and member of **Speak Out**)

Professionals, especially social workers, caregivers in development centres, and teachers, also suggested that collecting parenting experiences from parental users is one of the most significant benefits of joining virtual communities. They noted that before social network sites became popular, it was hard to understand individuals' parenting situations, since collecting parenting information from parents was challenging. However, through the virtual communities in which parents now naturally share their parenting experiences, professionals better understand parenting situations and provide more efficient support for those individuals.

We [the professionals] used to be the outsider. And we used to imagine what these parents may face or what problem they may have. But when we went on Facebook, we could read their experience from their Profile directly. It is then that I realised that all the problems I imagine are far different from the problems they are actually facing. [...]Facebook helps me to become more and more able to understand what they are facing. (Interview with **Shung**, special education teacher and Group administrator of **Little Star**)

Zen, who created a public Page for his daughter to record her life, shared:

Because I think she needs to have her own Page, so I created this Page for her. [...] inside the page is all about her life. Where she went, what fun she had, who she met, so this is all about her. [...] So, when you read the posts, you will know the daily life of my daughter, including her mood, happy or sad. You will know who she really is. (Interview with **Zen**, father and member of **Speak Out**)

He said that the purpose of sharing his daughter's daily life with others was to advocate for his child and to encourage other parents, as well as other Facebook users, to live a positive life.

I hope more and more people can learn about the story of my daughter, how her story could also encourage others. That is mainly the reason why. [...] her story is mostly really positive and encouraging. (Interview with **Zen**, father and member of **Speak Out**)

Zen also stated that he avoided putting his personal opinion as a father on the Page, since the focus is on his daughter.

About parenting, I think I posted a little bit on my daughter's Page, but mainly on my personal Profile. [...] that is how I write about my emotions, but that is my emotion, not my daughter's emotion. So, on her Page, I post about where she went, what events she attended, the activities she did [...]. It is her Page, not mine. (Interview with **Zen**, father and member of **Speak Out**)

Diane also mentioned a similar motivation as Zen and noted that she shared whatever she could to encourage these parents of children with special needs to 'come out' and share that their children can enjoy life just like other children who are considered as 'able' by Taiwanese society.

I want to tell these parents that our children [with intellectual disabilities] are just like other normal kids. They can have fun, they can work, they can go to a concert. So, I will share the photo of my daughter having fun at a concert, so they [the parents] know that I am not boasting. [...] I want those parents to come out and let everyone know about their kid. I want them to come out. (Interview with **Diana**, mother and member of **Speak Out**)

However, even though these parents were willing to openly share their children's growth and detailed life experiences in the virtual communities, most of them had received some negative responses and attacks from other Facebook users. Quini said that one user made fun of her son's disability on her Page.

I just had one really bad experience, and it was the first time that I was so angry about a comment on my son's Page. You could go and check the comment on the page yourself. A guy made fun of my son because of my son's disability on the page. Well, it is possible that he didn't mean to hurt my son or me, but that joke [children with Down syndrome are hopeless] he made was really unfriendly. He

didn't understand what happened to my son. Besides him, most of the other comments were positive. (Interview with **Quini**, mother and member of **Speak Out**)

Dee, who did not set up a Page for her son, suggested that she also experienced online verbal attacks from other users on her own Profile when she shared about her son's childhood experience. She also said that her friend warned her not to be so explicit in sharing details about her son's life with other users. Despite that warning, Dee continued to share details of her son's daily life with others because she believed it would help other people facing a similar situation.

My friend told me that I put too much detailed information about my son on Facebook, and people may attack me for this. And she is right. I was hurt badly once. But I don't care, because that is the person's action. He is responsible for his behaviour. My purpose in posting things on Facebook is to care about people who need me, not those who hurt me. (Interview with **Dee**, mother and member of **Lovely Dove**)

Zen also described his negative experience with inappropriate comments on his daughter's Page.

I posted a post about my daughter turning 15. One user just comments on the post rudely. He is not my Friend on Facebook, but a Friend of a Friend. He said that when he was 15, he was already helping within earning a living for his family and doing things such as chopping down trees in the mountains. He didn't understand my daughter's situation. He didn't even *read* my post properly. You know, there are many people like this on the internet. They don't read before they comment. (Interview with **Zen**, father and member of **Speak Out**)

Zen also mentioned another frustrating situation related to sharing his daughter's life on Facebook. He said that some parents who did not have children with cerebral palsy gave him parenting suggestions through his Page.

Do you know what I don't like the most on Facebook? Some users who don't even know my children or who don't even know what cerebral palsy is trying to teach me how to raise my kid. When they see the photo of my daughter on Facebook, they will say 'Oh there are some problems with her muscle, she needs to drink more milk!' (Interview with **Zen**, father and member of **Speak Out**)

Ming then gave examples of how her parenting style had been criticised by different parents in her virtual community and how she subsequently learned to accept or ignore some of the suggestions and comments.

Some parents criticised me on my Profile for being a ‘Tiger Mother’ [a strict mother]. But I know it works for my son when he is not behaving. [...] they will comment on my note [electronic note on Facebook] saying ‘Oh, you shouldn’t do this to your son’ or ‘You shouldn’t do that’. I always treat these comments as different opinions, and it is up to me to decide if I want to accept them or not. [...] I have still been learning to accept these different voices until now. (Interview with **Ming**, mother and **Speak Out**)

In addition to attempting to accept these opinions, Ming created different private Groups and invited certain groups of parents to join those forums to avoid criticism. For example, parents who did not agree with her parenting style and parents with whom she was not familiar were added to Groups for acquaintances. As for parents who were closer to her and who shared similar opinions regarding parenting styles, she asked them to join a private Group that exclusively consisted of her close friends. In this way, she could receive support from, and also provide a certain level of support for, parents who did not employ her parenting style and parents who were not close contacts.

Well, I will create a Group for parents who accept how I teach my son, and I will share almost everything with them. And those who did not accept me, I will put them in another Group [...]. I still hope to help them through sharing useful information with them, but just not my parenting experience. (Interview with **Ming**, mother and member of **Speak Out**)

In other words, Ming created a virtual space in which Face was guaranteed to be given by other members in her Group. Zen also had similar experiences of benefiting from sharing information on his public Page. Since most members who paid attention to his Page were people who cared about him and his daughter, they supported him when rude comments appeared.

I didn’t delete the rude comment on the Page. Because others who also read the comment would reply to the person that his comment was rude. My Friends would always help me out in situations like this. So, I think it is a good way to educate the person. (Interview with **Zen**, father and member of **Speak Out**)



Selecting and inviting different members to share diverse types of information was a common theme across the three cases. Most of the interviewees shared the experience being included in, or excluded from, certain Groups, or even of creating Groups and determining their member lists. It is possible to suggest that the parents joined or created Groups to access more support and their preferred type of information.

Having Friends who are professionals who support the parents' experience and opinions was also suggested to be important for their parenting role by some of the parents. Zen implied that he was more knowledgeable about cerebral palsy than a user who was a certified physiotherapist because of his many offline friends and Facebook Friends who were physiotherapists (p. 188). In my research diary, I also recorded a special incident that happened after I interviewed Zen. I wrote:

Two hours after I got home from my interview with Zen, he shared a new post on his Page. He shared with his Friends that he was interviewed by a PhD student from England, referring to me. Several Friends of his clicked Like and replied in the comment praising him for being such a successful father. I did not know that this interview could be of such important to him. Being interviewed by a PhD student must have given him Face among his Friends. Maybe that is why he bragged about this experience straight after our interview this morning. (Research diary, 16 August, 2015)

Other parents also emphasised how they were both offline friends and Facebook Friends with different professionals. For example, Quini mentioned that she knew a famous professor in Malaysia and that he loved the parenting stories that she shared on her Page. In fact, the professor even shared these stories with his students. She said:

The professor is a famous cram-school teacher in Malaysia. He teaches education, so he is so interested in my son's story. [...] I realised that he was even telling the story of me and my son to his students [...] (Interview with **Quini**, mother and member of **Speak Out**)

These examples demonstrated that having a relationship with professionals was essential for parents to feel confident in giving opinions to other members of virtual communities.

## 6.4 Summary

This chapter has illustrated that rich information based on parents' personal parenting experiences was shared in the virtual communities. Parents also found comfort and affirmation of their identity and Face when reading about other parents' parenting experiences. The professionals also found it helpful to read about parents' parenting experiences, as those stories gave them a better understanding of those individuals. This chapter has also pointed out that certain parents, such as those who had more parenting experience, have more Face (being or 'are' respected) and received more attention than other parents, as their successful and rich parenting skills and knowledge were valued by the virtual communities. They were more powerful in these communities and were more likely than other parents to give suggestions and opinions to other parental members.

This chapter has indicated that certain parents used the diary function on Facebook to record the daily lives of themselves and their children to advocate for their children. These parents highlighted that their children were 'normal' (p.163) and that their stories could be encouraging to others. They also hoped to hearten other parents facing similar issues by sharing details about their day-to-day parenting. Parents fight for their Face and their children's Face through the social network platform. Parenting knowledge and experiences were identified as the most popular information in the virtual communities. However, some parents who shared detailed information in the virtual community were abused by other users. In order to avoid conflict and keep their Face, these parents also created private Groups that were only open to people who supported them and provided positive feedback.

The findings also underscored that the parents paid less attention to the professionals than to each other. Even though they were more likely to be ignored, these professionals also became Friends with the parents, and the parents were mostly positive about their relationships with those specialists.

## Chapter 7. Online medical resources

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Online medical resources, such as medical information regarding treatments and medical suggestions and experiences shared on the internet, was identified as one of the frequently shared types of online resources among the parents using virtual communities to search for parent support. A range of online medical resources were identified as being shared by different users, including parents and professionals, in all three virtual communities. All of the parental participants also mentioned their experience with sharing or receiving online medical resources through virtual communities.

Chapter 7 presents the content of the online medical resource and the ways that the parents shared and discussed it amongst themselves. There are two main sections of this chapter. **Section 7.1** presents how the parents shared and searched for formal medical information, such as published medical knowledge. This section demonstrates that the parents were cautious about sharing that type of information and used different strategies to disseminate it in the virtual communities. This section also indicates that informal medical information, such as personal medical suggestions based on experience, were preferred and more likely to be shared by the parents within their virtual communities. **Section 7.2** shows how parents encourage each other through this process of sharing medical experience. Finally **Section 7.3** also shows how parents also took the initiative to contact professionals for medical information and support.

Both sections of this chapter yield important insights regarding differences in how the parents shared formal and informal information. Actions of emotional support, such as encouragement, when searching for medical advice and suggestions from the members of the virtual communities were also identified. These interactions of emotional support are discussed in both sections.

### *Definitions of different types of online medical resource*

During the data analysis process, I identified online medical resource as a form of frequently shared and often-mentioned information that supported parents of children

with special needs in these virtual communities. However, I also realised that it is difficult to categorise medical resource, since it always overlaps with other classes of information, especially those related to parenting skills for raising children with special needs. For example, treatments for mental illness could easily overlap with information about healthy lifestyles and parenthood. Therefore, it was important to arrive at a clear definition of online medical resource to efficiently identify and fully examine the medical resources that were shared in the virtual communities.

In this study, the term ‘medical resource’ refers to formal medical information related to children’s physical or mental status (such as information about epilepsy), medical treatments (such as eye therapies). The term also refers to informal medical information such as parents’ suggestions or experiences related to treatments or medical conditions. Finally, medical resource also includes emotional support parents of children with special needs received through internet interactions with other patients, professionals and parents, and/or through sharing of the medical information and the parental or professional network. In turn, ‘medical treatments’ refers to therapies both with and without medication. As regards eye treatment, for example, both eye exercises and eye drops would fall into that category. However, eye exercises would be categorised as therapy without medicine, and eye drops would be counted as a type of medication. The reason why it is important to distinguish between treatments with and without medication is that for Taiwanese parents, these two types of therapies are different. Medication for children with special needs is considered as a serious medical treatment, which in turn suggests that the child’s condition is serious, or even dangerous, to most parents and professionals (Liao, 2007). Treatment involving medication is typically avoided if possible (Liao, 2007). Therefore, in this study, all types of medical resource were carefully identified, categorised, and examined in order to provide a clearer idea of how different kinds of online medical resource were shared in the virtual communities.

## **7.1 Information**

### **7.1.1 Formal medical information**

In this section of the chapter, I present how formal medical information was shared among the parents in the three virtual communities. On the Speak Out Page, a user

shared a post introducing schizophrenia, which is a type of psychosis. The post gave basic information about schizophrenia, cited a member of Speak Out an example of a celebrity who had schizophrenia, and finally provided a brief history of the condition in Taiwan.

A few days ago, Dr John Forbes Nash Jr. and his wife, the actual characters in the movie 'A Beautiful Mind', died in a car accident. Along with the shocking news of their death, the issue of schizophrenia once again became the focus of social media. In Taiwan, many people suffer from the same mental illness—schizophrenia. The term 'schizophrenia' has been listed in the Diagnostic and Statistical Manual of Mental Disorders (also called DSM-5) as an official umbrella term referring to diagnosing a combination of symptoms of hallucinations, delusions and abnormal speech last year. It is really important for our medical history. (**Post** shared in **Speak Out**, 26 May 2015)

This case is a typical example of how information related to a specific medical condition was introduced and shared in the virtual communities. After this post was shared, a high number of parental users (118) Liked it, and 18 parental users shared the original post to their Profile or private Groups. However, none of the parental users commented on this information. As I examined multiple posts containing medical information in all three virtual communities, I found that most of them received similar responses from the parental users—a high number of Likes and Shares, but no comments from the parents.

When interviewing the parental participants, most suggested that they would prefer to just read about the formal medical information in the public platforms and privately sharing that information through their Profiles and/or Groups. Chi explained:

When they share medical information or other information which is useful for my son, I will share it to my Profile. It [my Profile] becomes my tool to collect information as such. (**Chi**, mother and member of **Lovely Dove**)

However, the parents were less likely to comment directly on these posts within the public platform. Dee explained her reasons for not commenting on formal medical information, saying:

Because medicine or education is not my profession, I won't give my opinion on that type of information. (Interview with **Dee**, mother and member of **Lovely Dove**)

Most parents underscored that they were parents, not medical professionals. Half of the respondents even deemed medical knowledge 'those kinds of professional things'. Parents also expressed their worries about the validity of comments on formal medical information in the virtual communities. Kuai said:

Because many people will claim that they are medical professionals. They will claim that they have done such and such courses and lessons that made them the professionals. But they are not. [...] Two mothers died because they followed the wrong suggestions and believed the information shared on that website. [...] I don't want to make such a mistake. (Interview with **Kuai**, mother and member of **Little Star**)

In addition to only sharing that information privately via their personal platform, when sharing information on public platforms, parents claimed that they were not responsible for its content and that they were only forwarding material from other websites. For example, a father in the Lovely Dove community left a comment stressing that he did not 'own' the information after he shared a post about the bone development of children with cerebral palsy:

I didn't own this information, but I want to share it with all of you so you have this knowledge. But please check the original source, here is the link (**Comment 1** shared in **Lovely Dove**, 28 August 2015).

Dee suggested that formal medical information received less attention from the parental users who viewed her page and was less likely to be Liked or thoroughly reviewed. She mentioned that parents were tired of receiving similar medical information over and over again in the virtual communities.

Because I realised that other parents rarely click like on these posts [posts about formal medical knowledge] [...] The reason why no one pays attention to this type of information is because that it often keeps on repeating on the internet. Oh my! We [parents] got so tired of it. So, I won't share that on my page. [...] (Interview with **Dee**, a mother and member of **Lovely Dove**)

Therefore, she did not share formal medical information via public platforms, such as the Lovely Dove Groups or Page, since doing so would be ‘pointless’ as the information would not catch the attention of other parental users and would just be ignored.

Therefore, this might also suggest that the less attention from other parental users could be a potential reason why the formal medical information was less likely to be shared or commented. The overly repetitive information which circulates in the virtual communities may also be another reason why parents paid less attention to comment about the information.

In summary, most of the parents did not prefer to share formal medical information in the public platform and the fact that the same information tended to be circulated repeatedly may have played a role in the parents’ tendencies in such regard

### *Information about face-to-face support services*

In addition to formal medical information, in several situations, the administrators of the virtual communities posted invitations asking the parents to attend face-to-face workshops or support services related to the medical interventions the organisations offered. That is, medical information was not shared directly with the parents in the virtual communities. Parents needed to access face-to-face settings and services to obtain the desired medical information. For example, a timetable for a physical therapy service was posted in Group 2. Parents needed to make an appointment with the local physical therapy centre to receive more suggestions about their children’s physical therapy.

The 2015 timetable for therapy sessions at the local physical therapy centre is out! These sessions include free physical assessments and therapy. For your information!

If you need any further information, please visit the physical therapy centre~~[10 users Liked the post] (**Post** shared in **Lovely Dove** Group 2, 13 March 2015)

This common means of indirectly sharing medical information may suggest that the professionals preferred to provide that information in face-to-face settings or such

information was easier to be provided through face-to-face settings. It might also imply a strong sense of control over medical information by the administrators of the virtual communities.

A possible reason explaining why the administrators encouraged parents to attend face-to-face sessions is the influence of marketisation. Since Lovely Dove and Little Star obtained the majority of their income through fees for workshops and other support services, it was reasonable for them to want to advertise these events and programmes. On the other hand, Speak Out was almost fully financially supported by the government. Therefore, even though Speak Out still featured several posts introducing face-to-face support services, the number of posts in that category was lower than for both Little Star and Lovely Dove.

Posts that encouraged parents to access face-to-face services or to attend offline workshops also tended to receive few comments from the parental users in the virtual communities. Most of the comments on these posts were primarily asking for further information about the workshop or session in question. For example, after Lovely Dove posted an invitation to a music therapy session, Mrs. Lin, a mother and a member of Lovely Dove, replied to ask if she could bring her seven-month-old son to it:

I would love to attend the session, but I need to bring my other kid who is only 7 months, can I still come? (**Comment 1** shared in **Lovely Dove**, 5 February 2015)

Yeh, the administrator then replied to the mother 40 minutes after that member posted the comment:

Hi Mrs. Lin! Thank you for your reply! Yes, you can bring your baby! Please remember to register and let me know! ^\_^ [happy face emoticon] Thank you! [received 1 Like from Mother 1] (**Comment 2** shared in **Lovely Dove**, 5 February 2015)

However, these posts with information about face-to-face support services were also more likely to be shared to the parents' personal spaces in their virtual community. Similar to the other types of formal medical information mentioned in the previous section, the parents may have shared this information to their personal virtual space



for personal use and as a means of collecting potentially useful information for themselves and other parents.

### 7.1.2 Information about medication

Within all three virtual communities, only one post related to medication was identified. This post in Little Star introduced a medicine called Clioquinol (Cq) that helps to improve the brain functioning of children with autism. It detailed how this medicine could improve the social behaviour of persons with autism by increasing the amount of Zinc, a chemical element, a person can absorb. Shin started the post with a long introduction of how this medication was discovered, writing:

Academia Sinica's [a research organisation] researcher Mr. Xue, who discovered the link between D-cycloserine [a medicine for tuberculosis] and the brain function system of a person with autism last year, discovered that medicine containing Clioquinol [Cq] could help improve autistic behaviours. This discovery has been announced and published in Nature Communication, a famous international journal. (**Post** shared in **Little Star**, 3 June 2015)

This post, which was published in Little Star, received substantial attention from the parents. It was given the high number of Likes and was shared by many parental users of Little Star. This may suggest that even though information about medicine was less likely to be shared in the virtual communities, it was important to the parents.

After the introduction, she then referred to a news article about this discovery:

According to the news report from Central News Agency today, recent research shows that persons with autism often have 'Zinc deficiency'. [...] (**Post** shared in **Little Star**, 3 June 2015)

Finally, she described the process of how this medicine was discovered and explained that it was still the focus of ongoing experiments:

The research team realised that mice injected with Cq in the laboratory had better social abilities compared to mice without Cq. The researcher from Academia Sinica suggested that this experiment may provide important evidence of the connection between Cq and Zinc deficiency. Hopefully, more research will be done in the future. (**Post** shared in **Little Star**, 3 June 2015)

After this post was shared by Shin, users left a high number of Likes (262), and 62 users shared this information to their Profile. However, three members of Little Star commented on Shin's post, questioning the reliability of the news article that she shared. A father shared the original link to the research study under Shin's post, and a mother criticised Shin's post by stating that all parents should read the original report rather than Shin's remarks.

I hope all parents visit the original to this research report the father posted in his comment. That is a better report than this post [Shin posted]. It shows what the researcher really wants to share. (**Comment 2** shared in **Little Star**, 3 June 2015)

Another father criticised the experiment and suggested that the researchers' efforts were useless in the absence of an actual human experiment.

This research did not mean anything. Only research which actually involves experimenting on proper human beings can prove that a study is useful. The scariest thing about researchers nowadays is that they always think they found something. It feels like when someone who saw a tree comes and tells you that they have been to the woods. They just want attention and money. There were so many parents and children who got hurt due to these studies and experiments. It is not good! (**Comment 5** shared in **Little Star**, 3 June 2015)

Following the comments questioning the reliability of Shin's post and the research, a mother then commented on the potential connection between Zinc deficiency and autistic behaviour. She wrote:

I think this Zinc deficiency is just a possible reason that causes autism. We cannot ask our kids to keep eating food with Zinc! The connection between Zinc and autistic behaviour is still a mystery. We mothers can only hope for the best~ (**Comment 6** shared in **Little Star**, 3 June 2015)

Finally, the discussion ended after another mother from Little Star commented and stated her assumptions. She wrote:

That's true. We really want to tell the reporter that there are so many factors that cause autism, especially genes. The newest research this year shows that there are more than 900 types of nerve cells which are related to autistic behaviours. If any one of the genes went wrong, the behaviours appear. So maybe this Cq improves these genes, and that's why it is effective. (**Comment 7** shared in **Little Star**, 3 June 2015)

Through these comments, all parents voiced their strong opinions regarding medication and the relationship between autistic behaviours and Zinc deficiency. Some parents even shared more professional knowledge about autistic behaviours, such as comment 7, to support their argument. Cheng, the mother of a 10-year-old son with autism, was excited when I asked her about her experience of sharing or discussing information about medication with other parents in her virtual communities, including Little Star. She said:

Yes, yes, yes! I will share [information about medication], because I hope other parents can also learn about this. [...] Like should their son with ADHD [attention deficit hyperactivity disorder] take medicine? Most of the time when you go to the doctor, they will just give you a small booklet with some information on it. You know that is really irresponsible. So, I will find some information on the internet and books to help them [other parents] (Interview with **Cheng**, mother and member of **Little Star**)

Cheng mentioned how parents were likely to be paid less attention by the medical professionals. Her suggestion echoes the Taiwanese parents' experience, as discussed in Chapter 2, where parents of children with special needs were not given Face and were ignored in the Taiwanese society. Therefore, in order to be respected by the medical professionals, Cheng suggested that parents should gain more medical knowledge. She, however, said that not all parents accepted her suggestions. Some replied to her offering a different opinion.

Most of the time, they [other parents] will reply. They will tell me what they think, how they think with a different point of view. They will also show me other articles they read that I haven't read before. We will discuss. But, you know, in the end, we make our own decision. What is good, what is bad. We just discuss. (Interview with **Cheng**, mother and member of **Little Star**)

However, when asking other parents about medication during the interviews, most of them suggested straightforwardly that their children did not need medication. This may hint that parents' opinions regarding sharing information about medication may differ. In addition, this finding might also imply the majority of parents might still consider medication as a treatment for severe illness, as Liao (2007) suggested. Thus,

when asked about medication, the parental participants were cautious about connecting their children with that concept.

When I asked Shin during the interview about her reasons for posting this information about Cq she shared on Little Star, she stated that she even though she tried to avoid sharing such information within Little Star, but she decided that such information was important enough to be shared. However, she also suggested that she was cautious about sharing such information and hoped to keep medical information as close to the original report as possible.

The first post I shared on Little Star today is related to medicine. Because it is an important article about how Zinc might have an influence on children with autism. But you see, I don't know much about medicine, so I don't want to give any opinion on this experiment. So, I posted the content from the original article without changing it. I am always cautious about posting things I don't know, like this medical article. (Interview with **Shin**, administrator of **Little Star**)

She later explained that children with special needs have different experiences with taking medicine and that their body response may vary, and so parents' views on medication can be highly dissimilar. Conflicts may occur between parents when sharing information about medication. For that reason, she claimed that parents should always go to medical professionals for medical suggestions, especially when medication is involved.

I have told them [the parents] pros and cons of taking medicine for ADHD in the Q&A section on the website, so they should go and read it before they share or ask such things. I explained how my son didn't need any medicine to survive his depression, but I do for mine. So, do you see the point now? Everyone has their unique body response to different medicine! [...] This issue is serious, because a child's life is in your hand, so how could you just tell others to take medicine like that? (Interview with **Shin**, administrator of **Little Star**)

Shin suggested that since there are no absolute answers as to which medication is helpful for children with autism, parents should not discuss but instead read the information provided within Little Star. She also mentioned her strong aversion to

parents sharing information about medication, even within Little Star's Groups. She gave an example of how information about medication could be harmful for parents:

You see, I faced a big crisis once; it was about a parent who shared information about medication in the Group of Little Star. Everyone was fighting and arguing with each other in the Group when they saw the post about medication! And you know, the parent who shared the information was even introducing a particular brand of medicine to other parents! Then a doctor who is also a member of the Group started to argue with that parent. (Interview with **Shin**, administrator of **Little Star**)

Shin became quite angry when she told me her experience. Most of the administrators also suggested that they would not post information about medication in virtual communities or would only do so infrequently. Most of them reacted similarly to Shin. Lee, the administrator of Group 3, stated firmly and straightforwardly:

As long as the parents don't discuss things related to medication, then it is fine for them to keep on having discussions in Group 3.  
(Interview with **Lee**, administrator of **Lovely Dove** Group 3)

Lee even mentioned that in Group 3, professionals who are not medical specialists should not post information about medication.

Umm, we've got two therapists, they will share stuff in the Group, but I have told them not to share information related to medicine.  
(Interview with **Lee**, administrator of **Lovely Dove** Group 3)

Lee explained that she hoped to provide helpful and uncontroversial information to the parents in the Group. Nevertheless, all the administrators exhibited a strong sense of control over medical information in their virtual communities.

Speech therapist Mei suggested that all medical professionals were taught in medical school that they should not develop a personal relationship with their patients. She also mentioned that this factor was the main reason that she would not share any medical information with parents through virtual communities or build a relationship with those individuals through those platforms.

When we work in the hospital, we have the medical ethical knowledge that we need to separate our work and personal life. So, it

won't be too complicated when you work. We don't want to get into a personal relationship with the patients. So, if they want to ask questions, ask me at the centre [development centre] or hospital [...] That's why I won't add parents as my Friends on Facebook. (Interview with **Mei**, speech therapist and member of **Little Star**)

However, Mei suggested that she would sometimes view parents' parenting experiences through other professionals' personal pages.

Yes, sometimes I will see the parents' information through the teachers' Profile. Because I am Friends with those teachers, so I could see the information on their page when they click Like on the parents' post. (Interview with **Mei**, speech therapist and member of **Little Star**)

Interestingly, she also claimed that other professionals who are not medical specialists, such as teachers, tend to be more likely to add parents as Friends on Facebook.

Yes! The special education teachers! Especially when they are the class teacher [teachers who help manage the class and communicate with parents]. They will discuss things with the parents on Facebook. So, yes, they will [add parents as Friends]! (Interview with **Mei**, speech therapist and member of **Little Star**)

In short, information about medication received more attention among the parental users in the virtual communities than did other types of formal medical information. However, most administrators were cautious or negative when it came to posting information about medication in those spaces. It is possible to suggest that in all the virtual communities, users rarely shared information related to medication to avoid conflicts caused by members' different opinions on that topic.

### **7.1.3 The accuracy of online medical information**

Since medical information requires a high level of accuracy, page administrators and Group administrators often chose medical information that is published by a scientific research centre or medical professionals with years of experience. They also stated the original website to provide a reference for the medical knowledge that they shared. For example, Shin always gave a citation for the knowledge being introduced at the beginning of the post.

The Japanese National Institute of Mental Health and Nerve Research Centre announced that its team found and clarified the role of a specific type of protein and its connection with schizophrenia and autism and other psychiatric disorders. They hope to help develop a method to diagnose and provide treatment for such diseases. [...] (**Post** shared in **Little Star**, 3 January 2015)

By choosing published and authoritative information, the risk of sharing false information declined. All the administrators of the three virtual communities suggested that all medical information was carefully selected or filtered before being posted to their platforms. A Lovely Dove administrator even said that the organisation had a specific team of experts select the information for its Page.

Our medical information was selected and checked by our team of experts from the healthcare department in our organisation. After they have filtered the information, we will then post it out on our Pages and Groups. (Interview with **Yeh**, Page administrator of **Lovely Dove**)

These findings suggest that the accuracy of medical information was essential for all three virtual communities. Moreover, the results revealed that the professionals were seemingly controlling the quality of that information.

Interestingly, most of the parents were also aware of the possibility of reading false information, which frequently appears on the internet. When false medical knowledge was posted on Pages or Groups, different parental users quickly commented on the post in question and reminded the poster the information was not correct. For example, a false report about the cause of leukaemia was posted in Group 3 by a mother:

The real cause of leukaemia has been found! [...] Never give your children any artificial juice, soda or any drinks that have artificial additives!!! You will know what I mean after you read this article!! [Link to the website of the false report] [received 10 Likes and 1 share] (**Post** shared in **Lovely Dove** Group 3, 30 December 2014)

Ten minutes after the post was published, six other parental users started to warn the mother who had shared the information that the report was not genuine.

This is an internet rumour. (**Comment** 1 shared in **Lovely Dove** Group 3, 30 December 2014)

I have a friend who got leukaemia when she was 12 years old. It has been 30 years since she got it. And 30 years ago, artificial juice or drinks were not popular at all. So the reliability of this report is really low. (**Comment 2** shared in **Lovely Dove** Group 3, 30 December 2014)

The main website of this report is dodgy! Most of the articles it posted were rumours. So don't believe it. The website wants you to click and read the article so it can sell the website to a commercial buyer. (**Comment 3** shared in **Lovely Dove** Group 3, 30 December 2014)

At the end of the discussion, a mother drew this conclusion:

No matter if the information is false or not, we still need to be careful of what food or drinks we give our child. (**Post** shared in **Lovely Dove** Group 3, 30 December 2014)

Several parents also suggested in their interview that they checked the reliability of information before posting it on their Profile and sharing it with other users or parents.

Quini said:

If I am interested in this information, I won't share it right away. I will call the person or organisation who posted this information. Like what I said before, even though you only hope to help others, but if you share the false information, you are just making things even worse, or even putting someone's life at risk. (Interview with **Quini**, mother and member of **Speak Out**)

These web-based observations and interview data indicated that the parental users in each virtual community were aware of the potential lack of reliability of information from social network sites and virtual communities and thus checked information before trusting it. Rather than simply receiving information, they also examined such materials and left comments correcting posts when they found conflicting evidence.

#### 7.1.4 Informal medical information

Informal medical information, on the other hand, was more likely to be discussed publicly in the virtual communities by the parents. The parents also exhibited greater interest in sharing this type of information versus formal medical information. Parents shared their experiences in the comments, as well as sought other parents' opinions.



For example, in Group 3 of Lovely Dove, parental users directly discussed issues related to therapy with other parental users or professionals. These discussions all started with a simple question about therapy or about the medical condition of one parent's child. Other parental users then remarked on the questions and gave suggestions to the askers by commenting on their posts. For example, a mother in Group 3 posted a question in the Group about eye therapy.

Excuse me... has anyone been taken amblyopia therapy [a type of eye therapy] before? My son needs it. Please let me know! I live in central Taiwan. [received 22 Likes] (**Post** shared in **Lovely Dove** Group 3, 8 March 2015)

A few parents then answered the question, sharing the names of hospitals and describing their children's past treatment experiences.

They got this treatment at St. Mary's Hospital! (**Comment** 2 shared in **Lovely Dove** Group 3, 8 March 2015)

You could visit the Lucy Clinic in Central Taiwan. It's on ChungShan Street. My son went there before. But I am not sure if it is still open now. (**Comment** 3 shared in **Lovely Dove** Group 3, 8 March 2015)

The little one in my home has also done the amblyopia therapy before. But the doctor only asked him to do eye training exercises on the computer half an hour a day. (**Comment** 4 shared in **Lovely Dove** Group 3, 8 March 2015)

The mother who authored the post then took over the discussion and asked a further question to the member who had posted the fourth comment:

Where did you [the mother who posted the fourth comment] do this treatment? Is it good? (**Comment** 5 shared in **Lovely Dove** Group 3, 8 March 2015)

The mother who posted the fourth comment then answered the question:

The clinic on ChanKuo road.... I don't remember its name though...let me find it for you later.... But just want to remind you that the doctor only asked my son to do the eye training exercise every day at home. (**Comment** 6 shared in **Lovely Dove** Group 3, 8 March 2015)

In the comment, she mentioned forgetting the name of the clinic but said she would still search for the name for the mother. She then reminded the mother that the treatment may not be suitable for her son. She used the term ‘only’ to describe the eye treatment her son received. The way the word ‘only’ was employed in this situation has negative connotations in Mandarin. Another member who knew the name of the clinic quickly replied and shared that information.

The clinic on ChungShan road is called Sunshine Clinic! My daughter has been there before. They do amblyopia therapy there. Her eyesight improved well in the first few months. But after we stopped going, it got worse again. The doctor just reminded us to keep doing the eye training. (**Comment 7** shared in **Lovely Dove** Group 3, 8 March 2015)

Both the mother who asked the original question and the author of the fourth comment then clicked Like to thank the member who replied. The author of comment 7 also suggested that the treatment might not be ideal for the mother’s son, and she imparted that idea by remarking on her daughter’s eyes condition after they visited the clinic. Several members also complained about the eye treatment after this comment was made.

This discussion demonstrated how parents shared their experiences with searching for medical treatment for their children in the virtual community and also highlighted that the parents were making judgements about medical services. However, not all of the comments consisted of complaints; a mother whose daughter had had a successful experience with the eye treatment posted a short comment to reminded the members who were complaining that continuing the training is vital. She wrote:

Well, it is still important to keep on doing the eye training. My daughter’s eyesight did improve eventually. (**Comment 16** shared in **Lovely Dove** Group 3, 8 March 2015)

However, this comment did not receive any Likes, and the mother who posted the question did not reply to her. After this comment was made, the mother who posted the question drew a conclusion:

I think I will try Lucy Clinic.....Thank you all for answering my question! (**Comment 19** shared in **Lovely Dove** Group 3, 8 March 2015 in)

As can be seen in this discussion, parents made their own assessments of medical treatments and chose information that they preferred. They selected and shared the medical information that they believed to be useful to themselves and others. It was also interesting to see that parents who shared different opinions were sometimes ignored in discussions in the virtual community.

In addition to giving suggestions, some parents even helped other parents to negotiate with medical professionals. In Group 3, a mother hoped to find a doctor who could provide a certain operation for her daughter. After her message was posted, a father replied:

You could go to Dr Lin for the operation. Here is his number #####. But I will suggest you to ask the doctor if there is a possibility to avoid the operation. (**Comment 1** shared in **Lovely Dove** Group 3, 1 March 2015)

In this example, the mother not only received the name and number of the doctor, but also a suggestion that could have potentially helped her daughter to avoid the procedure.

According to the interview data, 8 of 12 parental participants suggested that they had been participating in different private Groups to discuss medical information with other parents. Most of them asserted that joining these discussions and reading the comments had helped to gain more medical knowledge.

I will go in these Groups and read [the comments], and some of the parents will share their experience, for example, how their kids cope with the disability. Sometimes when the question is similar to my kid, I will try to reply and help. But if someone replied before me with a similar idea, I will not reply again. (Interview with **Jade**, mother and member of **Little Star**)

Tim mentioned his experience of interacting with parents of children with rare disabilities. He noted that parents of his students and also parents in Speak Out had formed a private Group within the virtual community just to discuss medical information related to this rare category of disability.

Some of the situations of the students were really unique, and the disability was really rare. So, the parents went on Facebook and created a Group just for discussing the disability of their children, for example, the Group parents created for Rett syndrome.  
(Interview with **Tim**, teaching assistant and member of **Speak Out**)

Tim also noted that these parents were more knowledgeable than him in discussions regarding the medical condition of their children. He did not even need to provide medical information to them.

They knew already. Just as I said, they were really active about finding information. So, they knew this information already.  
(Interview with **Tim**, teaching assistant and member of **Speak Out**)

Social worker Ann also mentioned that she was impressed with parents taking the initiative to share and discuss medical information with other parents on Facebook.

For example, one of our children got a rare disease, and even doctors don't know how to help him. Our parents then went online and found a lot of information from other countries, they are now even better than the doctors! There are so many examples like this! [...] And they shared this information with each other [both on Facebook and in real life]. (Interview with **Ann**, social worker and member of **Lovely Dove**)

These examples might suggest that the virtual communities provided significant opportunities for parents to collect and discuss medical information, both formal and informal. Some parents even had better understandings of specific medical situations than did doctors or other medical professionals.

However, Zen also shared a negative experience related to sharing his daughter's treatment experience in which other professionals commented on that material. He mentioned that even though most of the professionals, such as the physiotherapist, were encouraging and commented positively on his daughter's medical situation, a few of them commented on the case in a manner that he found inappropriate.

When I discussed medical treatment my daughter received, I shared a photo of her on her assistive device. Everyone has their opinions about it. For example, a physiotherapist said that the legs were well attached to the support. [...] But a lady who was the director of an early treatment organisation left a poor comment on my post. The

lady wrote ‘Good! Her legs didn’t bend out of shape!’ What a rubbish comment! (Interview with **Zen**, father and member of **Speak Out**)

After sharing this negative interaction, Zen told me that as his wife was a certified physiotherapist and many of his friends were medical professionals, it was impossible for his daughter to be in a poor condition or to receive low-quality treatments. He said:

My wife is a certified physiotherapist, how on earth is it possible for my daughter’s legs to bend out of shape?? When she [the director of an early treatment organisation] left comments like this, she shouldn’t even keep her title. [...] and I’ve got loads of friends who are nurses or physiotherapists, so I understand these situations, they will give me suggestions as well. [...] I just ignore her [the director of an early treatment organisation]. (Interview with **Zen**, father and member of **Speak Out**)

This illustrates that in virtual communities, parents might receive suggestions or come in contact with opinions that they consider offensive, or which leads to them losing Face. However, similar to the strong beliefs that surfaced when the parents commented on the post about medication for children with autism (p.176), this example suggests that parents may also hold strong opinions and so defend their Face regarding their understanding of medical information and these opinions may be based on their past experience or social networks. This example from Zen demonstrated that parents had the authority to disagree with opinions stated by other users, even professionals, in the virtual community.

## **7.2 Emotional support**

### **7.2.1 Seeking comfort**

Some parents directly asked for emotional support from other members by posting about their needs in the virtual communities when their children were going through a difficult time in their medical treatment. For example, one Little Star post consisted of a mother urging other parents to give her son blessings. She was also seeking comfort and sympathy. She shared details of the critical health condition of her son, who had severe epilepsy and cerebral palsy. At the very end of the post, she stated that she hoped other parents on Little Star could bless her son, since it was his birthday:

It has been 12 years since Wenzi started his medical treatment for epilepsy. He could not eat, stand, or sit. He could only eat through his nasogastric tube. [...] due to epilepsy, he experienced multiple organ dysfunction syndromes several times in the past few years few years. After several operations, his brain also got damaged. [...] it is his 15<sup>th</sup> birthday today, but he needs to go through another big operation this afternoon. Please, could you just send him some blessings here? He will be really happy if you do so. [...] Can you leave a comment and bless him? (**Post** shared in **Little Star**, 14 March 2015)

On the date this post was published, it received 875 Likes, and 35 users shared it to their personal virtual spaces. It also received 108 comments wishing a happy birthday to Wenzi.

~^o^~ [singing and exciting emoticon] Happy Birthday Wenzi  
~^o^~ Happy Birthday Wenzi ~^o^~ (**Comment** 1 shared in **Little Star**, 15 March 2015)

Happy Birthday Dear Wenzi! And let's press on together!  
(**Comment** 6 shared in **Little Star**, 15 March 2015)

Jade and Shung also posted happy birthday on this post. In addition to the birthday wishes, the parents in Little Star also encouraged Wenzi's mother in the comments.

Happy Birthday Wenzi! And to the mother of Wenzi, having a mother like you who tried so hard to support Wenzi, Wenzi must be really blessed and happy already! (**Comment** 3 shared in **Little Star**, 15 March 2015)

Finally, the mother who shared this post replied with gratitude in her comment.

This post demonstrated how parents expressed their encouragement through the virtual communities. It also revealed the speed at which such encouragement could be given through the virtual communities.

Lovely Dove also shared the same post about blessing Wenzi in Group 1 and Group 3. After the administrator of Group 1 shared the post in that space, it received 32 Likes and 3 comments from the Group's members, including the director of Lovely Dove. Compared to other posts in Group 1, this one received more attention from the parental users. This same post was also shared in Group 3 of Lovely Dove, although it was not posted by Lee, that Group's administrator, but directly by Shin. During the

interview, Lee mentioned that Shin was invited to be one of the members of Group 3 since ‘she provides helpful information for other parents in the Group’.

Interestingly, however, this post received little attention. Only 20 parents Liked the information, and none of the parents commented on the post to wish Wenzhi a happy birthday. I identified several situations in which Shin was advertising a support workshop in Group 3 and received a muted response from other parents. Thus, it is possible that Shin might not have been as trusted or popular among the members of Group 3 as in Little Star, the virtual community that she managed. This reaction among parents in Group 3 to Shin’s posts also highlighted that members of different communities may have distinct preferences regarding the information posted in their communities.

### **7.3 Advocacy: Direct contact with professionals**

In addition to sharing and discussing medical information in Groups, some parental participants shared their experience of directly contacting professionals to obtain medical information. Jade mentioned that she was proud of herself for having the confidence to contact a professional directly and ask medical questions.

I used my own strength to find him [the psychologist], this person who supports me, the psychologist I mentioned just then [in the interview]. I found him through the internet, I found many doctors. Through different routes, I found him [the psychologist]. (Interview with **Jade**, mother and member of **Little Star**)

She also mentioned that she would try to keep her questions short to avoid disturbing the psychologist too much.

The psychologist is quite busy, actually. So, if I need to ask him a question on Facebook, I will try to make it short and clear. For example, I will write down ‘One: What is the issue? Two: What methods have I tried to solve it? And, three: What else could I try?’ Then I will wait for his opinion. (Interview with **Jade**, mother and member of **Little Star**)

Even though most parents were positive about contacting professionals through private messages, others, however, suggested that they would not do so unless it was

necessary. They did not want to add more pressure or work for those professionals. Fu mentioned that:

They have been working hard during the daytime to take care of our kids. So, I don't want to add more of a burden to them in their private time. Unless it was something urgent. (Interview with **Fu**, father and member of **Lovely Dove**)

Some parents who had been parenting for a lengthy period of time mentioned that they received private messages from other users who were new parents. These new parents asked them for suggestions about their children's medical issues.

They often wrote me about what happened to their kid and then asked for my recommendation of which doctor they could go to. (Interview with **Quini**, mother and member of **Speak Out**)

Taken together, these results suggested that parents considered private messages an efficient way to access medical information and also to express their needs. It was also interesting to see how parents were taking control of the type, amount, and importance of the medical information they hoped to receive from the professionals, rather than just passively accepting communication. It is important to note that through the virtual communities, parents were taking the initiative to seek out, and ask for, information from professionals.

## 7.4 Summary

Overall, medical information played an important role in parent support within the virtual communities, and a wide variety of medical information was shared. First of all, this chapter has pointed out that formal medical information was more likely to be simply read, Liked, and Shared to parents' personal platforms in the virtual communities than to be discussed through a public platform. Parents suggested that they did not have the authority to discuss this professional knowledge. However, parents had strong opinions on specific topic connected to medical information, such as medicine. They exhibited a strong sense of control over such information, had confidence in their knowledge, and even questioned professionals or engaged in debates with those specialists. The administrators also displayed strong concerns about sharing medical information in public spaces and preferred for parents to join a



face-to-face workshop to obtain such information. This preference of parents attending the face-to-face workshop among administrators may have been influenced by marketisation, as these private organisations for parents still relied on collecting fees for support services from parents as their main income.

Secondly, this chapter has illustrated how informal information was preferred and was more likely to be discussed publicly by parents in virtual communities than was formal information. Parents joined specific groups in search of opinions and suggestions regarding medical decisions. Other parents also provided recommendations on the basis of their personal experiences. During this process of searching for and providing medical suggestions, similar to what has been seen in previous chapters, parents used Likes to demonstrate their acceptance of an idea or even to demonstrate to the Group that they were ignoring certain users. Likes were also used to encourage the conversation to continue. These findings might underscore that the Like played an important role in interactions among parents. Parents were also found to have strong opinions and beliefs as regarded informal medical information, and these views were based on their past experience. They were also found to criticise suggestions from other users, and even professionals, due to their confidence in their personal experience and knowledge.

Overall, the parents behaved quite differently towards formal and informal medical knowledge. The results highlighted that the parents were gaining control of medical knowledge and that the virtual communities allowed these parents to demonstrate that mastery in various ways to administrators, professionals, and general users.

## Chapter 8. Educational provision, welfare, and leisure

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This chapter explores parental users' strategies and motivations related to sharing and searching for information associated with children's services via virtual communities. The main focus is on information on education and welfare support. This chapter also explores information about leisure, such as entertainment and plans for family vacations, shared among parents in virtual communities. Their motivations for, and experiences of, sharing this type of information are also discussed.

**Sections 8.1** highlights how information related to children's education was shared in the three virtual communities. Three categories of educational information were identified as frequently shared among the parents, namely, information about educational placement, information about school activities, and communication with teachers. How parents advocate for their children's educational needs is also presented in Section 8.1.4. **Sections 8.2, and 8.3** demonstrate how welfare information and leisure activities were shared by the parents within the virtual communities. In both parts of the chapter, the limitations and negative experiences encountered by the parents participating in the virtual communities are also presented.

### 8.1 Educational provision

#### 8.1.1 Information: Educational placement

Educational placement is one of the most frequently discussed and most commonly shared types of educational information among parents in virtual communities. Similar to medical information, the administrators preferred sharing information about face-to-face support services and workshops on educational placement. The following post is an example of the kind of information that was commonly posted in all three communities.

How much do we know about the career development of our children? How much do we know about their primary, secondary school, and the special education support for them in school? Where shall our kids go when they graduate? If they do not go to work, what are the other options? How will society help our children?

‘Understanding these life phases of our children helps us to press on in the right direction for them.’ Therefore, the Taipei Development Centre invites all of you to attend this workshop on career development for children with disabilities. They invite all professionals from different fields to share about the current situation in different states of education. Please join us! (**Post** shared in **Lovely Dove**, 20 November 2015)

This post advertised a workshop held by the Taipei Development Centre on educational and vocational provision for children with special needs. Similar to other invitations to face-to-face workshops, none of the parental users commented on the post, and only 8 parents clicked Like.

On the contrary, parents were identified as actively commenting on, and discussing, educational placement according to their experience in the virtual communities, especially in the Groups. Parental users posed their questions directly through the comments or posts, and other parental users who had undergone a similar experience or who had related information replied to them. In the following example, a mother was asking for information about primary schools for children with cerebral palsy in Group 3 of Love Dove. To receive an accurate answer, the mother even provided short but detailed information about her son and a photo of him. She wrote:

Hi all,

I am Billy, I was born in 2011, and I have cerebral palsy.

I got a tracheostomy [surgically created hole in a person’s windpipe to provide an alternative airway for breathing], but I can also breathe by myself.

I hope to know more about the nursery in the local primary school in Taoyuan.

Does anyone know any information that could help me? (**Post** shared in **Lovely Dove** Group 3, 18 September 2015)

A mother quickly replied in the Group with names of schools that could potentially be suitable for Billy.

You could go to the Special School of Taoyuan, the government will provide you with an allowance each month, and you do not need to pay the tuition fee. Other than that, there are Complete Development Centre, Taoyuan Development Centre, Seashell, ... these are private schools, but you could still apply for an allowance from the government. You could go and have a look

and see which one is best for your son. (**Comment 1** shared in **Lovely Dove** Group 3, 18 September 2015)

After reading this information and the suggestions, Billy's mother replied to the mother who had commented on her post. She mentioned that she had not received an invitation from the schools. She typed:

I am waiting for them [the school] to send me their information, but they never send anything. (ಠ\_ಠ) [emoticon signifying frustration] (**Comment 2** shared in **Lovely Dove** Group 3, 18 September 2015)

Billy's mother replied with an emoticon 'ಠ\_ಠ' to demonstrate that she was helpless in this situation, since she had not received any invitation from the schools. However, the author of comment 1 did not understand what she meant. Thus, she left a second comment stating, 'I don't understand what you mean?'

However, Billy's mother did not reply to her question. The author of comment 1 then posted another comment suggesting that Billy's mother needed to take the initiative to visit the school instead of waiting for it to send her an invitation or information.

The schools I mentioned in my previous comment came from my past experience visiting these schools! So you need to bring your child to these schools and see which one is best for him. Don't wait for them to contact you. And remember, not all environments and teachers are suitable for your child. Besides that, you also need to consider how to balance your income and the tuition fee in the future. [received 3 Likes](**Comment 4** shared in **Lovely Dove** Group 3, 18 September 2015)

Billy's mother did not reply or click Like on this comment. However, some other parents and the Group administrator did click Like. Several other parents also tried to help Billy's mother and provided their suggestions under her post. However, Billy's mother made only short replies and did not click Like on any parents who responded to her post. As Billy's mother did not, for example, click Like or express her gratitude to the members who replied her, the discussion quickly ended. As can be seen in this example, the virtual communities potentially had accepted rules and patterns of interaction for searching for information and building connections with other parents.

It is possible that Like could be considered as a way of showing gratitude and also giving Face to a person in the virtual communities.

Other than searching for general information about placement, some parents sought out specific information about education through the virtual communities, such as in the following example regarding homeschooling for children with severe health conditions. Since that type of information was more specific, parental users or administrators who did not know the answer referred to the original poster to specific Group members or professionals with the desired material. For example, in Group 3, a mother asked for information about home-schooling:

My friend's son was diagnosed with acute myeloid leukaemia recently. Her biggest problem at the moment is how to home school her son and if in the future, her son hopes to attend mainstream school again, how would the assessment work during the period of his home schooling? Does anyone have information about this? (Post shared in **Lovely Dove** Group 3, 28 August 2015)

About five minutes later, Lee then commented on the post and tagged a mother who may have known the answer to ask if she could help with the question. The second mother replied within an hour:

All academic assessments are done by the home schooling teacher. So no need to worry. So will her son return to school after the chemotherapy? (Comment 3 shared in **Lovely Dove** Group 3, 28 August 2015)

The mother who asked the question did not mention the boy's chemotherapy. As can be seen in the above example, author of comment 3 was experienced and understood the boy's medical condition through the information given in the post. The discussion then carried on after knowing the boy was having chemotherapy at the time the author of comment 3 then provided more detailed answers about home schooling to the person who asked the question.

This finding indicated that the parents in these virtual communities cooperated with each other to search for information. Through virtual communities, parents were given more opportunities to contact community members with specific knowledge or experience that could provide precise support for them and their children. Some

parents also mentioned that in addition to asking questions through Pages or Groups, they directly contacted the school teacher or other related professionals through the private message function of Facebook. Jade mentioned that she directly contacted Shung, Little Star's special education teacher, to ask questions about her son's educational placement.

I asked Shung directly through Messenger [the private message function of Facebook] last time, because my son is preparing for the high-school entrance exam this year. She said, 'There are two ways to get into the school he wanted, it is either through an entrance exam or through school recommendation and interview.' So, I asked her for her opinion through Facebook. (Interview with **Jade**, mother and member of **Little Star**)

This type of interaction pattern had similarities with the parents' approach to obtaining medical information through directly asking professionals for it (see p.190). These examples demonstrated that virtual communities provided the parents with quick and efficient access to professionals so that they could collect more information of benefit to their children and potentially build connections with those specialists.

Even though the instant messaging function of Facebook provided the parents with an easy and efficient way to search for needed information, some issues still appeared. Tung, a social worker and the administrator of Lovely Dove Group 2, mentioned that some parents relied too heavily on asking questions through instant messages. She stated that sometimes, parents texted her about minor issues, such as how to write the character 'R':

The parents sometimes rely too much on sending us Facebook messages [...] They don't have the ability to decide and make good judgements themselves due to this overdependence on us to give them the answer through instant messages. (Interview with **Tung**, administrator of **Lovely Dove** Group 2)

Interestingly, the parents took the initiative to contact the professionals and even were overly reliant on those individuals to a certain extent. These findings might suggest that the instant messaging function on Facebook may be convenient for parents but could potentially lead to overuse issues and overreliance on that form of communication.

### 8.1.2 Information: School activities and school life

On the other hand, some teachers publicly shared school announcements and detailed information on students' school lives through the virtual communities to involve the parents in the educational process. For example, Tim shared details on his students' behaviour in school with the parents almost every day to engage those parents in his teaching.

I shared with my parents what I did in school for their kids. [...] Like, one day we brought a student with cerebral palsy on a field trip. And during lunch time, we ordered a really cute set meal for her. But she only ate half of it and said that she was full, and then she started to cry. We started to wonder why, since she was hungry just before we arrived at the restaurant. So, we then took her to the playground at the restaurant, and she started to smile again. So, when we posted on Facebook, the mother then commented on the post saying that she always did that when she wanted to play. So, the mother told us that we need to make sure she finishes all the food before going to the playground next time. [...] If I put the picture on my Profile, the mother would reply, too. (Interviewed with **Tim**, teaching assistant and member of **Speak Out**)

Some professionals used private instant messaging as a tool to remind parents about school activities or about their children's problematic behaviour at school.

I started using private message to contact parents who work at night. So, during the daytime, the mother would be asleep. So, I leave her a message, which she is more likely to reply to. (Interview with **Winni**, special education teacher and member of **Little Star**)

Some parents also mentioned that their children's teachers had formed private Groups for parents and the child's current and former teachers to discuss how to support the child. These private Groups created semi-virtual individual education plan (IEP) meetings for the children.

For example, we meet excellent teachers, and they are like families to us. When my son had just entered primary school, if anything were to happen at school, I would still contact his kindergarten teacher.. And, the current primary school teacher and the kindergarten teacher formed a private message Group on Line [another social network site], so we would contact each other and share what had happened to my son each day. So, the current teacher would ask the kindergarten teacher what to do in some situations. (Interview with **Quini**, mother and member of **Speak Out**)

Zen suggested that he even took the initiative to contact professionals and create such a Group for them.

The primary school teacher was really close to my daughter, since she had been taking care of her for six years of primary school [...] she always knows what my daughter needs and what is best for her in school. So, when my daughter went to secondary school, I added the primary-school teacher and the new team of teachers in to the same Facebook Group, so they can talk to each other and exchange experience. (Interview with **Zen**, father and member of **Speak Out**)

Su, the family counsellor working for Lovely Dove, also detailed her experience of being added to a Group for fathers of children with special needs due to the potential help she could provide to them.

For example, a group of fathers in Lovely Doves loves baseball, so they formed their baseball Group on Facebook. And they don't allow everyone to join. You need to be a father and also someone who loves baseball to join the Group. [...] but one day they added me to the Group, because they needed more volunteers to help them with some events. And I know those volunteers. Plus, they also needed me to book the venue for them, so I was added. (Interview with **Su**, the family counsellor from **Lovely Dove**)

However, Su also mentioned that parents have excluded her from Groups if some of the messages are 'confidential'. In such instances, only parents with a direct link to the information could read it.

Some Group are quite strict, they will post things about their choir. They will post their practice videos or discussions about their choir. They think these [videos and discussions] are considered as confidential. So, no one, including me and other unrelated parents in Lovely Dove, can join the Group unless you are one of them. (Interview with **Su**, the family counsellor from **Lovely Dove**)

Another mother, Jade, mentioned that when she shared school announcements on Facebook with other parents whose children attended the same school as her son, those users seemed more willing to listen to her than to the teachers from the school.

When you use your identity as a mother to remind these parents, it is way more efficient than teachers reminding them. I live in NanTao, I met a lot of parents from my son's school. I can't help but want to



share the school information with them. So that they can attend some of these [school] events. (Interview with **Jade**, mother and member of **Little Star**)

These examples illustrate that the virtual communities were used as an efficient platform for parents and teachers to communicate about children's behaviours in school and to share about school activities. They might suggest that joining a virtual community helps to enhance the efficiency of communication between professionals and parents. It allows the parents and professionals to provide quality education for the children. However, it was also interesting to see that these parents had great control over initiating and maintaining communication with teachers and in supporting the teachers in communicating with other parents. It is possible that through communicating and connecting with other parental users virtually, parents find Face within their virtual communities. This study suggests that participating in a virtual community provides parents with more opportunities to take control of their relationships, including related communication, with professionals in schools.

### **8.1.3 Information: Communication with teachers in school**

How to communicate with school teachers, especially during IEP meetings with teachers and staff (such as the teaching assistants) was frequently discussed among the parents.

The IEP is a legal document that records the learning needs of students with special needs in Taiwan. Most schools in Taiwan use the IEP to understand the student's needs, provide sufficient support and services, and plan the teaching course and curriculum for that student. For parents, it is an appropriate opportunity, as well as a responsibility, to communicate with the school and offer sufficient information so that teachers and other professionals can learn to support their children. During the IEP meeting, parents provide information on their child's learning strengths and needs on the basis of his or her learning experience at the previous education level. Parents also need to plainly state their expectations regarding their children's academic achievements to the school staff, teaching assistants, and teachers so that the school can develop a clear plan to help the children learn.

Therefore, it was not surprising that all three Pages shared several posts about how to communicate during an IEP meeting. However, again, in most of the Pages, these posts were primarily invitations to workshops or other face-to-face services that the organisations provided. For example, Speak Out published a post about a workshop for the IEP meeting. It read:

We often receive phone calls from parents about the difficulties they faced during their IEP meetings. What shall we do when we face challenges in the meeting? How do we communicate with the teachers?

★Time: 9th November (Sun)10:00-16:10 ‘How Do I Participate in the IEP Meeting Workshop.’

★Place: No. ###, Zhongzheng #th Rd, Qianjin District, Kaohsiung City

Please share this post, so that other parents who also need this information can also attend this workshop. Sharing is powerful.

Please Share Share Share! ^+++^ [happy face emoticon]

★Link of website: [Website link] (Post shared in **Speak Out**, 7 November 2014)

Again, similar to how the parents responded to other types of formal information posted on the Pages, they did not comment on the post and instead only Liked it. It is also important to note that this post started with a reference to the parents experience in communicating with professionals in schools being ‘difficulties’. The topic of communication with the teachers and other professionals was commonly shared in most of the posts about IEP meeting. For example, in Group 3, a teacher penned another post sharing suggestions for parents on participating in IEP meeting. The teacher wrote:

1. If the children haven’t gone through the evaluation for special education placement, school teachers will not know about them and it will be hard for the teachers to give parents and their children support.
2. There are many students in a general mainstream school classroom, and most teachers are under high pressure. Most of the teachers do not have sufficient experience of teaching students with special needs. If possible, please don’t argue with the teacher in the parent-teacher contact book [a notebook where parents can leave weekly or daily notes for the school teacher].

3. When communicating with the teacher, please keep in mind that all members are there to help you and your kids. So you need to keep on communicating with them.

Please share your experience in the comments! [received 75 Likes]  
(**Post** shared in **Lovely Dove** Group 3, 15 March 2015)

After this post was shared, 8 parental users commented, and 5 shared their personal experience of attending an IEP meeting. Most of the comments supported the idea of parents needing to cooperate with the teacher and reminded other parental users that the teacher is ‘on their side’ and not against them. A mother wrote:

You need to let the teacher know that you are on the same side with them. And if the teacher needs your help, please let him or her know that you are available to help. For example, you could help advocate for the teachers for better working hours and pay for teachers, since teachers are still struggling to get better hours and pay. [received 6 Likes] (**Comment 1** shared in **Lovely Dove** Group 3, 15 March 2015)

Two minutes after this comment was posted, a mother added her suggestion:

You also need to ask other special education teachers to join this meeting too! Because they are the ones who understand more about your child’s needs. (**Comment 2** shared in **Lovely Dove** Group 3, 15 March 2015)

Another mother warned other parents that if they gave up in communicating with the teacher, their children would ‘suffer’. She then shared her negative personal experience that occurred when she did not pay attention to cooperating with her child’s teachers.

Please do not give up communicating with your teacher, or else, if you are not good at communicating, your children with disability will suffer in their school!

I did not participate in the parent-teacher discussion actively when my first-born son with ADHD started his second year. He ended up being punished with no break time the entire semester by the new teacher at school. I only found out the teacher did this to him at the end of the semester. So please keep communicating guys! [received 3 Likes] (**Comment 3** shared in **Lovely Dove** Group 3, 15 March 2015)

A father reminded other parental users that they also needed to be careful when communicating with the teacher. He suggested that the parents take care to develop a positive relationship with the relevant teachers.

When we discuss our children's situations or issues in learning with the teachers and fight for ['Zhēngqǔ' (爭取), which also means negotiating] better resources and teaching, we need to be really careful with what we say. Because we need to build a steady relationship with the teachers. If your relationship with the teacher is bad, it is not good for your kids. [received 4 Likes] (**Comment 4** shared in **Lovely Dove** Group 3, 15 March 2015)

These comments indicate that virtual communities allowed parents to share important tactics in communicating with school teachers. These comments also point out potential issues of trust and poor communication between teachers and parents in Taiwan. Most of the suggestions were trying to persuade parents not to confront teachers, to try their best to communicate with instructors, and to trust teachers. When examining the data, these 'difficulties in communication' appeared to be one of the common themes in all three cases when parents discussed and shared their experiences of interacting with teachers.

A post by Shin from Little Star reminded parents that if they cannot trust teachers, they should not volunteer in schools. Shin wrote:

Teaching is the profession of the teachers, please respect them. They are the ones who are responsible for teaching. [...] if you can't let go of your child, don't volunteer to help the teacher. [received 219 Likes] (**Post** shared in **Little Star**, 9 January 2015)

In Taiwan, parents are allowed to help in the local primary school during the early morning hours from 8am to 9am. Most of the time, parents volunteer to tell stories to the class or to help students with their school work individually during the morning hour. During this period, the classroom teacher can prepare for the day's lesson. Thus, Shin was suggesting that parents who might 'interfere' with the teacher's lesson after the first hour should not volunteer at school. Shin mentioned that many teachers have told parents to talk to her before contacting them. Those teachers hoped that Shin could communicate with the parents for them so that they could easily cooperate with the parents. Since Shin was an experienced mother who had significant influence on

the parents in Little Star, the teachers considered her as someone highly capable of persuading parents. Shin said:

So, when I gave speeches in different schools, I met a lot of teachers. These teachers then told the parents to meet me and talk to me. Because I understand these parents and they could cry on my shoulder...I understand them, because I am a mother. (Interview with **Shin**, administrator of **Little Star**)

Jade and Dee also mentioned similar experiences of a teacher initiating contact with them and asking them to help other parents to more effectively communicate or participate in school activities. Dee explained:

The teachers, especially those who are good at their teaching, really like me. Because I always help them by chatting with the parents of their students [through virtual communities]. After the chat, these parents will be more likely to listen to these teachers. (Interview with **Dee**, mother and member of **Lovely Dove**)

It is possible that parents who are not only respected in the virtual space, but also in the face-to-face environment, such as Shin, are more likely to be given Face by the professionals. With Face, these parents then helped the professionals to communicate with the other parents. However, it was also interesting to see that Dee was judging the teaching by suggesting that only good teachers, who work hard at their jobs and help their students, would like her to help them. She also indirectly suggested that not all teachers would take the initiative to cooperate with parents. It also demonstrates how some parents with longer experience had become the gatekeepers that gave suggestions on the behaviour of the professionals. These 'gatekeepers' also decide which professionals they give Face to in their virtual communities. This behaviour again suggests that some parents were more powerful than other parents in the virtual communities and that these parents held more authority to make decisions in their communities.

#### **8.1.4 Advocacy: raising the awareness of the issue of bullying in school**

Sharing problems and struggles about their children's school life, such as bullying, to raise awareness through the social network sites is also an important way these

parents advocate for their children's needs, as mentioned in Chapter 5. However interestingly, I identified that the parents tended to share more positive aspects related to their children's school lives in all three virtual communities. When a negative experience was shared, the member who had posted it was often ignored by the majority of the other virtual community members. A typical example from Group 2 of *Lovely Dove* highlights this reaction on the part of the parents in the virtual communities. In Group 2, a mother shared a comment about her son being bullied in school and her hope that other parents could help her protest against the school to bring attention to the issue of school bullying. She wrote:

The greatest fear of my life happened today! Pang [the mother's son] was bullied in school today. When he got home, I saw bruises everywhere, on his face and both hands. When I bathed him today, I discovered, even more bruises under his trousers. If you were facing a similar situation to this one, what would you [members of Group 2] do? (**Post** shared in **Lovely Dove** Group 2, 24 November 2014) ·

After she posted this information, however, she received no responses from the other parents. The administrator Tung then replied to her:

Hi, if possible, please can you send us a private message so we can contact you privately and discuss this situation? (**Comment** 1 shared in **Lovely Dove** Group 2, 25 November 2014) ·

Tung explained that the reason she hoped to directly contact the mother was that complex issues, such as bullying, were better managed privately, instead of through comments. She said:

And if you only use these simple comments to describe these complicated things, it is really hard to say it completely and correctly. Issues like this are better communicated through the phone. (Interview with **Tung**, administrator of **Lovely Dove** Group 2)

However, ignoring the comment posted by Tung, the mother shared another post:

Hi, I am Pang's mother. You [members of Group 2] met me last time when you all came to the advocacy event held at my son's school. By the way, I just want to let you all know that I went to the police today and reported this incident. And I might sue the boy who harmed my son. We took pictures of the bruises in the police station

today just to keep the evidence as well. \*\*Please can you tell me if I need to get the injury diagnosis certificate for my son? \*\* (**Post** shared in **Lovely Dove** Group 2, 25 November 2014) .

After this post was published, no members of the Group replied to the mother. Later that night she provided an update on how she had resolved the incident.

I got the injury diagnosis certificate from the hospital for my son! And the teacher, the bully and his parents just came and visited us [the mother and her son] to apologise. Because I did not want to make the situation awkward for all of us, I forgave the boy when they visited us. The school also promised that it will make sure Pang is not bullied again in school and will change his seat in the classroom. Thank you [the member] for listening to me! (**Comment** 1 shared in **Lovely Dove** Group 2, 25 November 2014)

The next morning, the mother left a new comment on her post reminding other parents about how to deal with issues such as bullying.

Good morning all! I hope to share this information with you so that if similar things happen to your children you will know how to deal with it. Here's the link: [the link to a website set up by Ministry of Education about reporting school bullying] [received 1 Like] (**Post** shared in **Lovely Dove** Group 2, 26 November 2014)

Finally, one member of the Group Liked her post after it was shared. Tung also replied to the mother thanking her for sharing this information with the public.

Dear mother of Pang: Hi! Thank you for sharing your experience publicly with us. Showing us your emotion and the process through which you solved this incident of bullying. The reason why we [other parents who are members of Lovely Dove] went to your school for the advocacy event was to advocate for a friendlier learning environment for our children in the school. We need to encourage other parents in your school to also advocate for us and also educate others about the different situation of our children. But at the current stage, we really need more people to join us. Let's press on together! [Received 6 Likes] (**Comment** 1 shared in **Lovely Dove** Group 2, 26 November 2014)

However, later the same day, the mother posted another comment to update members about the situation, which had not improved but had taken a turn for the worst for her son.

The school did not take care of this situation seriously today, so I am asking the local education authority to investigate the case now. I

thought it would all go peacefully today. I felt cheated when my son told me that he was bullied again today. (**Comment 2** shared in **Lovely Dove** Group 2, 26 November 2014)

No parents replied to her. Wa, one of the Group administrators of Lovely Dove and also a mother, then stepped in and asked the mother to contact her. Wa wrote:

Please, can we talk through the details on the phone? So we can make sure about how can we help. [received 1 Like] (**Comment 3** shared in **Lovely Dove** Group 2, 27 November 2014).

Wa received a Like from another member of Group 2. The discussion regarding this incident then ended after this comment from Wa. A few days later, the mother shared a post about a promotion at an amusement park. However, no one replied to her or clicked Like. After that post, this mother also published several posts sharing information that was not related to bullying, but she still received little response from the other members of the Group.

Before Tung explained her experience of replying to this mother, there was a long pause. As I wrote in my research diary:

Tung seemed to be hesitating when I asked her about the mother who shared the bullying information in Group 2. Tung sighed, 'This is an issue we were discussing recently as well.' (Research diary, 14 August 2015)

Tung cautiously explained that the mother may have been overreacting and wanting attention from the Group members:

That mother posted a lot of information about her son during that period of time. I guess it is because she was shocked and felt she was the victim when the bullying happened. She hoped to get everyone's attention and to relate to the situation she was facing. But for other parents, it [the bullying of her son] was out of nowhere! They didn't know and understood what had happened. [...] Other parents didn't want to reply or make any comment. (Interview with **Tung**, administrator of **Lovely Dove** Group 2)

Tung also mentioned the behaviour of the majority of the members, noting that they were cautious and hoped to avoid conflicts in the virtual communities.



They were worried that they might comment wrongly and upset this mum again. [...]. The parents in Lovely Dove wanted to make sure that things were okay, so if they could not be sure what had happened, they would not reply. Maybe these parents were just not brave enough to comment on such a thing, they remained silent. (Interview with **Tung**, administrator of **Lovely Dove** Group 2)

Tung also mentioned that she did notice that the mother posted frequently to get attention from other members after this incident happened. However, the mother was still ignored by the other members in the Group. Tung said:

Her [the mother] main goal was to let everyone know about this incident, so even if we had talked to her already through the phone, she still wanted to share it with others. She wanted to let everyone know that bullying is a serious issue. But after a few posts, she told us that she felt that she was given a cold shoulder and that others didn't really care. So, she tried again to post other unrelated information. Even though some parents did reply, she still got ignored most of the time. [...] after a while, she stopped posting on Group 2. (Interview with **Tung**, administrator of **Lovely Dove** Group 2)

This practice of excluding others happened in all three virtual communities. Examples include the father who was ignored by the Little Star members when he shared an opinion about parenting that contradicted what others thought (p. 155). One potential explanation is that each virtual community may have had unspoken rules, preferred types of behaviour or information, and different definitions of Face. In each virtual communities, powerful 'gatekeepers' then decided what information was allowed in the community. When a member did not fit with these shared values or follow the rules, that person may have been ignored, lose Face or even excluded.

## 8.2 Welfare

### 8.2.1 Welfare information

In addition to searching for educational information, parents frequently shared information on the welfare system in the virtual communities with the exception of Little Star. For example, Lovely Dove shared information on how to apply for the Caregiver Allowance for Physical and Mental Disorders. The post offered detailed information on an increase in that stipend and reminded parents to apply for the funding. It wrote:

The ‘Caregiver Allowance for Physical and Mental Disorders in Taichung City’ has recently been amended by the government. The current amount of the allowance is 3,000 NTD per person per month, and the deadline for it is on the 6<sup>th</sup> of March. Remember to apply! [received 34 Likes] (**Post** shared in **Lovely Dove** Group 3, 21 January 2015)

After the information was posted, a father asked a question about whether he qualified for the allowance.

My child, who has the disability card – intellectual impairment, is now in kindergarten, she got education welfare support from the government. My wife needs to take care of him full time, including bringing him to the early treatment sessions during both morning and evening. Could she apply for the allowance from the government? (**Comment** 1 shared in **Lovely Dove** Group 3, 21 January 2015)

The Yeh then quickly answered his question under the comment:

Your wife is eligible only if she also stays at school with your girl as well! [received 1 Like] (**Comment** 2 shared in **Lovely Dove** Group 3, 21 January 2015)

The father then thanked the administrator by clicking Like under the reply.

However, a mother complained that she could not apply for the allowance, since she was not a resident of the county issuing it. She wrote:

There is nothing in Yunlin! We can’t even apply for the education welfare allowance. Because my in-laws are farmers and have farmland over 650 hectares, so the government thinks we are rich. Hahaha! That is not even my land! If we are rich enough, we will move out of here straight away [received 2 Likes] (**Comment** 3 shared in **Lovely Dove** Group 3, 21 January 2015)

As explained in the context chapter, parents struggle to find sufficient support due to a lack of resources within their local government. Certain cities and counties, however, may have more resources than others. Therefore, parents who live in these locations may receive better support from the government. Zen explained his struggles by sharing about the education allowance that his daughter received with parental members of Speak Out from other cities.

Actually, there are things I cannot share, such as the welfare system here in Taipei. Taipei is the capital, and it has the best resources for people with disabilities, and the educational allowance for a person with disabilities is also the highest among all counties. My daughter gets 5,000 NTD each month here in Taipei. But if we moved out of Taipei, we get nothing. [...] So how could I share this with other parents who are not in Taipei? They will probably get really angry about me. (Interview with **Zen**, father and member of **Speak Out**)

These differences in access to resources caused by physical location and dissimilar policies can be a potential issue for parents searching for resources through virtual communities. That is, in some situations, the online support service is still limited by the physical location of the parents. To deal with this issue, parents formed smaller Groups focused on sharing local information and resources. For example, Min mentioned that her private Speak Out Groups were organised according to the different locations of the parents to give them access to local information. Furthermore, Little Star and Lovely Dove also organised their public and private Groups according to location, with North Taiwan, South Taiwan, and Central Taiwan the primary regions. Thus, the parents could decide which Group to join when becoming members of a virtual community. This online support system provided useful platforms for parents to discuss and receive direct support and necessary information.

In addition to sharing welfare information, parents also gave ideas on how they could advocate for a better welfare system for themselves and their children. A post in Speak Out stated:

Housing prices have been higher and higher these days. And these increasing housing prices have been influencing our children's future. We have raised our children to have an independent life. And

when we think we can finally be confident that they will have a good future, the government ignores the increasing high price of housing. We need a better plan for policy and also a welfare system to support our children in order to solve these issues. [...]

So, join us! Speak Out is holding a press conference on the 2<sup>nd</sup> of October. And after that on the 4<sup>th</sup> of October, let's go in the street and protest for our rights! We will be gathering at ChungChi Road. See you there! [received 20 Likes] (**Post** shared in **Speak Out**, 1 October 2014)

This example highlights another common way that the virtual communities allowed parents to network and take action in advocating for their rights. Parents used their connections on Facebook to spread information and raise awareness about their needs among other users on the site. However, of the three virtual communities, Little Star was less likely to share such information. Little Star also did not share any information about the welfare system on its Page.

As has been mentioned in Chapter 5 (p.137), Shin, the administrator of Little Star, believed that welfare support is useless for children with autism. She suggested that the main purpose of Little Star is to help parents and others to develop skills to support children with autism through social interactions. Therefore, Shin did not share posts about welfare information on the Little Star Page. I also did not identify members of that community sharing this type of information in its Page. However, Jade, a member of Little Star, noted that she contacted parents who lived in the same county as her through Facebook. She shared different types of information with them, including information about the welfare provisions of their local government. She said:

If the person lives in the same county as me, I might share more information, such as what school, what resource of our local government, with him through a private message. Because I know I could help him more. I could even meet up with him if he needs help. (Interview with **Jade**, mother and member of **Little Star**)

This demonstrates that even though Jade was a member of Little Star, she was not limited to that community in her ability to access or provide information. Most of the parents also shared similar experiences and mentioned that they had joined multiple Groups and communities on Facebook to build their network and search for needed

resources and support. Some even created a personal Page to advocate for their children and themselves, and examples include Zen and Quini (p. 165).

### 8.3 Leisure

It is important to note that in this section, it is hard to clearly classify the three categories of support since they are closely connected with each other. Information about family vacations, enjoyable activities, entertainment, and leisure was identified as shared by parents and administrators in these virtual communities.

These posts related to leisure were identified and categorised into two main classes: firstly, those related to parents' social gatherings and vacations, and secondly, entertaining information not related to parenting or special needs, such as videos and pictures. In the following sections, I introduce both types information.

Parents were also suggested to be emotional supported when sharing these information about leisure. For example, they build relationship and confidence for their family by reading how other parents are able to

#### 8.3.1 Social gathering Parent's social gatherings and events

Social gatherings, such as parents' dinners and parties, seemed to be important for the parents to build connections with each other and nurture solidarity. Virtual platforms on Facebook were used as a tool to organise these events and were generally parents' first choice for distributing invitations. In most instances, the time, location, and other event details were shared in the Group. Ming mentioned:

When I held some events for parents, like going out for dinner or small gatherings, I would put it [the information about the event] in the Group. So, these parents can come out and chat. Through these events, it is easier for us [members of Speak Out] to know if all of us are doing well. [...] and for those who just joined the Group, it is a chance, a chance for them to reach out to us. Because we cannot know who they actually are behind the screens through the internet. (Interview with **Ming**, mother and member of **Speak Out**)

After events, photographs and stories were shared in the virtual communities. For example, Shin held a social event for mothers in Little Star. After the occasion, she shared photographs and highlights with other members of Little Star. She wrote:

What a fun and joyful event! In the Heart-to-Heart Cook Off event today, we got the best chefs in the entire universe to cook for us. When they cooked, all of us were stunned. It was the best dinner ever! [...] (**Post** shared in **Little Star**, 19 May 2015)

Under the post, the members of Little Heart bantered with each other. A mother teased Shin for forgetting to upload the photograph of the food they had eaten during the event. She wrote:

[...] Hahaha, apparently the food was too good so we didn't even have time to take pictures before it was eaten. (**Comment** 2 shared in **Little Star**, 19 May 2015)

Even though Jade and Cheng did not attend this event, they clicked Like on this post. Cheng explained:

I am quite shy, so I will not go to most of the events [Little Star holds]. But I like to read about these events on Facebook. I feel like I am part of them when they share their photos and the details of the event with me. (Interview with **Cheng**, mother and member of **Little Star**)

A-lin also described a similar experience in which she shared information and photographs of past events so that members who could not attend could still be engaged with the community and build connections with other members. She said:

I am the main host of a lot of events in Taoyuan, so when there is an event coming up, I will post it in the Group [private Group of Speak out] so they [members] could join. [...] And when other parents who can't come see the post, they will at least know how everyone is doing, and how our kids are doing. (Interview with **A-Lin**, mother and member of **Speak Out**)

Some parents also shared information and photographs of them attending other social events or vacations in the Group or on their Profile with other parents. For example, Fu mentioned that he shared about camping with his family and other friends to

demonstrate to other parents and general users that families like his could also enjoy themselves. Fu said:

The main reason I use Facebook is that of our family travel sometimes, we run marathons together, and we camp, too. So, I wanted to promote camping and marathons. I want other families that are also interested in camping or marathons to see that families like us [families of children with special needs] can also do such things. And to be honest, camping is really good for your family if you have a child like this [special needs]. It is a way your kids relax, and it is also a way we [parents] change our mood. (Interview with **Fu**, father and member of **Lovely Dove**)

In Lovely Dove, parents even suggested that if they could travel together, they would potentially face less discrimination than if they travelled alone. Yeh wrote:

[...] We will participate in these activities [outings] as a group, so there is no need to worry. Many parents are reluctant to step out of their house in that they feel insecure, and wonder what others may think of them. So when we step out together, we feel more secure. So we are more willing to bring our children out. (**Post** shared in **Lovely Dove**, 16 April 2015)

These findings suggest that sharing information about social events and trips not only helped the parents to build connections with each other but also provided them with a way to encourage each other through sharing the same identity and also gain Face when facing discrimination in society.

However, Zen mentioned an unexpected negative experience related to sharing information about his vacation with his daughter. He said:

When I posted that photo about how I and my daughter had a great vacation on my Profile, I received loads of messages asking me how I remodelled the wheelchair for my daughter. Some of them asked me where to buy this wheelchair. I don't understand. Why wouldn't they just ask about our vacation? [...] they focused only on the assistive devices my daughter uses. (Interview with **Zen**, father and member of **Speak Out**)

The parents who read his post were more interested in the wheelchair than in his vacation. It is possible that information shared in such virtual communities may be interpreted in vastly different ways by users, including in manners not intended by the

person who shared it. Such information may be misused or misunderstood by other users. Moreover, due to the anonymity of the virtual environment, the poster might not be able to identify others who use or misunderstand the content. In other words, parents may have less control over how their information is used once it has been shared. This may be one of potential limitation of sharing information through virtual communities.

### 8.3.2 Entertaining information not related to parenting or special needs

In addition to sharing about social events and travelling experience, some parents also offered information that was not linked to parenting or their children with special needs. For example, during Christmas season, a parent in Group 1 posted information about how to make Santa Claus origami, a type of paper decoration that is popular in Taiwan. He posted a picture and wrote:

It is almost Christmas! Let me teach you how to make a Santa Claus origami! Isn't it cute? You can also do it with your kids! (**Post** shared in **Lovely Dove** Group 1, 21 December 2014)

After the father posted the origami instructions in Group 1, 34 parents clicked Like, and 1 parent shared the information to her Profile. Similar posts were identified in all three virtual communities, and most of them received a high number of Likes from parents. The majority of the parents also suggested that information that is entertaining and heart-warming but not related to parenting was also important for them to rest and relax. Cheng explained that reading amusing content helped her to relax and unwind from the stress of being a parent. She said:

Yes! Because when I watch cat videos or pictures of cats on Facebook, I felt so relaxed! Those are my favourite, so I will share them with other parents. They would even post their own cat photos as well! I think it is like a buffer for our mood as stressful parents. (Interview with **Cheng**, mother and member of **Little Star**)

Therefore, it is possible to suggest that even though sharing such information may seem irrelevant to parenting, in reality, doing so is beneficial and meaningful for parents. As can be seen, this shared information without a link to parenting and



children served as an important buffer for the stress the users faced in their daily lives as parents.

## 8.4 Summary

In summary, Section 8.1 of this chapter suggest through the virtual space, parents were given increased access to experience-based information about school choice and cooperation with teachers at their children's school. These sections have also highlighted that some parents also raise sensitive and personal issues, such as seeking support when their children are being bullied at school. However, not all parents received support from other members of the communities. Some parents were ignored by the other users when they asked for suggestions and support. Sensitive issues were also avoided in the public space of the communities but were more likely to be dealt with in private spaces or via private one-to-one messages. These findings suggest that there are certain patterns of interaction and specific types of information shared in virtual communities that were not accepted by the members. One example is the fact that the members of Lovely Dove's Group 3 avoided interacting with the mother who shared about bullying. Parents who mention or advocate for these needs to seek support from these virtual communities may experience difficulties in those spaces.

The administrators who were also parents, and parents who have longer parenting experience had more control over what types of information and support were appropriate in the virtual communities than other members. For example, Shin held the majority of the power regarding what was suitable to be shared in Little Star. In most situations, the members of the communities followed these administrators' lead.

Parents also shared their experience with cooperating with teachers, although their stories were mainly negative. In addition, they also gave advice to other parents on how they could avoid these challenges in cooperating with teachers. The parents used the Group function of the social network site to help involve teachers in the educational process of their children. They utilised Groups as a tool to enable their child's current and former teachers to interact. That strategy helped them to provide higher-quality education for their student at the current level. Some parents, such as Shin, Dee, and Jade, shared their experience of helping professionals to build better

relationships with other parents at the same school through virtual communities. These examples also illustrate the importance of having the identity of a parent when supporting other parents or giving them suggestions. However, issues could potentially arise if these parents who have the power to represent teachers seek to take too much control of other parents' interactions with those instructors. Even though there may be potential issues, these findings still suggest that the social network site was used as an important tool and platform for parents and teachers to communicate and cooperate.

Sections 8.3 and 8.4 of this chapter explored how information about the welfare system and leisure was accessed by parents in the virtual communities. This chapter has demonstrated that the parents joined local virtual communities in search of information about the welfare system, since policies differ from city to city in Taiwan. It has underscored how some information shared in the virtual setting—which itself is not limited by location—can still be restricted by physical location due to parents' actual needs. Even though such information may entail restrictions, the parents still found searching for welfare information through virtual communities to be an efficient strategy.

Information related to leisure was identified as one of the most commonly shared types of information in the three virtual communities. A wide variety of kinds of information was identified, from interesting stories to travelling information to photographs of social events held among the parents. Information about leisure also provided emotional support for these parents, as it built connections among members and helped the parents to relax.

## Chapter 9: Discussion

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In the previous chapters, I presented the findings of the study. These findings explored parents' experiences of interacting for support in virtual communities. In this chapter, I discuss how this study answered my research questions:

- How do virtual communities provide support for parents of children with special needs in Taiwan?
- What motivates Taiwanese parents of children with special needs to search for support through virtual communities?
- How does support provided through virtual communities impact the relationship between Taiwanese parents of children with special needs and professionals?

I also discuss the influence of the Taiwanese culture of Face and the marketisation of support services, as reflected in the context chapter. This chapter also explores how these findings reflect on, contrast with, and contribute to the literature on online support for parents.

In **Section 9.1**, answering my first research question, I discuss how parents received information and emotional support and also advocated in virtual communities. This section illustrates how the Taiwanese experience reflects that of the West, the setting in which most current research has taken place.

In **Section 9.2**, answering my second research question, I outline how the parents intended to redefine their Face, which is accepted by Taiwanese society, through joining virtual communities. In the second part of this section, I discuss different motivations for the actions of seeking and sharing formal and informal knowledge.

In **Section 9.3**, answering my third research question, I address the influence of virtual communities on the parent-professional relationship. Since the virtual communities provided more opportunities for parents to gain control of knowledge and to maintain Face, they likewise gave those users the chance to gain control over

their relationships with professionals. I explain how the parents used such relationships as a resource to negotiate for more support. The section further describes why these shifting power relations are important for parents not only in Taiwan but also around the world.

## **9.1 How do virtual communities provide support for parents of children with special needs in Taiwan?**

In this section, I discuss how support is provided in the virtual communities and potential challenges associated with offering support in that manner. This section is organised according to the three main concepts of support: information, emotional support, and advocacy.

However, it is important to note that several issues related to how parents seek support and interact for support were closely linked to the second research question, which examined parents' motivations for performing such actions. Therefore, **Section 9.1** and **Section 9.2** are closely connected.

### **9.1.1 Information**

By reading posts, commenting, and sharing posts, parents efficiently disseminate and collect information in virtual communities. Some parents joined particular Groups, such as Groups formed by other parents in their local communities, to receive specific information relevant to their needs, such as information about the local welfare system or the education system for their children. This echoes the majority of the literature, including Madge and O'Connor (2006) and Duquette et al. (2012), which has found that parents with similar needs or experiences are more likely to gather in virtual communities to efficiently search for information together. This action of jointly searching for information as a group through virtual communities, rather than on an individual basis, is important, as this approach not only efficiently provides knowledge for parents but also empowers those individuals to be more confident regarding their identity (Doty & Dworkin, 2014; Ammari & Schonenebeck, 2015).

The parents also suggested that accessing information through virtual communities is beneficial and helps in their journey of taking care of their children. This easily accessible information in virtual communities was also revealed to boost parents' confidence in their parenting role. For example, parents were found to help each other to 'come out' (p.161) from their struggles and low self-esteem not only through offering each other mutual emotional support but also by providing each other with their parenting experience and other useful information. This beneficial experience was similar to those that have been reported in the literature on face-to-face support groups for parents (Kerr & McIntosh: 2000; Samadi, McConkey, & Bunting, 2014; Wolfendale, 1992). As Wolfendale (1992) has argued, the formation of parent support groups offers parents the opportunity to share important information, such as their experiences with advocating, with each other and to be empowered by it. The difference, however, is that virtual communities provide more accessible information, have a convenient functionality in that they are not limited by time and location, and offer virtual settings that provide anonymity for individual users. These characteristics of the provision of support in virtual communities enable a much wider constituency of parents to participate, such as parents in rural areas in inconvenient locations (Plantin & Daneback, 2009) and suicidal parents who find it hard to articulate their challenges and needs in face-to-face settings.

However, I argue that this searching for, and sharing of, information is not completely straightforward and that parents' experiences might not always be positive. Due to parents' different intentions, some types of information, such as formal medical information, are more likely to be shared in private spaces within a virtual community, while other kinds, such as information on informal parenting experiences, may be more likely to be shared through the public platform of the community. Since these behavioural differences regarding the sharing of information are more related to my second research question, this issue is discussed in Section 9.2.2 (p.233).

### **9.1.2 Emotional support**

Most of the parents received emotional support through encouraging comments, constructive suggestions, and demonstrations of solidarity in their virtual communities. Parents not only used text-based comments or conversations to encourage each other,

but also engaged in virtual interactions—Likes—to express encouragement and support. For example, when parents posted about a negative experience or shared negative thoughts, in most situations, other parents not only left comments with words of reassurance, such as ‘You are doing amazing’ or ‘let’s press on together!’, but also clicked Like on the person who shared the negative thoughts or demonstrated the need for encouragement.

Similar to Brandes and Levin’s (2014) research on teenage girls’ online behaviour, this study found that clicking Like signified approval and such action was strongly attached to the users’ emotions. This study has also come to the same conclusion as Brandes and Levin (2014) and Blease (2015) that emotional support and interactions based on simply clicking Like may be dangerous. In particular, parental users may be overly attached to their desire to be Liked. In this study, some parents were found to rely on the number of Like as an indicator of the importance of issues and relationships. Some parents were also excluded—or, as I argue, othered—by members of the community who refused to give them any Likes. (Parents’ motivations for excluding certain members are discussed in Section 9.2.) By ‘othering’, I use the definition of Okolie (2003):

Social identities are relational; groups typically define themselves in relation to others. This is because identity has little meaning without the ‘other’. So, by defining itself, a group defines others. Identity is rarely claimed or assigned for its own sake. These definitions of self and others have purposes and consequences. They are tied to rewards and punishment, which may be material or symbolic. There is usually an expectation of gain or loss as a consequence of identity claims. (Okolie, 2003, p.2)

Thus, it is possible to suggest that even though providing emotional support through a virtual community may be a rapid process, as such interactions are not limited by the need for physical actions and contact, a hazard may potentially exist if parental users are overly attached to this form of emotional support.

### **9.1.3 Advocacy**

Similar to previous studies on advocating using the internet, such as Mitra (2005), this analysis has suggested that the parents used the public platforms of the virtual

communities to express their thoughts and needs to other general users and decision-makers. They not only posted their stories, opinions, and comments about the government, their needs, and the welfare system on the public platform of the virtual communities, but also engaged in discussions with other parents and users. Certain parents even argued with administrator about their opinions and suggestions. Similar to Duquette et al. (2012), this study has found that for most parents, the public platform of the virtual community gave them an opportunity to communicate with professionals, express their needs, and have their voices be heard.

In addition to stating their needs, some of the parents also shared their daily lives with other users who were not parents through their personal platforms, such as Profiles in the virtual communities. These parents even documented their children's growth in detail using the diary function of Facebook. They did so to illustrate to other general users that they children were as 'normal' (p.163) as other children. I argue that their motivation in sharing their personal lives with other users had to do with not only advocating for their children, but also demonstrating that they were also parents who needed respect, care, and support from others in society. In other words, they were parents who had Face in society (see p.164). I argue that this motivation is important, as it helps parents to both accept their identity and redefine themselves in relation to society's accepted image of Taiwanese parents. Thus, in the following section discussing my second research question, I give more details on how their search for Face prompted the parents to join virtual communities.

## **9.2. What motivates Taiwanese parents of children with special needs to search for support through virtual communities?**

There are two main parts of this section. In the first sub-section, I argue that the virtual community has become an important platform for Taiwanese parents of children with special needs to gain Face in the community. I discuss how the parents participated in virtual communities to connect with other parents, build their social networks, and redefine the meaning of Face. I then argue how different networks and parent Groups may have their own definitions of Face, rules, and values. Finally, I indicate that this process of networking and gaining Face is empowering for parents,

even if in some situations, a parent may experience different levels of ‘othering’, the inclusion and exclusion of other users.

In the second part of this section, I also point out the difference between accessing formal and informal knowledge. Similar to previous findings in the literature, this study found that formal knowledge, such as published medical information, was less preferred by parents in the public space, and informal knowledge, such as experience-based knowledge, was more likely to be shared and favoured. However, unlike the previous literature, I argue that this preference is related to the function of the information and that different types of information are shared in distinct ways in virtual communities.

### **9.2.1 Finding Face: Public self-image and identity**

#### *The social stigma of the person with special needs*

Losing Face is one of the main struggles for Taiwanese parents in raising children with special needs and in accepting their identity as parents, as suggested by previous studies and the findings of this inquiry (Chang & McConkey, 2008; Chang, 2009; Lee, Long, & Boore, 2009; McConkey et al., 2008). Face is integral to the daily life of Taiwanese people and is taken seriously in Taiwanese society (Hwang, 2012), as introduced in Chapter 2 (p.26). It is a complex concept involving a person’s public self-image and identity as approved and recognised by society or the community on the basis of that individual’s behaviour and achievements. If a person has abilities or a moral character that is valued by society, he or she is considered to have Face in Taiwanese culture. A person with Face is respected by others and is also influential in his or her community. However, if a person does not have these abilities or character traits, he or she loses Face and is despised or ignored by others in society (Hwang, 2012). Moreover, due to the complex Confucian perspective of the ‘self’, a person’s life is considered an extension of the life of his or her parents. Thus, Face represents not only the identity of the person but also the entire family (Hwang, 2012). Therefore, all family members, including children, are responsible for gaining and maintaining Face for the family and for ensuring that it is not lost.



Taiwanese parents of children with special needs experience high stress and anxiety, as they must fight against or seek to avoid the judgement and stigma of losing Face when raising those children (Chang, 2009; Chen, 2001; Gau et al., 2012; Hsu et al., 2017). For example, parents of Lovely Dove (see p.202) did not complain directly to the teachers in school about their children's education, but instead turned to the parents' virtual community. The overwhelming stress, fear, and frustration caused by not being able to maintain Face for the family, such as by raising a healthy son and sustaining a happy family, among Taiwanese parents of children with special needs was also clearly demonstrated by the father who became so frustrated that he killed his son mentioned in Chapter 5. The example of the critical incident (see p.132) also demonstrated Taiwanese society's bias against these parents. News stories referred to them as 'pitiful' and 'losing Face', and all of the news corporations focused on blaming the father and the son when reporting on the incident. As Chang and McConkey (2008) have suggested, children with special needs and their parents are often seen by Taiwanese society as individuals who lack valuable abilities or character traits. The findings of this research have also illustrated that some parents would rather avoid going out in public to search for help due to the judgement and bias that they receive from Taiwanese society (see p.29).

Similar to the concept of losing Face, Shakespeare (1998) has argued in his study on disability rights in relation to parents' choices before and after prenatal testing that various societal systems, such as those related to medicine, government, and politics, are biased and do not incorporate the voices of persons with special needs. This lack of awareness of the rights of persons with special needs leads to a dilemma. The culture pressures parents to forego prenatal testing and/or to continue a pregnancy when the child will have special needs, and parents are 'consequently more likely to be blamed for their situation' (Shakespeare, 1998, p.676).

This stigma that Shakespeare (1998) describes has also been echoed by several studies from around the world, such as those on parents in the global South, including in countries such as India and South Africa (Wickenden & Elphickp, 2016). In her reflection on her journey of becoming a disability advocate, Tataryn (2014) even shared a similar story of a Canadian father killing his daughter with cerebral palsy in

the late 1990s. Tataryn (2014) stated that even in the Western context (as she was sharing the incident in Ghana), persons with special needs may still face extreme situations of pressure, as societal stigma remains as a tremendous challenge. In many situations, persons with special needs and their parents are seen as the ‘victim’, the ‘impaired’, and the ‘minority’ around the globe.

However, countering the negative societal image, in this study, these parents were identified as rejecting that stigma and regaining Face in virtual communities. These parents became more confident in voicing their thoughts and advocating for their rights through social network sites. For example, in all three virtual communities, parents argued that the media should not blame the parents but should review and examine the fact that the existing support services and welfare system were not sufficient or of help for those parents. They condemned the government for not giving adequate support to the family and argued that the public should not look down on other families in similar situations (see p.140; p.141). In other words, even though the mass media suggested the father and son in the news were the main cause of the tragedy, most parental users refuted the idea of being seen as ‘unfortunate’ by the media. These parents strongly argued that they had the very same right to live and enjoy a ‘normal’ life in society with their children (see p.163). Furthermore, most of the parental participants suggested that they would take the initiative to advocate for their families and to seek support through their virtual communities.

These parents’ responses offer a very different image of parent identity from the picture painted by Taiwanese society of them as powerless and lacking Face. Instead, they held an identity that was powerful and confident. This finding echoes Ammari and Schonenebeck’s (2015) research on American parents searching for empowerment through Facebook. In that analysis, the parents become more confident in negotiating their rights and in presenting themselves to society. It is possible that such gains in parental confidence from joining virtual communities, even within a society biased against them, are important for parents in similar situations around the world.

### *Finding Face through joining virtual communities*

In this study, the phrase ‘We [parents] understand’ was frequently used by the parental users to suggest that they, as parents of children with special needs, could comprehend other parents’ parenting situations or struggles. It is possible that these parental users hoped to reassure other parents that the virtual communities would provide them with Face and that they would not encounter discrimination. A possible explanation for the parents’ act of claiming that their identities were similar is that they wanted to assure other users that they would find a sense of familiarity, belonging, and solidarity in these Groups. Familiarity, belonging, and solidarity are essential for parents in coping with pressure and challenges related to taking care of their children (McConkey, 2016; Todd, 2003). This solidarity refers to a full understanding and a non-judgemental connection based on the shared experience of dealing with the same issue between the provider and the recipient of support (Todd, 2003). It provides a sense of security for parents to express their emotions and share their problems with other members of the Group.

McCabe (2008) researched a parent-to-parent support group of Chinese parents of children with autism and found that parents felt ‘more equal and less discriminatory than was experienced from others in the society’ when they were with other parents (2008:303). This sense of security is similar to the feeling that Chang (2009) mentioned as the new sense of self found by Taiwanese parents of children with special needs when they participate in local face-to-face support groups or join organisations formed by others with similar identities. Chang (2009) suggests that this new sense of self left these parents ‘empowered’ and able to ‘confront social stigma and refuse to be limited by it [the social stigma].’ (Chang, 2009, p.46). This sense of security is also similar to the solidarity that McConkey (2016) has suggested can remedy these parents’ sense of loneliness. That study found that meeting parents who had been through similar experiences was beneficial.

According to the findings, the parents were solidly connected through various actions of reinforcement of relationship and emotion, such as Liking each other’s posts to demonstrate support, sharing sorrow via stories, and providing encouragement through comments in the virtual communities. That is, the virtual communities may

have possibly provided the parents with opportunities to seek a community in which they could safely share their emotions and regain their self-confidence, even within a society with negative cultural attitudes toward people with special needs. It is essential for such virtual communities to be formed by members sharing the same identity and parenting experiences as their users. These communities provide parents with emotional support and give them a sense of solidarity, which then results in them regaining Face or self-esteem in the offline world.

Moreover, I also identified that the parents had been redefining their identities in relation to the social understanding of Face to be included in society. For example, in Taiwanese society, having the ability to raise children into independent adults is seen as a normal parenting goal (Hwang, 2012). Achieving this goal is seen as fundamental for gaining Face for the family (Hwang, 2012). In all three cases, I identified several situations in which members of the virtual communities celebrated and honoured parents when they achieved this objective of raising their children into adults who could live an independent life (see p.159). This accomplishment in raising children was somehow celebrated in an exaggerated manner. It is possible that these parents were making claims to show general Facebook users that they also had the ability to fulfil the parental identity defined by the dominant social understanding of having Face.

This claiming of Face has also been seen in face-to-face parent support groups in Taiwan (Wang, 2008; Chang, 2009). As Wang (2008) has suggested, parents of children with special needs receive more affirmation, recognition, and praise related to their parenting skills and their children's behaviour from other parents or professionals in a parent support group than in traditional society. Chang (2009) noted that through these Taiwanese parents' actions of affirmation and recognition, they are able to advocate for their rights and stand together against discrimination in society. Therefore, similar to a face-to-face support group, the virtual communities gave the parents an opportunity to redefine themselves through receiving affirmation, recognition, and respect from other members. Through this reclaiming of Face, they advocated for their rights together as a community, as seen in the example of the critical event.

However, several situations of parental users losing Face, such as parents being ignored, isolated, or even excluded, were identified within the support communities. For example, a mother who shared several posts about her son being bullied at school was neglected by other parental users in a Lovely Dove Group. Feeling the frustration, the mother eventually left the Group (see p.207). The Group administrator explained that the reason that no one replied or Liked her post was that the majority of the parents in that community did not want to have conflicting information or discussions, such as the conversation on the topic of bullying. That is, even though evidence suggests that parents are more likely to be given Face in virtual communities due to their shared identity with other members, there may still be situations where parents lose Face or are even excluded by others.

### *The fragmented Face*

Even though all three virtual parent support communities in this study had similar goals in supporting parents of children with special needs, each Group had a different focus on how a parental identity develops and which abilities are relatively more valuable. For example, in response to the critical incident, Speak Out focused on urging the government to change and stated the importance of parents' need to raise awareness about their rights among the people around them. In contrast, Little Star stated that changing government policy was impossible and that parents should focus on supporting their children in pursuing a lifelong career to have independent lives in the future. This study has pointed out the importance of parents joining the 'right' community, meaning one that would support them, rather than 'other' them.

As Okolie (2003) states, when a group of people 'define themselves in relation to others' (2003:2) the process of othering starts. Within this, the identity of the 'Self' is closely connected to the 'rewards and punishments' (Okolie, 2003:2) of gaining or losing an identity claim, which in this study is the Face which is given to the parents by the virtual community. In this study, parents identified themselves as 'we the parents' (p.140) suggesting the first layer of Self, is the identity of parents of children with special needs. As Holliday (2010) suggests, these parents were accepting and strengthening the self-identity which is different from all others in the society. This constructed image of 'parents of children with special needs' helped parents to show

solidarity and give Face to each other. However, when this constructed image of Self was challenged by different innate values, practices or culture among the members, the image of Self as parents of children with special needs reconstructed into more precise image of identity, such as ‘we the parents of children with autism’(p.137) and ‘we the parents who are positive’(p.153).

Since a shared value among members is essential for a community to develop and enhances the internal cohesion among members (Okolie, 2003), othering is practised to maintain this precise shared value and Face. As Holliday (2010) suggests, the action of othering includes the ‘construction of moral reasons to attack, colonize or help’ (2010, p.72) other people who do not support or agree with the ‘deficient values, arte-facts and behaviours’ (2010, p.73) of the group. This action of othering in the virtual community can take the form of giving no response to specific members to exclude them from a virtual community. For example, as mentioned previously, the mother who shared information about bullying in Group 2 of Lovely Dove was ignored and excluded by the Group for sharing content that contradicted the Group’s implicit value system. The mother did not receive any Likes or responses to her posts and comments.

As Chapter 3 explained (p.62), clicking Like can demonstrate an emotional connection with the receiver (Blease, 2015). The parental users suggested that they felt supported and accepted by the community when they received Likes from other members. On the contrary, if a parental user received few or no Likes from other members, he or she. For example, as mentioned in the previous paragraph, the mother in Lovely Dove who was given no Like in most of her posts in her virtual community. She felt being isolated in the virtual community and felt frustrated when facing the issue of her son being bullied in school alone. (see p.207). Moreover, since the Facebook system automatically adds up the number of Likes each user receives, permitting all other users to see that sum, it is possible that the members were aware who was being excluded from their community. That is, it is highly possible that this action of othering was intentional.

Taiwanese culture claims to pursue harmony and to value avoiding conflict with others within the community (Chang & McConkey, 2008; Yu & Wen, 2003), and

those norms may also influence the action of othering within virtual communities. Under this cultural influence, most people are likely to remain silent and allow othering to happen in the community without interfering, since they do not want to find themselves in trouble. This is especially true when the othering is done by members who are powerful within the virtual community. Therefore, most of the time, when arguments and exclusion happened in the virtual communities, their members remained silent. For example, the father who Shin ignored in Little Star received similar treatment from the other members of that community (see p.155). This situation then allowed those powerful parents to exert even more control regarding including or excluding other parents who were less powerful and vocal within the communities. It also strengthened the structure of the hierarchy in the community and resulted in existing power dynamics being maintained.

This mechanism of othering is also used by individuals to keep their own Face in the community. This study found that the parents tended to believe that posts with higher numbers of Likes implied that the information contained therein was more important. Moreover, the parents who received more Likes in the community were also considered by the members to be more influential in that group. They became the 'gatekeepers' who filtered information and gave suggestions to other parents in the community. Some powerful parents even set out rules for members to follow. For example, A-lin, a member of Speak Out, was one of the gatekeepers due to her rich parenting experience. She indirectly created a culture which encouraged members to share positive information and parenting experiences by excluding parents who repeatedly shared negative emotions and experiences from the private Group (see p.153). This action of othering helped the parents with Face to remain in power in the community.

However, this study also pointed out that parents with power in their community may not have the same authority and influence in other communities that do not recognise them. Shin offered one such example. In Little Star, Shin always received a high number of Likes on her posts and comments. However, when posting in the Lovely Dove Groups, she received few or even zero Likes from the parental users. This may again support the assumption that different virtual communities have their own value systems and that just because one community values a person's abilities and treats

that individual as having Face does not necessarily mean that other communities will judge that person in the same manner.

The discovery of power struggles among the parents within the virtual communities yielded an important insight regarding what parents actually experienced when negotiating for resources and support. It illustrated that besides negotiating with professionals, parents need to compete with other parents and members and to continue maintaining their Face in their communities. This finding is important for the current body of research on both parent support and the internet and parent support in general. That is because most existing studies have focused on the power relations between professionals and parents, with examples including Wickenden and Elphick (2016), and Todd (2003), but have rarely mentioned the power dynamics between parents within a support group or organisation.

As Bennett (2016) has suggested in his research on charitable organisations, even though the members of organisations often share the same goal and passion, innate conflicts and political struggles still happen within such associations. In many situations, these conflicts are difficult to identify on the surface of the organisation, as many such entities primarily project a positive image (Bennett, 2016). This study has pointed out that under the united front of virtual communities being empowering and beneficial for parents, struggles, exclusion, othering, and power competitions were taking place among the parents. It has demonstrated that this negotiation of power among the parents also influenced the process of parent support. For example, parents with power were more likely to access resources and support than parents with less power.

Therefore, it is important to note that not all experiences of seeking support through virtual communities were positive for parents. Instead, parents may experience difficulties, or even become powerless, when negotiating for power and resources with other members in virtual communities.



### *Coping with losing Face*

Despite encountering struggles as they negotiated for resources or even being excluded, the parents still found it relatively easy to search for resources and support through the social network site. Since the natural settings of social network sites entail fewer limitations in terms of location and physical boundaries, parental users can easily find and join a new virtual community if they lose Face or become powerless in their current community. Noticing the convenience of building a support network on social network sites, some parents created new support communities that reinforced their opinions and gave them Face. Interestingly, parents who created a personal virtual support community tended to include their family members, friends, or others with whom they had a close relationship within the support community. It is possible that these parents were building a new support network guaranteed to facilitate positive interactions due to being based on existing relationships from the offline world. This action of selecting members who are more likely to provide support is similar to the motivations of Facebook users who only accept family and friends as Friends and members of their virtual communities (Walther et al., 2008). In this way, the parents reduced the probability of being excluded or losing Face in the virtual space.

In addition to joining or creating a new community, some of the parents also ‘lurked’ in a virtual community with which they may have had negative experiences (for example p.154). In order to avoid conflict and being excluded from the Group, some parents became lurkers who only searched for and read information in the virtual community but did not contribute or interact with other members (Rafaeli, Ravid, & Soroka, 2004). Mickelson (1997, p.172) has stated that through lurking, these parents ‘obtain validation for their feelings of stigma without having to communicate the feelings to others’. All parental participants, including the parents with Face, such as Shin, mentioned the experience of lurking in different virtual communities. They suggested that the lurking experience comprised a passive but efficient way to continue collecting information they needed from the community despite being no longer welcomed there. However, as Walther et al. (2008) have suggested, this passive way of collecting information may have been less beneficial to the users,

since they did not participate in the discussion, which could have provided more precise information according to their needs.

Both actions, creating new virtual communities and lurking, are important adaptation skills for parents facing challenges or changes in their virtual communities. Barnett et al. (2003) have argued that the ‘adaptation’ (p.184) of all such parents’ role as parents of children with special needs is an ongoing process. The needs for childcare also keeps on being redefined by these parents in different stages of their parenting life (Grimshaw, 2013). These redefined needs then lead to a search for new types of support. Therefore, parents need to keep learning and improving to fulfil their children’s changing needs during different stages of their growth (Barnett et al., 2003). Therefore, despite facing challenges in a virtual community, parents lurk in the original community, join another new group, or even create a new virtual community to maintain their access to information and resources. As compared to face-to-face support in the traditional setting, joining a new support community and finding information through virtual communities is still significantly easier. That is because it is challenging for parents to lurk within a face-to-face support group, and even harder for parents to create a new offline support group on their own, due to the constraints of location, time, resources, and a small social circle.

### **9.2.2 Searching for and sharing information for different purposes**

As mentioned in Section 9.1.1, parents received rich and beneficial information addressing their parenting needs. However, different behaviours were identified in connection with accessing formal and informal information. The parents suggested various reasons for why they accessed these two types of information in different ways. Therefore, in the following sections, I explain and discuss multiple reasons and motivations that may have prompted the parents to search for formal and informal knowledge through virtual communities.

#### *Formal knowledge*

This study found that formal knowledge, such as published medical information about a children’s health condition, was shared and discussed less frequently than informal knowledge among parental users in the public space of the virtual communities.

According to the findings, posts about formal knowledge received less attention from the parental users and were less likely to receive Likes from them. The parents in the virtual communities were significantly less likely to prefer formal knowledge. This is consistent with the findings of Plantin and Daneback's (2009) review of online parent support, which revealed that parents generally prefer experience-based information, rather than simple and descriptive information from professionals.

However, in contrast to Plantin and Daneback's (2009) discovery, this study found that even though formal knowledge was less likely to be shared in the public space of the virtual community, it was commonly shared by the parental users within their private virtual social network spaces. For example, even though Dee claimed that she rarely shared formal knowledge in the public space of her virtual community, she often shared that knowledge with other parental users through private messages. Most of the parents had been privately collecting formal knowledge by, for example, lurking, to support their parenting situation. Some parents also used it as a resource to advocate for their children's rights and to negotiate for more resources. For example, Jade collected articles about medical treatment through virtual communities and used those materials to negotiate for better treatment for her son when visiting doctors.

A possible explanation for this behaviour of privately sharing formal knowledge may be the lack of a need to share formal information in the public space. The motivation for collecting formal knowledge is more likely to be related to personal use than to sharing with others to build connections or relationships. For example, according to McConkey (2003), such information is most likely to be needed by younger parents, who require such materials to understand their child's medical situation and to inhabit appropriate parental roles. For parents with older children may, therefore, found this information less relevant to their needs. This explanation is consistent with the finding that several parents mentioned that formal knowledge could be 'boring' and 'repetitive' (see p.173) in the public space. Therefore, sharing formal information in the public space may be considered as unnecessary for some of the parents, especially those with longer parenting experience.

Another potential reason for sharing formal knowledge in personal spaces pertained to the parents' lack of confidence regarding publicly sharing such information. Most of

the parents suggested that they were cautious about sharing formal information and claimed that they were not qualified to do so since they were not professionals but only parents (see p.199) Parents also stated that they were not responsible for the knowledge. Some of the participants even mentioned that parental users should be restricted from sharing formal knowledge, and especially medical knowledge. They suggested that parental users may make mistakes, such as sharing false information, that could be harmful to other parental users.

The findings, however, suggest that parental users were aware of the false information shared in the virtual community. Moreover, these parents even demonstrated that they had the ability and knowledge to quickly identify the false information and, on several occasions, prevent such information from spreading in their virtual communities (see p.182). Most parents, however, did not recognise their ability and still showed a lack of confidence in sharing formal information in the public virtual platforms.

This lack of confidence has been frequently reported in the literature on parents of children with special needs (Chiu, 2013; Ferguson, Hanreddy, & Ferguson, 2013). As Ferguson, Hanreddy, and Ferguson (2013) pointed out in their study, parents often self-regarded as less knowledgeable or skilful than professionals. The parents also suggested that it is the ‘experts and specialists [that] know and decide what their child needs’ (Ferguson, Hanreddy, & Ferguson, 2013, p.766). It was therefore not surprising that the parental users in this study were reluctant to share formal information in public spaces where professionals might see such information too.

Informal knowledge, on the other hand, is more likely to be shared confidently and Liked by parents in these support communities.

### *Informal knowledge*

One consistent theme across all three cases was that the parental users paid more attention to informal knowledge, such as parenting stories, than to its more formal counterpart. The parents preferred reading and sharing informal knowledge in the public space of the virtual communities. They also suggested that this type of information was more helpful for parents facing challenges regarding their children.

This preference for informal knowledge is consistent with the findings of different studies on online parent support in the Western context, including Sweden (Sarkadi & Bremberg, 2005) and other post-industrial English-speaking countries, such as the US (Plantin & Daneback, 2009). Sarkadi and Bremberg (2005) have suggested that other parents' advice is more valuable to parental users than recommendations or published knowledge from experts. However, very little was found in the literature regarding why parents prefer practical experience (Doty & Dworkin, 2014; Plantin & Daneback, 2009).

A possible explanation for this preference for informal knowledge is the crucial sense of security that parents gain through realising that 'they are not alone' (Kerr & McIntosh: 2000:317). Kerr and McIntosh (2000) studied face-to-face parent support groups and explained that parents develop a sense of comfort and relief when recognising that others are also facing similar challenges. This sense of comfort is also linked to solidarity and to the mutual understanding through which parents can share their pain (McConkey, 2016; Rogers, 2007; Todd, 2003). Several parental users also mentioned that reading and sharing informal parental knowledge in the virtual community helped them to deal with the challenges of raising children with special needs. For example, Jade mentioned that reading about other parents' experiences helped her to manage the challenging behaviours of her son with autism (see p.158). Similar to Chang's (2009) research on face-to-face support groups for Taiwanese parents, the parents in this study suggested that knowledge shared by parents facing comparable challenges is more helpful and relevant to their needs than information shared by non-parents. Thus, when given more opportunities to search for information, such as using virtual communities, collecting parenting experience from other users may be one of the top priorities.

Another possible explanation pertains to the original purpose of using social network sites. Since the natural aim of using social network sites is to build one's social circle, it is typical for parents to pay more attention to other parents' personal narratives to build connections with users who have undergone similar parenting experiences. This is in line with Bylund's (2005) study of a virtual community for pregnant women. Through the virtual community, these women read the posted informal information and searched for the contact information of a mother who shared similar pregnancy

issues, since knowledge regarding how to handle such challenges was essential for them (Bylund, 2005). Thus, one could suggest that the preference for informal parental knowledge might also be influenced by the need to build a social circle that is beneficial with respect to one's parental role.

Parental users were also aware of the importance of their parenting experience. They claimed the informal knowledge regarding their personal parenting experiences as the resource that they 'owned' in the communities. In addition to 'owning' informal knowledge, parents who had 'rich' or 'successful' parenting experiences were more likely to be recognised as powerful parents or parents with Face. For example, detailed information about how the parents managed challenging behaviours and about the experience of helping children to improve their social skills with parental support were both recognised as valuable strands of informal knowledge in the virtual communities. As a result, these parents took control of their informal knowledge through selecting users with whom they hoped to share their experiences and by controlling the amount of information that they were willing to share. This action of selecting users is linked to the act of othering to gain Face. Therefore, informal knowledge seemed to be the central resource that the parental users shared to negotiate for more Face within the virtual communities on Facebook. For example, Ming mentioned that she only shared specific parenting skills with parents with whom she had a relatively close relationship on Facebook and that she excluded other parents from her private Group (see p.167).

However, many researchers have pointed out concerns about the potential for children's privacy to be invaded when parents share their experiences in the public spaces of a virtual community (Brosch, 2016; Blum-Ross, 2015; Marasli et al., 2016). Two parental participants, Dee and Quini, likewise mentioned their experiences of being verbally abused by other internet users when they shared detailed parenting stories in the virtual communities. Violations of children's privacy and image rights (Brosch, 2016) and internet bullying (Marasli et al., 2016) are potential issues that may affect the wellbeing of children with special needs and their families. It is important for parents to be more aware of the potential risk to themselves and their children when sharing their parenting experiences (Marasli et al., 2016). Moreover,

professionals also need to prevent these parents from being cyberbullied or verbally abused on the internet (Blum-Ross, 2015).

This informal parenting information was not only preferred by the parents. One unexpected finding was that most of the professionals, and especially social workers and school teachers, considered the parents' act of sharing their informal knowledge as a valuable opportunity to collect information about those parents and their children and families to better understand them. These professionals' preference for sharing and seeking informal knowledge was a common theme across all three cases in this study. This idea of virtual communities being a valuable opportunity to collect parents' information could possibly be the natural needs in the job of these categories of professionals, since professionals such as social workers are more likely to be trained to collect information from parents to provide timely, helpful suggestions or supporting actions for parents and their families. Social workers employed by Lovely Dove suggested that through the virtual communities, they collected useful information that could help them target the types of support needed by parents or children and to better understand their clients.

One of the greatest difficulties in supporting parents of children with special needs is developing a firm foundation of relationships between professionals and parents (Todd, 2003), and a lack of information on these children and their families is one of the main causes of this problem (Todd, 2003). Ferguson, Hanreddy, and Ferguson (2013) have suggested that online text-based information regarding parents' experience filled the gap left by the absence of parents' voices in professional training programmes for teachers, other education professionals and social workers. Thus, it was not surprising that these professionals in this study suggested that being able to collect information from the parents through the virtual communities was important for them.

However, by gaining control of knowledge and recovering Face, the parents altered their interactions and relationships with these professional. In the following sections of this chapter, I discuss how gaining control of knowledge and acquiring Face through virtual communities influence the relationship between parents and professionals.

### **9.3 How does support provided through virtual communities impact the relationship between Taiwanese parents of children with special needs and professionals?**

In this section, I review the ways that the parents gradually took control of their relationships with professionals through the power they had gained in the virtual communities. I also discuss how marketisation may influence this altered relationship between parents and professionals.

#### **9.3.1 Becoming Friends with professionals through Facebook**

Contacting professionals and building a relationship with them have become ‘easy’ and ‘straightforward’ through the virtual communities, according to most of the parents in this study. The parental users shared the common experience of contacting these specialists for professional information. The parents also took the initiative to build a relationship with the professionals and to become Friends with them through the virtual communities. This action of taking the lead in developing relationships with professionals is very different from parents’ behaviour in the face-to-face support environment and traditional social settings.

Chang (2009) has suggested that there is a significant gap between professionals and parents in the traditional setting of Taiwanese support services for parents. The parents often found it difficult to communicate and build a relationship with the professionals due to the lack of opportunities, confidence, and trust (Chang, 2009; Chang & McConkey, 2008). And, according to McConkey et al.’s (2008) study on mothers of children with intellectual disabilities in Taiwan, Ireland, and Jordan, Taiwanese mothers even became anxious when interacting with professionals, such as special education teachers, in their local community. McConkey et al. (2008) argued that due to their negative experiences with these professionals, the mothers of children with special needs are less likely to seek support from these specialists.

However, in the three virtual support communities in this study, most of the parents were found to be more comfortable in taking the initiative to contact professionals and build relationships with them. The parents were found to gain confidence in sharing their thoughts with the professionals and negotiating with them through the virtual



communities. This increased confidence among parents who are considered powerless in society echoes global research on internet empowerment and online social movements (Mitra, 2005; Mittler, 2016). For example, Indian refugees gained a voice through social network sites and the virtual communities, even though they are considered to be silenced by societies in the Western hemisphere after the 9/11 terrorist attacks in the US (Mitra, 2005). Another example is the asylum-seeking detainees on islands in the Indian Ocean who sought support and advocated for their rights using social network sites (Coddington, & Mountz, 2014). Since this virtual community for Taiwanese parents virtual reflected other international virtual communities' experiences of empowerment, one might suggest that such communities are beneficial for empowering parents in general. Moreover, the experience of engaging in a community of parents facing similar struggles may have advantages for parents around the globe. For example, such communities might help address parents' struggles worldwide in building relationship with professionals (Fletcher et al., 2006).

In addition to gaining confidence, parents also found more opportunities to contact professionals due to the natural settings of the virtual communities. Since the social network site is an open virtual platform that everyone can join, most of the professionals had a personal account on it. With contact information attached to their personal accounts, it is easy for parents to contact these professionals and invite them to become their Friends. This straightforward means of contacting professionals suggested a substantial difference from the literature, which has stated that the difficulty of contacting professionals is one of the main reasons why parent-professional relationships or cooperation is difficult (Chadwick et al., 2013). It is possible to suggest that virtual communities can be beneficial for the parent-professional relationship and for cooperation between the two groups.

However, it is important to underscore that an invitation to become Friends in a virtual community is very different from building a relationship and becoming friends within traditional social settings. Conventionally, building a relationship requires time and mutual effort, and both parties need to agree to the connection and enjoy it to certain extent. On the contrary, becoming Friends with a virtual community may only mean that a user has permitted the individual to access the personal information on his or her private platform (boyd, 2006; Walther et al., 2008). Therefore, one potential

implication is that Friendship on social network sites might less about emotionally connection and more about benefits.

Agreeing with the assumption that Friendship is more benefit-oriented in virtual communities, the majority of the parents in this study indicated that their main reason for adding professionals as Friends was to access more resources and negotiate for more support. For example, the administrator Su was only included as a member of a parents' Group when she was needed to rent a venue for the parents using her identity as a staff member of Lovely Dove (see p.199). And that Zen invited the teachers of their children's previous education level to join the private Groups with other teachers to carry on providing support to his daughter (see p.198). The parental users selected the professionals with whom they wanted to build a relationship and decided how much information they hoped to share with those experts. When contacting the professionals, the parental users even determined the type and quality of the information they hoped to receive. Parents listed the specific type of support they needed from the professionals, such as specific medical information Jade asked through private message with the psychologist (see p.190). The topics of 'which professional is better' and 'what service is worth a try' frequently emerged in the discussions among parents. Experiences related to how to select professionals and services were also shared among the parental users in the virtual communities.

As Ammari and Schonenebeck (2015) argued in their study based on 43 American parents using Facebook, parents constantly collaborate with other parents whose children have similar needs and conditions. Through virtual communities, parents of children with special needs build up an efficient and powerful network system that allows them to map out both formal and informal information from different sources and to easily navigate different services for their children (Ammari & Schonenebeck, 2015).

One surprising finding was that in most instances, the parental users utilised the virtual communities not only to negotiate for more support but also to take control of the parent-professional relationship. Some parents were also found to exclude professionals from their private Groups to prohibit those specialists from joining in their parents-only discussions (see p.199). Most of the professionals were also less

likely to receive Likes within Group discussions and more likely to be ignored by parental users, even though they were Friends or member of the community. This situation of taking control of relationships serves a similar purpose as the ‘fight’ that Ryan and Runswick-Cole (2009) suggest in their research on parent advocates and activists in the UK. As Ryan and Runswick-Cole (2009) explained, when given a voice or power, parents ‘fight’ (2009:50) against the system or professionals for more support and resources due to their previous negative experiences with such experts or others in society. The concept of ‘fighting’ means to request and negotiate for more resources to ensure and safeguard the rights of one’s children and family. In fighting, a parent may use any resources, such as lobbying a local member of parliament (Ryan & Runswick-Cole, 2009).

In this study, the term ‘Zhēngqǔ’ (爭取), which means negotiating or fighting, was frequently used by the parents when referring to the social system or the services provided by professionals. Building connections with professional was identified as one of the ways that parents ‘Zhēngqǔ’ for better services and resources. However, as mentioned previously in relation to parental users’ control of the parent-professional relationship, in certain situations, this act of ‘Zhēngqǔ’ may become more like demanding and commanding than negotiating. The marketisation of support services may be the key factor responsible for this change in the parent-professional relationship.

### **9.3.2 The influence of marketisation on the parent-professional relationship**

As mentioned in Chapter 2, with the encouragement of the Taiwanese government, more and more private organisations that provide support services for children with special needs and their families have been founded. And most of these private organisations, such as Lovely Dove, rely heavily on income earned from providing support to these parents (Chang, 2010; Chang & Yan, 2011). In order to advertise and reach out to more potential customers, these organisations set up Pages, such as that of Lovely Dove (Qiu & Zhuang, 2013). The influence of marketisation also explains why advertisements about the face-to-face services or workshops held by the organisations frequently appeared in the virtual communities. However, compared to

face-to-face services, providing support through the internet and virtual communities may be much more competitive. Due to the limitless boundaries of the internet, organisations need to compete not only with the other private local providers but also with all other organisations around the world with an internet presence. Therefore, ensuring that parents have positive experiences with their services is critical for these organisations. Keeping parental users revisiting the virtual communities and building a strong connection with users are also essential. Parents are also aware that they now enjoy more choices and greater authority in terms of choosing services for their children, their families, and themselves. As Duncan (2003) suggests in a study on the parent-professional relationship in the UK, most parents are more aware of their role as the consumers or quasi-purchasers in the modern education and support service marketplace (Duncan, 2003).

Therefore, facing pressure to provide high-quality services and experiences to compete with other virtual support communities on Facebook or other social network sites, the professionals were identified as behaving submissively towards the parental users to create positive interactions and relationships with them in the virtual communities. The professionals also collected informal knowledge that had been shared by the parents in the communities to efficiently provide specific support, such as emotional encouragement, to parents. The virtual platform, which is not limited by location and time, offers them plentiful opportunities and resources to support parental users, and it is even possible to 'customise' a service according to the parenting experiences shared by members of virtual communities. These findings might imply that joining virtual communities, reading about parents' experiences, and providing instant assistance over the internet help professionals to provide efficient support services.

However, not all informal knowledge was collected for marketing reasons. I also identified organisations that did not create or join a virtual community to sustain the business. For example, Speak Out, which is a governmental non-profit organisation, mainly created its virtual community to provide platforms for parents to advocate for their rights and to provide those users with support. I also identified several professionals who joined the virtual community mainly to improve their professional knowledge and develop connections with parents. Therefore, it is possible to suggest

that a virtual community may serve complex usage needs for users with different purposes.

In general, this research suggests that the parent-professional relationships in virtual communities is changing extensively. One potential implication is that under the influence of both marketisation and empowerment through gaining control of knowledge and having Face in the virtual communities, parents are becoming more and more powerful.

## Chapter 10. Conclusion

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This chapter presents the contribution to knowledge of this study. A brief summary of this study and the limitations of the research are illustrated, and recommendations for future research are likewise offered.

### 10.1 Contribution to knowledge

There are five elements of this paper's contribution to knowledge. In the following sections, the term 'body of literature' refers to the literature on online support for parents of children with special needs.

**Firstly**, adding to the current body of literature, this study has illustrated that virtual communities allow parents to redefine themselves in relation to the dominant social understanding of parent identity. Through the platforms in virtual communities, these parents present themselves as general parents and as having Face in society. This perspective of parents using the internet as a way to be included in the dominant society—in this case, Taiwanese society—has been examined and mentioned in the current literature only rarely (see p.69). Thus, the results regarding how parents negotiate for Face through a safe environment and support network created with ease in their virtual community are essential for the current body of research.

In broader terms, this redefinition of Face in the Taiwanese context is analogous to the redefinition of self-identity among parents in their cultural context. This redefinition of Face among Taiwanese parents echoes Mitra's (2005) research, in which Indian immigrants used virtual communities to redefine their former identities in relation to their new American identities. Thus, it is possible that this experience of redefinition that I identified in this study among Taiwanese parents could be helpful for other groups of parents in different culture contexts.

**Second**, this research provides indicative evidence that virtual communities are starting to shift the power relationships between parents and professionals. Though four mechanisms, parents are gaining more control of the parent-professional

relationship and are gradually becoming the decision-makers in terms of their needs. These four mechanisms are:

1. Taking the initiative to contact professionals
2. Inviting professionals to become members of their virtual communities
3. Becoming Friends with professionals
4. Creating parents-only platforms that enable parents to exclude other users, but including professionals when needed

All four mechanisms help parents to obtain resources and support from professionals. However, at the same time, they allow parents to set boundaries to retain control of their interactions with those experts.

This study has also pointed out that the parents recreated these mechanisms of gaining control in the parent-professional relationship through sharing their experiences with each other in their virtual communities. This demonstrates that parents are gaining more control and becoming increasingly powerful through the networks they develop by joining virtual communities. I believe this study's findings on gaining control over relationships with professionals is important for filling the gap in the main field of the study on parent support.

**Third**, in addition to the shifting relationship between parents and professionals, parents also use virtual communities to exercise power to renegotiate their identities and resources with each other. This study's findings on the negotiation of power among parents, and not only professionals, in the virtual communities extends the current knowledge on parent support for parents of children with special needs. Existing research has mainly focused on examining the power relations between professionals and parents (for example, Featherstone, & Fraser, 2012; Todd, 2007; Ryan, & Runswick-Cole, 2009), while this study has offered a different perspective on how parents can gain power in their relationships not only with professionals but also with each other. Some parents become paraprofessionals or gatekeepers for the other parents in the virtual community. They become powerful by using various strategies and multilayer virtual interactions to negotiate for power.

This research, however, has also indicated that parents encounter power struggles, hierarchy, and the need to negotiate for power within virtual communities for parents. Power was found to be negotiated through othering by parents. Parents controlled the knowledge, resources, and social networks that they gathered and built, and used them to negotiate with other parents in the virtual communities. Some parents were also found to be struggling and were ignored within their virtual communities. I believe that this research extends the current knowledge regarding online parent support by viewing interactions of support in virtual communities from parents' perspective.

This recognition of the power struggles among parents extends the current knowledge on online parent support, which mainly suggests positive and beneficial experiences (for example, Doty and Dorwkin, 2014; Ammari & Schonenebeck, 2015), by indicating that parents also face negative experiences and challenges, such as being excluded or ignored by other members, in virtual communities. This finding on parents' negative experiences provides a different vantage point on how support is received and negotiated in a virtual community that relies on the parents' point of view. This has hopefully provided readers with various aspects to consider when examining the parent support provided in virtual communities.

**Fourth**, this research has contributed to the existing literature, which is dominated by studies from the Western context—and primarily the American one —by providing a Southeast Asian point of view. Moreover, since this study was based in a country with a high internet usage rate, its findings are very likely to mirror the situation in digital-first countries, which are those countries with a large population of internet users and smart technologies. The findings might also reflect countries that are moving towards becoming a digital-first nation in the future, since almost all states around the world, and especially developing countries, have rapidly growing populations of internet users. Therefore, these Taiwanese parents' online experiences of support and changing power relationships with other users, including parents and professionals, may be helpful to many nations around the world by reflecting their virtual communities for parents of children with special needs.



**Fifth**, this study has developed a potential conceptual framework which identifies the core purposes of the parents in using virtual communities are to access and generate information, advocacy and support in relation to parenting skills, medication, education, welfare, and leisure. Underpinning these more specific purposes, are a set of a more general purposes: of parents positively defining their identities as parents of children with special educational needs, and in turn, gaining and maintaining Face through their engagement with the virtual community. This conceptual contribution has demonstrated an alternative but useful way to understand support for parents of children with special needs in an online environment. This conceptual framework has potential to be helpful for future research on online parent support in terms of examining interactions and content and their underpinning purposes.

## **10.2 Summary of the thesis**

The aim of this research was to understand the role that virtual communities play in providing support for parents. This thesis began with an introduction that presented my personal journey and rationale for conducting this study. It also provided the academic justification for this study. The research focus was additionally introduced, and I outlined my three research questions:

- How do virtual communities provide support for parents of children with special needs in Taiwan?
- What motivates Taiwanese parents of children with special needs to search for support through virtual communities?
- How does support provided through virtual communities impact the relationship between Taiwanese parents and professionals?

After the introduction, the contextual background of the research was examined, and that chapter gave a brief history of Taiwan, the Taiwanese culture of Face, and the country's healthcare system and support services for parents and their children. This chapter also outlined the experiences of Taiwanese parents and the challenges facing them in Taiwanese society.

The existing literature on online parent support highlights that parents can benefit from the support provided through virtual communities. Such communities offer

easily accessible information, timely emotional support, and opportunities for parents to advocate for their needs through the public platform. The literature, however, appeared to be lacking in-depth examinations of the interactions of support among parents in virtual communities. The current literature has also been mainly based on Western contexts and experiences. These gaps in the literature are suggested to be problematic in the field of online parent support, since existing studies may have made overly positive assumptions regarding online support and may have been biased towards Western culture. Thus, it seemed appropriate to explore the experiences of parents interacting in virtual communities in the Taiwanese context.

A conceptual framework based on the three concepts of support—informational support, emotional support, and advocacy—was adopted to address the research questions. It was further employed in the categorisation stage of the data analysis process.

This research indicated that parents were able to access useful information, such as medical information or content on parenting experiences, and receive timely emotional support, such as help in addressing suicidal thoughts and comfort and solidarity, from other members of the virtual community. By using this collected information and building support networks in their virtual communities, the parents could advocate for their needs and ‘fight’ with the general public to win respect. The parents were able to undertake these actions despite facing pressure from a biased society, such as the critical incident mentioned in Chapter 5.

This study contributes to literature by pointing out that parents redefine their societal identities in relation to the dominant expectation for parenting roles through virtual communities. They create safe virtual spaces in their communities to perform their identities and allow their voices to be heard. To secure their power and support networks, parents may also exclude or ignore other users, including other parents, who do not share their parenting values or follow the virtual community’s unspoken rules. Parents were also found to be altering their power relationships with professionals through virtual communities by gaining control of knowledge and power. This research fills in the gap in the current field of research on online parent

support, as close examinations of parents' experience of interacting with virtual communities for support were lacking, as was an East Asian point of view.

### **10.3 Potential future studies**

This study provides a critical view of how virtual communities provide opportunities to empower parents of children with special needs. This research also enhances our understanding of the influence of the virtual community in providing support for such parents. However, it is important to bear in mind that how virtual communities affect parents' actual face-to-face social interactions has not been examined. Therefore, research exploring how the increased parent power gained through virtual communities affects face-to-face interactions could be conducted in the future to gain a complete picture of the impact of that empowerment.

Due to Facebook being the most used social network site in Taiwan, this study's samples only included parents who were committed users of Facebook. Even though Facebook is one of the most typical and popular social network sites worldwide, different social network sites, such as Instagram, might yield other factors that influence online parent support. Hence, further research could be undertaken to investigate parents who use different social network platforms, and even those parents who do not use social network sites. Furthermore, more research could be conducted to understand the potential influence of the parent's gender, education, and social background, on the ways that parents gain support in virtual communities and their usage of social network sites as tools for parent support. Such studies could examine factors such as social class and income differences.

Additionally, this research mainly focused on text-based data, and other forms of data, such as photographs and videos, were not included. As a researcher, I have learned that online data collection methods, such as the web-based observations of this study, collect rich and complex data, since online archive data feature a variety of formats, such as text, photographs, and videos. Thus, while gathering online data, researchers may easily collect too much data, and the data themselves can also be too rich and complex to analyse. To avoid amassing an overwhelming amount of data, this research mainly focused on text-based data. Therefore, more investigations of data

based on photographs and other types of information shared in virtual communities are a potential focus for future research.

## References

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- Adedoyin, A. C. A. (2016). Deploying virtual communities of practice as a digital tool in social work: a rapid review and critique of the literature. *Social Work Education, 35*(3), 357-370.
- Al-Kandari, H.Y. (2014), Parents' and Professionals' Perceptions of the Services of Families of Children with Intellectual Developmental Disabilities, *Child and Adolescent Social Work Journal, 31*(2), 119-142.
- Allcott, H., & Gentzkow, M. (2017). Social media and fake news in the 2016 election. *Journal of Economic Perspectives, 31*(2), 211-234.
- Alsem, M. W., Ausems, F., Verhoef, M., Jongmans, M. J., Meily-Visser, J. M. A., & Ketelaar, M. (2017). Information seeking by parents of children with physical disabilities: An exploratory qualitative study. *Research in developmental disabilities, 60*, 125-134.
- Ammari, T. and Schoenebeck, S.Y. (2015). Networked Empowerment on Facebook Groups for Parents of Children with Special Needs. In Proceedings of the ACM Conference on Human Factors in Computing Systems (CHI '15). Seoul, Korea. April 18-23, 2015.
- Apple Daily (2015) The worst tragedy of our society – Father killing his son with cerebral palsy. *Apple Daily*. Available at <http://www.appledaily.com.tw/appledaily/article/headline/20150323/36452086/>. [Accessed on 04 April 2015]
- Baldick, C. (2008) Oxford Dictionary of Literary Terms. 3rd ed. New York: Oxford University Press.
- Barling, J., MacEwen, K. E., & Pratt, L. I. (1988). Manipulating the type and source of social support: An experimental investigation. *Canadian Journal of Behavioral Science, 20*(2), 140-153.
- Barrett, J. R. (2007). The researcher as instrument: Learning to conduct qualitative research through analyzing and interpreting a choral rehearsal. *Music Education Research, 9*(3), 417-433.
- Bachrach, Y., Kosinski, M., Graepel, T., Kohli, P., & Stillwell, D. (2012, June). Personality and patterns of Facebook usage. In *Proceedings of the 4th Annual ACM Web Science Conference*, 24-32.
- Barnett, D., Clements, M., Kaplan-Estrin, M., & Fialka, J. (2003). Building new dreams: Supporting parents' adaptation to their child with special needs. *Infants & Young Children, 16*(3), 184-200.
- Bennett, R. (2016). Factors contributing to the early failure of small new charity start-ups. *Journal of Small Business and Enterprise Development, 23*(2), 333-348.

## Reference

- Beresford, B. A. (1994). Resources and strategies: How parents cope with the care of a disabled child. *Journal of Child Psychology and Psychiatry*, 35(1), 171-209.
- Berry, N. (2014). Facebook Worldwide (Part 1). *Data Genetics*, <http://www.datagenetics.com/blog/november52010/index.html>. [accessed 31 July 2016].
- Black, A. P., & Baker, M. (2011). The impact of parent advocacy groups, the Internet, and social networking on rare diseases: the IDEA League and IDEA League United Kingdom example. *Epilepsia*, 52(s2), 102-104.
- Blanchard, A. L. (2008). Definition, antecedents, and outcomes of successful virtual communities. *Encyclopedia of E-collaboration*, 126-132.
- Blease, C. R. (2015). Too many 'friends,' too few 'likes'? Evolutionary psychology and 'Facebook depression'. *Review of General Psychology*, 19(1), 1.
- Blum-Ross, A. (2015). 'Sharenting': parent bloggers and managing children's digital footprints. *Parenting for a Digital Future*. Available at: <http://blogs.lse.ac.uk/parenting4digitalfuture/2015/06/17/managing-your-childs-digital-footprint-and-or-parent-bloggers-ahead-of-brit-mums-on-the-20th-of-june/> [Accessed 23<sup>th</sup> April, 2016]
- Boblin, S. L., Ireland, S., Kirkpatrick, H., & Robertson, K. (2013). Using Stake's qualitative case study approach to explore implementation of evidence-based practice. *Qualitative Health Research*, 23(9), 1267-1275.
- boyd, d. (2006). Friends, Friendsters, and MySpace Top 8: Writing community into being on social network sites. *First Monday*, 11(12). Available at: [www.firstmonday.org/issues/issue11\\_12/boyd/](http://www.firstmonday.org/issues/issue11_12/boyd/) [Accessed 14<sup>th</sup> December 2015]
- boyd, d. m. & Ellison, N. B. (2007) Social network sites: Definition, history, and scholarship, *Journal of Computer-Mediated Communication*, 13 (1), 210-230.
- Brady, E., & Guerin, S. (2010). Not the romantic, all happy, coochy coo experience: A qualitative analysis of interactions on an Irish parenting web site. *Family Relations*, 59, 14-27.
- Brandes, S. B., & Levin, D. (2014). "Like My Status" Israeli teenage girls constructing their social connections on the Facebook social network. *Feminist Media Studies*, 14(5), 743-758.
- Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3 (2). 77-101.
- British Broadcasting Corporation (BBC) (2017). Facebook hits two billion users. Available at: <http://www.bbc.co.uk/news/business-40424769> [accessed 30th June, 2017]
- Brosch, A. (2016). When the Child is Born into the Internet: Sharenting as a Growing

- Trend among Parents on Facebook. *The New Educational Review* 43(1), 225-235.
- Bryman, A (2012) *Social Research Methods*. 4<sup>th</sup> Edition, Oxford: OUP.
- Bureau of National Health (2015) Medical Services. Available at [http://www.nhi.gov.tw/English/Content\\_List.aspx?n=1D1ECC54F86E9050&topn=1D1ECC54F86E9050](http://www.nhi.gov.tw/English/Content_List.aspx?n=1D1ECC54F86E9050&topn=1D1ECC54F86E9050) [accessed 7<sup>th</sup> July 2017]
- Bylund, C. L. (2005). Mothers' involvement in decision making during the birthing process: a quantitative analysis of women's online birth stories. *Health Communication*, 18(1), 23-39.
- Carpenter, B. (2005) Early childhood intervention: possibilities and prospects for professionals, families and children, *British Journal of Special Education*, 32 (4), 176–183.
- Carpenter, B., Addenbrooke, M., Attfield, E. & Conway, S. (2004) ‘Celebrating Families’: an inclusive model of family-centred training, *British Journal of Special Education*, 31 (2), 75–79.
- Castells, M. (2011). *The rise of the network society: The information age: Economy, society, and culture* (Vol. 1). London: John Wiley & Sons.
- Chadwick, D. D., Mannan, H., Garcia Iriarte, E., McConkey, R., O'brien, P., Finlay, F., & Harrington, G. (2013). Family voices: life for family carers of people with intellectual disabilities in Ireland. *Journal of Applied Research in Intellectual Disabilities*, 26(2), 119-132.
- Chang, C. W. (2011). *Headteachers' views on the inclusion of students with special educational needs in Taiwan*. PhD thesis. University of Edinburgh.
- Chang, H. H. (2009). From housewives to activists: Lived experiences of mothers for disability rights in Taiwan. *Asian Journal of Women's studies*, 15, 34–59.
- Chang, H. H. (2010) State transformation and the Development of the Disability Rights Movement in Taiwan. Paper presented in Association of Asian Studies Annual Meeting, Session: Democratizing Democracy: Politics of Social Movements in Contemporary Taiwan. Philadelphia. March 25-28, 2010.
- Chang, H. H & Wang, J. (2016) From “Handicapped” to “Disabled” : A Content Analysis of Disability Labels and Discourse in Taiwanese Newspapers. *Taiwanese Sociology*, 31(1), 1-41. (in Chinese)
- Chang, H. H., & Yan, S. K. (2011) From Charity toward Civil Rights: The Development and Challenges of the Disability Social Welfare in Taiwan. *Community Development Bulletin*, 133, 402-416. (in Chinese)
- Chang, M. Y., & Hsu, L. L. (2007). The perceptions of Taiwanese families who have children with learning disability. *Journal of Clinical Nursing*, 16(12), 2349-2356.

## Reference

- Chang, M. Y., & McConkey, R. (2008). The perceptions and experiences of Taiwanese parents who have children with an intellectual disability. *International Journal of Disability, Development and Education*, 55(1), 27-41.
- Chen, Y. C. (2001). Chinese values, health and nursing. *Journal of advanced nursing*, 36(2), 270-273.
- Chen, K. H. (2010). *Asia as method: Toward deimperialization*. Duke University Press.
- Cheng, Y. (2011) The Support and Needs of Families with Infants and Young Children Who Had Special Needs. *Kaohsiung Normal University Journal. Education and Social Sciences*, 31, 1-25. (In Chinese)
- Chiu, C. Y. (2013). *Family needs and family quality of life for Taiwanese families of children with intellectual disability and developmental delay*. PhD thesis. University of Kansas.
- Chiu, C. M., Hsu, M. H., & Wang, E. T. (2006). Understanding knowledge sharing in virtual communities: An integration of social capital and social cognitive theories. *Decision support systems*, 42(3), 1872-1888.
- Coddington, K., & Mountz, A. (2014). Countering isolation with the use of technology: how asylum-seeking detainees on islands in the Indian Ocean use social media to transcend their confinement. *Journal of the Indian Ocean Region*, 10(1), 97-112.
- Cohen, L. Manion, L. & Morrison, K. (2007). *Research methods in education*. London: Routledge.
- Cole B. A. (2004) *Mother-Teachers: Insights into Inclusion*. London: David Fulton.
- Creswell, J. W. (2013). *Research design: Qualitative, quantitative, and mixed methods approaches*. Sage publications.
- Davis, K. (2015). Teachers' perceptions of Twitter for professional development. *Disability and rehabilitation*, 37(17), 1551-1558.
- DeLegge, A., & Wangler, H. (2017). Is this the end for Facebook? A mathematical analysis. *Applied Mathematics and Computation*, 305, 364-380.
- Dichtelmiller M, Meisels SJ, Plunkett JW, Bozynski MA, Claflin C, Mangelsdorf SC. (1992). The relationship of parental knowledge to the development of extremely low birth weight infants. *Journal of Early Intervention*. 16:210-220.
- Doty, J. L., & Dworkin, J. (2014) Online Social Support for Parents: A Critical Review, *Marriage & Family Review*, 50 (2), 174-198
- Duncan, N. (2003) Awkward Customers? Parents and Provision for Special



## Reference

- Educational Needs, *Disability & Society*, 18:3, 341-356
- Duquette, C. A., Stodel, E. J., Fullarton, S., & Hagglund, K. (2012). Educational advocacy among adoptive parents of adolescents with fetal alcohol spectrum disorder. *International Journal of Inclusive Education*, 16(11), 1203-1221.
- Eastern Broadcasting Corporation (2015). Person with Cerebral Palsy Beat His Grandmother Violently. Father Strangled Him and Cried Bitterly in Car. *Eastern Broadcasting Corporation*. Available at: <https://www.ettoday.net/news/20170619/948281.htm> [Accessed 4th June 2015]
- Enebrink, P., Högström, J., Forster, M., & Ghaderi, A. (2012). Internet-based parent management training: A randomized controlled study. *Behaviour research and therapy*, 50(4), 240-249.
- Eriksson, H., & Salzmänn Erikson, M. (2012). Supporting a caring fatherhood in cyberspace—An analysis of communication about caring within an online forum for fathers. *Scandinavian Journal of Caring Sciences*, 27, 63–69.
- Eranti, V., & Lonkila, M. (2015). The social significance of the Facebook Like button. *First Monday*, 20(6), 1-14.
- Etzioni, A. (2004). On virtual, democratic communities. In A. Feenberg & D. Barney (eds.), *Community in the Digital Age*. Lanham: Rowman & Littlefield, 25–38.
- Evans, M., Donelle, L., & Hume-Loveland, L. (2012). Social support and online postpartum depression discussion groups: A content analysis. *Patient education and counseling*, 87(3), 405-410.
- Eynon, R., Fry, J., & Schroeder, R. (2008). *The ethics of internet research* (pp. 23-41). Sage: London.
- Facebook, (2017a) *Share Button*. Available at: <https://developers.facebook.com/docs/plugins/share-button/> [Accessed on 22th July 2017]
- Facebook, (2017b) *What does it mean to "Like" something?*. Available at: <https://en-gb.facebook.com/help/like> [Accessed on 22th July 2017]
- Facebook, (2017c) *What's the difference between Page and Group*. Available at: <https://www.facebook.com/notes/facebook/facebook-tips-whats-the-difference-between-a-facebook-page-and-group/324706977130/> [Accessed on 22th July 2017]
- Featherstone, B., & Fraser, C. (2012). 'I'm just a mother. I'm nothing special, they're all professionals': parental advocacy as an aid to parental engagement. *Child & Family Social Work*, 17(2), 244-253.
- Ferguson, D. L., Hanreddy, A. N., & Ferguson, P. M. (2013). Finding a voice:

## Reference

- Families' roles in schools. Florian, L. (Ed.). *The SAGE handbook of special education: Two volume set*. London: Sage. 763-783.
- Feng, Y. T (2011) *The experiences of the family caregivers participating in the self-help group*. Master Dissertation of National ChenChi University.(in Chinese)
- Finfgeld, D. L. (2000). Therapeutic groups online: the good, the bad, and the unknown. *Issues in mental health nursing*, 21(3), 241-255.
- Fletcher, L., O'Rourke, R., Payne, G., Smith, S., Holmes, G.U., Ridgewell, H. (2006) *Altered Images: Becoming Parents of Our Disabled Children*. York: York Publishing Services Ltd.
- Flood, G. (2009) Religion: Hindu concepts. Available at: [www.bbc.co.uk/religion/religions/hinduism/concepts/concepts\\_1.shtml](http://www.bbc.co.uk/religion/religions/hinduism/concepts/concepts_1.shtml) [Accessed on 30th July 2015]
- Formosa News, (2015) 'Everyone is Tired of You'—Father Killed His Son with Cerebral Palsy with Tears. *Formosa News*. Available at <http://m.ftv.com.tw/newscontent.aspx?sno=2015323S15M1> [Accessed on 03<sup>rd</sup> June 2015]
- Fusch, P. I., & Ness, L. R. (2015). Are we there yet? Data saturation in qualitative research. *The Qualitative Report*, 20(9), 1408-1416
- Fylan, F. (2005). Semi structured interviewing. In Miles, J., & Gilbert, P. (eds) *A handbook of research methods for clinical and health psychology*, (pp. 65-78) Oxford University Press.
- Gau, S.S.-F., Chou, M.-C., Chiang, H.-L., Lee, J.-C., Wong, C.-C., Chou, W.-J., et al. (2012). Parental adjustment, marital relationship, and family function in families of children with autism. *Research in Autism Spectrum Disorders*, 6, 263–270.
- Gabbert, T.I., Metze, B., Bühner, C. & Garten, L. (2013). Use of social networking sites by parents of very low birth weight infants: Experiences and the potential of a dedicated site. *European journal of pediatrics*, 172 (12), 1671-1677.
- Gerlitz, C., & Helmond, A. (2013). The like economy: Social buttons and the data-intensive web. *New Media & Society*, 15(8), 1348-1365.
- Grimshaw, R. (2013). 'She wants you to think for yourself, she doesn't want to give you the answer all the time': parents on parenting education and support. In: Wolfendale, S. and Einzig, H. (eds.) *Parenting Education and Support: New Opportunities*. London: Routledge, 150-166.
- Griffiths F., Lindenmeyer A., Powell J., Lowe P., Thorogood M. (2006) Why are healthcare interventions delivered over the internet? A systematic review of the published literature. *J Med Internet Res*, 8-10.
- Gundersen, T. (2011). 'One wants to know what a chromosome is': the internet as a

## Reference

- coping resource when adjusting to life parenting a child with a rare genetic disorder. *Sociology of health & illness*, 33(1), 81-95.
- Gupta, A., & Singhal, N. (2004). Positive perceptions in parents of children with disabilities. *Asia Pacific Disability Rehabilitation Journal*, 15(1), 22-35.
- Hall, W., & Irvine, V. (2009). E-communication among mothers of infants and toddlers in a community-based cohort: A content analysis. *Journal of advanced nursing*, 65(1), 175-183.
- Herman, J., Mock, K., Blackwell, D., and Hulsey, T. (2005) Use of pregnancy support web site by low-income African American women. *Journal of Obstetric, Gynecologic and Neonatal Nursing*, 34,713-720
- Hess, R. S., Molina, A. M., & Kozleski, E. B. (2006). Until somebody hears me: Parent voice and advocacy in special educational decision making. *British Journal of Special Education*, 33(3), 148-157.
- Holliday, A. (2010) *Intercultural Communication & Ideology* : SAGE Publications, London: SAGE Publications.
- Hong, Y.S.& Wu, S. C. (2015). A Study of the Experiences in Using Home Care Services by Families with Old Parents and Adult Children Having Intellectual Disability. *Journal of gerontechnology and service management* 3(3), 321-322.
- Hsieh, P. C., & Van Puymbroeck, M. (2013). Leisure as a means of coping: the experience of Taiwanese parents of adult children with disabilities. *Recreation and Society in Africa, Asia and Latin America*, 4(1), 1-22.
- Hu, S. N. (2015) The worst Tragedy of Humankind...Father Killing His Son with Cerebral Palsy, *China Times*. Available at: <http://www.chinatimes.com/realtimenews/20150322002425-260402> [Accessed on 2 June 2015]
- Hsu, Y. C., Tsai, S. L., Hsieh, M. H., Jenks, M. S., Tsai, C. H., & Hsu, M. T. (2017). On My Own: A Qualitative Phenomenological Study of Mothers of Young Children with Autism Spectrum Disorder in Taiwan. *Journal of Applied Research in Intellectual Disabilities*. 30. 147-156
- Huang, G. H. C., & Gove, M. (2012). Confucianism and Chinese families: Values and practices in education. *International Journal of Humanities and Social Science*, 2(3), 10-14.
- Huang, L. L., Liu, J. H., & Chang, M. (2004). 'The double identity' of Taiwanese Chinese: A dilemma of politics and culture rooted in history. *Asian Journal of Social Psychology*, 7(2), 149-168.
- Huang, R. (2016). RQDA: R-based Qualitative Data Analysis. R package version 0.2-8. Available at: <http://rqda.r-forge.r-project.org/> [Accessed on 10<sup>th</sup> September 2014 ]

## Reference

- Huang, Y. P., St John, W., Tsai, S. W., & Chen, H. J. (2011). Taiwanese fathers' experiences of having their child diagnosed with a developmental disability. *Journal of Nursing Research*, 19(4), 239-249.
- Huberman, B. A., Romero, D. M., & Wu, F. (2008). Social networks that matter: Twitter under the microscope. Available at SSRN: <https://ssrn.com/abstract=1313405> [Accessed on 9<sup>th</sup> May 2015].
- Hudson, D.B., Campbell-Grossman, C., Keating-Lefler, R., & Cline, P. (2008) New Mothers Network: the development of an Internet-based social support intervention for African American mothers. *Issues in Comprehensive Pediatric Nursing*, 31, 23-35
- Huen, Y. (2014). *Legislation on inclusive education in Taiwan, the United Kingdom and the United State, IN15/13-14*, Hong Kong: Legislative Council Secretariat Available at: <http://www.legco.gov.hk/research-publications/english/1314in15-legislation-on-inclusive-education-in-taiwan-the-united-kingdom-and-the-united-states-20140417-e.pdf> [Accessed on 23th July 2015]
- Hwang, K. K. (2012). Face and morality in confucian society. In *Foundations of Chinese Psychology* (pp. 265-295). Springer: New York.
- Hwang, A.W., Yen, C.F., Liou, T.H., Simeonsson, R.J., Chi, W.C., Lollar, D.J., Liao, H.F., Kang, L.J., Wu, T.F., Teng, S.W. and Chiu, W.T. (2015). Participation of children with disabilities in Taiwan: The gap between independence and frequency. *PloS one*, 10(5), p.e0126693.
- Internet Live Stats (2017). Internet Live Stats. Available at: <http://www.internetlivestats.com/> [Accessed on 30th June 2017]
- Internet World Stats (2017). Top 20 Countries in Internet Users vs. All the Wold – March 31 2017. Available at: <http://www.internetworldstats.com/top20.htm> [Accessed on 30th June 2017]
- Joseph Rowntree Foundation (2001) The Impact of Childhood Disability on Family Life. Available at: <http://www.jrf.org.uk/knowledge/findings/socialcare/631.asp> [Accessed on 3<sup>rd</sup> November 2007].
- Juan, C. Y., Wu, J. W., & Yang, K. H. (2014). A computer-aided system to categorize characteristics of children with special needs. In *Bridging Research and Good Practices towards Patients Welfare: Proceedings of the 4th International Conference on Healthcare Ergonomics and Patient Safety (HEPS)*, (pp. 223-228). Taipei, Taiwan, 23-26 June 2014.
- Kendall, L. (2011). Community and the internet. In Consalvo, M., & Ess, C. (Eds.). (2011). *The handbook of internet studies* (Vol. 14) (pp. 309-325), Oxford: John Wiley & Sons.
- Kerr, S. M., & McIntosh, J. B. (2000). Coping when a child has a disability: exploring

- the impact of parent-to-parent support. *Child: care, health and development*, 26(4), 309-322.
- Kilroy, G. (2013) *Looking at the participation of children and young people with social, emotional and behavioural difficulties (SEBD) in planning, review and decision-making around their needs in statutory review processes*. PhD thesis. University of Manchester.
- King, A. Y., & Bond, M. H. (1985). The Confucian paradigm of man: A sociological view. *Chinese culture and mental health*, 29-45.
- Kollock, P., & Smith, M. (1996) Managing the virtual commons: Cooperation and conflict in computer communities. In Herring, S. C. (Ed.). (1996). *Computer-mediated communication: Linguistic, social, and cross-cultural perspectives* (Vol. 39). (pp. 109-128). John Benjamins Publishing.
- Koltay, T. (2011). The media and the literacies: Media literacy, information literacy, digital literacy. *Media, Culture & Society*, 33(2), 211-221.
- Kraut, R., Olson, J., Banaji, M., Bruckman, A., Cohen, J., & Couper, M. (2004). Psychological research online: report of Board of Scientific Affairs' Advisory Group on the Conduct of Research on the Internet. *The American psychologist*, 59(2), 105-17.
- Lea, M., & Spears, R. (1992). Paralanguage and social perception in computer-mediated communication. *Journal of Organizational Computing and Electronic Commerce*, 2(3-4), 321-341.
- Lee, S. N. C., Long, A., & Boore, J. (2009). Taiwanese women's experiences of becoming a mother to a very-low-birth-weight preterm infant: A grounded theory study. *International journal of nursing studies*, 46(3), 326-336.
- Legislative Yuan (2015). *Law Cases Volumes (the 76th Volume): The Act of Special Education*. Taipei Taiwan: Taiwan Legislative Yuan. (In Chinese)
- Lewis-Gargett, A., Barton, R., Llewellyn, G., Tsaputra, A., Soe, K. Z. S., & Tawake, S. (2016) Global cultures and understandings of disability. In Iriarte, E. G., McConkey, R. & Gilligan, R. H. (eds.) *Disability and Human Rights: Global Perspectives*, (pp. 68-80) London: Palgrave.
- Liao, S. J. (2007) Understanding as a Basis of Praxis: A Special Educator's Self-Critique. *Journal of Educational Practice and Research*, 20 (2), 187-212. (In Chinese)
- Lin, C. R., Tsai, Y. F., & Chang, H. L. (2008). Coping mechanisms of parents of children recently diagnosed with autism in Taiwan: a qualitative study. *Journal of Clinical Nursing*, 17(20), 2733-2740.
- Madden, M., Cortesi, S., Gasser, U., Lenhart, A., & Duggan, M. (2012). *Parents, teens, and online privacy. Internet and American Life Project*. <http://>

- pewinternet.org/Reports/2012/Teens-and-Privacy.aspx [accessed 24 August 2014]
- Madge, C., & O'connor, H. (2006). Parenting gone wired: empowerment of new mothers on the internet?. *Social & Cultural Geography*, 7(02), 199-220.
- Malinga, J. T., & Gumbo, T. (2016). Advocacy and lobbying: the road map from charity to human rights. In Iriarte, E. G., McConkey, R. & Gilligan, R. H. (eds.) *Disability and Human Rights: Global Perspectives*. (pp. 49-67) London: Palgrave.
- Mason, J. (2002) *Qualitative Researching* (2nd edition). London: Sage .
- Marasli, M., Suhendan, E., Yilmazturk, N. H., & Cok, F. (2016). Parents' Shares on Social Networking Sites About their Children: Sharenting. *Anthropologist*, 24(2), 399-406.
- Marchionini G (1995) *Information seeking in electronic environments*, Cambridge, MA: Cambridge University Press.
- McCabe, H. (2008) The Importance of Parent-to-Parent Support among Families of Children with Autism in the People's Republic of China, *International Journal of Disability, Development and Education*, 55(4), 303-314,
- McConkey, R. (2003). Information needs of parents about learning disabilities. *Journal of learning Disabilities*, 7(3), 211-219.
- McConkey, R. (2016) Supporting Family Caregivers. In Iriarte, E. G., McConkey, R. & Gilligan, R. H. (eds.) (pp.231-245) *Disability and Human Rights: Global Perspectives*. London: Palgrave.
- McConkey, R., & Samadi, S. A. (2013). The impact of mutual support on Iranian parents of children with an autism spectrum disorder: a longitudinal study. *Disability and rehabilitation*, 35(9), 775-784.
- McConkey, R., Truesdale-Kennedy, M., Chang, M. Y., Jarrah, S., & Shukri, R. (2008). The impact on mothers of bringing up a child with intellectual disabilities: A cross-cultural study. *International Journal of Nursing Studies*, 45(1), 65-74.
- Meadan, H., & Daczewitz, M. E. (2015). Internet-based intervention training for parents of young children with disabilities: a promising service-delivery model. *Early child development and care*, 185(1), 155-169.
- Mickelson, K. D. (1997). Seeking social support: Parents in electronic support groups. *Culture of the Internet*, 157-178.
- Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis: An expanded sourcebook* (2nd ed.). Thousand Oaks, California, London: Sage.
- Ministry of Education (MOE) (1995). *A Report on Education for Individuals with*

- Disabilities*. Taipei: MOE.
- MoE (2014). *The Special Education Act*. Available at:  
<http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted> [Accessed: 8 January 2017].
- Ministry of Interior (MOI) (2017a). Family structure of persons with disabilities 2016.  
[https://www.gender ey.gov.tw/gecdb/Stat\\_Statistics\\_DetailData.aspx?sn=lDo2niJZ5VMnP2fDMqy24w%3d%3d](https://www.gender ey.gov.tw/gecdb/Stat_Statistics_DetailData.aspx?sn=lDo2niJZ5VMnP2fDMqy24w%3d%3d) [Accessed 06<sup>th</sup> May 2017]
- MOI (2017b) Population of persons with disabilities.  
[https://www.gender ey.gov.tw/gecdb/Stat\\_Statistics\\_DetailData.aspx?sn=SBhK1qUGuEFWBphB1qoGmg%3d%3d](https://www.gender ey.gov.tw/gecdb/Stat_Statistics_DetailData.aspx?sn=SBhK1qUGuEFWBphB1qoGmg%3d%3d) [Accessed 15<sup>th</sup> July 2017]
- MOI (2017c) Statistics of household numbers and structure.  
[https://www.gender ey.gov.tw/gecdb/Stat\\_Statistics\\_DetailData.aspx?sn=jIXIVtntjnJ2KvoqSnY0ig%3d%3d](https://www.gender ey.gov.tw/gecdb/Stat_Statistics_DetailData.aspx?sn=jIXIVtntjnJ2KvoqSnY0ig%3d%3d) [Accessed 06<sup>th</sup> May 2017]
- Ministry of Health and Welfare (MOHW) (2015). *People with Disabilities Rights Protection Act*. Taipei: MOHW.
- Mitra, A. (2005). Creating Immigrant Identities in Cybernetic Space: Examples From a Non-Resident Indian Website. *Media, Culture & Society*, 27(3), 371-390.
- Mittler, P. (2012). *Working towards inclusive education: Social contexts*. London: Routledge.
- Mittler, P. (2016) The UN Convention on the Rights of Persons with Disabilities: Implementing a Paradigm Shift. In Iriarte, E. G., McConkey, R. & Gilligan, R. H. (eds.) *Disability and Human Rights: Global Perspectives*.(pp.33-48) London: Palgrave
- Nadin, S., & Cassell, C. (2006). The use of a research diary as a tool for reflexive practice: Some reflections from management research. *Qualitative Research in Accounting & Management*, 3(3), 208-217.
- Nieuwboer, C. C., Fukkink, R. G., & Hermanns, J. M. (2013). Peer and professional parenting support on the Internet: a systematic review. *Cyber psychology, Behavior, and Social Networking*, 16(7), 518-528.
- Oakley, A. (1992). *Social support and motherhood: the natural history of a research project*. Oxford: Blackwell Publishers.
- Okolie, A. C. (2003). The appropriation of difference: State and the construction of ethnic identities in Nigeria. *Identity: An International Journal of Theory and Research*, 3(1), 67-92.
- Owen, H., & Dunmill, M. (2014). The long journey: Developing a model of professional learning and development for the future. *Australian Journal of Teacher Education*, 39(1), 117-136.

- Pain, H. (1999). Coping with a child with disabilities from the parents' perspective: the function of information. *Child: Care, health and development*, 25(4), 299-313.
- Petriwskyj, A., Franz, J., & Adkins, B. (2016). Parents, services and system: an exploration of power dynamics in future planning among parent carers for people with disability. *Disability & Society*, 31(8), 1081-1097.
- Plantin, L., & Daneback, K. (2009). Parenthood, information and support on the internet. A literature review of research on parents and professionals online. *Bio Mind Center: Family Practice*, 10(1), 34-46.
- Porter, C. E. (2004). A typology of virtual communities: A multi-disciplinary foundation for future research. *Journal of Computer-Mediated Communication*, 10(1), 00-11.
- Qiu, M. H., & Zhuang, M. C. (2013) A Content Analysis of Facebook Pages for Children with Disability. *Journal of Educational Media & Library Sciences*, 50(3), 355-392.
- Rafaeli, S., Ravid, G., & Soroka, V. (2004). *De-lurking in virtual communities: A social communication network approach to measuring the effects of social and cultural capital*. In Paper presented at the 34th Hawaii international conference on system sciences, Hawaii.
- Ridings, C., Gefen, D., & Arinze, B. (2006). Psychological barriers: Lurker and poster motivation and behavior in online communities. *Communications of the Association for Information Systems*, 18(1), 329-354.
- Riordan, M. A., Markman, K. M., & Stewart, C. O. (2013). Communication accommodation in instant messaging: An examination of temporal convergence. *Journal of Language and Social Psychology*, 32 (1), 84-95
- Robson, C. (2011). *Real world research* (3rd ed.). Chichester, UK: Wiley.
- Rogers, C. (2007). Disabling a family? Emotional dilemmas experienced in becoming a parent of a child with learning disabilities. *British Journal of Special Education*, 34(3), 136-143.
- Runswick-Cole, K. (2007). 'The Tribunal was the most stressful thing: more stressful than my son's diagnosis or behaviour': the experiences of families who go to the Special Educational Needs and Disability Tribunal (SENDiT). *Disability & Society*, 22(3), 315-328.
- Ryan, S., & Runswick-Cole, K. (2009). From advocate to activist? Mapping the experiences of mothers of children on the autism spectrum. *Journal of Applied Research in Intellectual Disabilities*, 22(1), 43-53.
- Sabatello, M. (2014). The New Diplomacy. In Sabatello, M. & Schulze, M. (eds.) *Human Rights and Disability Advocacy*. (pp. 239-258). Pennsylvania: University



- of Pennsylvania Press.
- Sarkadi, A., & Bremberg, S. (2005). Socially unbiased parenting support on the Internet: a cross-sectional study of users of a large Swedish parenting website. *Child: care, health and development*, 31(1), 43-52.
- Salamey, I (2015) Post-Arab Spring: changes and challenges, *Third World Quarterly*, 36(1), 111-129
- Samadi, S. A., McConkey, R., & Bunting, B. (2014). Parental wellbeing of iranian families with children who have developmental disabilities. *Research in Developmental Disabilities*, 35(7), 1639-1647.
- Scharer, K (2005) Internet social support for parents: the state of the science. *Journal of Child and Adolescent Psychiatry*, 18, 26-35.
- Schroeder, R., & Bailenson, J. (2008). Research uses of multi-user virtual environments. In *The SAGE Handbook of Online Research Methods*. (pp.327-342) Los Angeles: Sage Publications Inc.
- Scott, J. (2017). *Social network analysis 4<sup>th</sup> edition*. London: SAGE.
- Sekar, S., & Sudhira, H. S. (2017). Using social media for research and reaching out. *Bridging the communication gap in science and technology: Lessons from india*, 231-239
- Shakespeare, T. (1998). Choices and rights: eugenics, genetics and disability equality. *Disability & Society*, 13(5), 665-681.
- Shapka, J. D., & Law, D. M. (2013). Does one size fit all? Ethnic differences in parenting behaviors and motivations for adolescent engagement in cyberbullying. *Journal of youth and adolescence*, 42(5), 723.
- Siddiquee, A., & Kagan, C. (2006). The internet, empowerment, and identity: an exploration of participation by refugee women in a Community Internet Project (CIP) in the United Kingdom (UK). *Journal of Community & Applied Social Psychology*, 16(3), 189-206.
- Spradley, J. (1979). *The ethnographic interview*. New York: Holt, Rinehart & Winston.
- Stake, R. (2005). Qualitative case studies. In N. K. Denzin & Y. S. Lincoln (Eds.), *The SAGE handbook of qualitative research* (3rd ed.) (pp. 443-466). Thousand Oaks, CA: Sage.
- Stelma, J., Fay, R., & Zhou, X. (2013). Developing intentionality and researching multilingually: An ecological and methodological perspective. *International Journal of Applied Linguistics*, 23(3), 300-315.
- Shyu Y. I., Tsai J. L. & Tsai W. C. (2010) Explaining and selecting treatments for

## Reference

- autism: parental explanatory models in Taiwan. *Journal of Autism and Developmental Disorders* 40, 1323–1331.
- Taiwan Network Information Centre (TWNIC) (2016) Broadband Internet Usage Survey. Available at: <http://www.twNIC.net.tw/survey.xls> [Accessed 24th February 2017]
- Tataryn, M. (2014). My ‘disability and development’ journey: reflections, *Disability and the Global South*, 1(1), 153-160.
- Tesch, R. (1990). *Qualitative research: Analysis Types and Software Tools*. New York: Falmer.
- The Liberty Time (2015). Tired of taking care of the son with cerebral palsy? A father strangled his son and cried in the police officer’s arms. *The Liberty Time*, Available at <http://news.ltn.com.tw/news/society/breakingnews/1264777> [Accessed 04 April 2015]
- Todd, L. (2003). Disability and the restructuring of welfare: The problem of partnership with parents. *International Journal of Inclusive Education*, 7(3), 281-296.
- Todd, L. (2007). *Partnerships for Inclusive Education: A critical approach to collaborative working*. London: Routledge.
- Traustadottir, R. (1991) Mothers who care: gender disability and family life. *Journal of Family Issues* 12, 211–228.
- Tremblay R. E.,(2015) Parenting Skills. In Tremblay R. E., Boivin, M., & Peters R. D., (eds.) *Encyclopedia on Early Childhood Development*. Available at: <http://www.child-encyclopedia.com/parenting-skills/synthesis>. Updated September 2015. [Accessed on 29 August, 2017]
- Tseng, Y.P.(2016) *The Development of Self-help Group for Parents of Children with Development Delays*. Master Dissertation. National Taichung University of Education. (In Chinese)
- Tsai, I. L., & Ho, M. S. (2010). An institutionalist explanation of the evolution of Taiwan’s disability movement: From the charity model to the social model. *Journal of Current Chinese Affairs*, 39(3), 87-123.
- Tsai, P. C. (2015) Could I Kill You? Mr. Ho Killed His Son with Cerebral Palsy After Being Exhausted of Taking Care of His Son. *Central News Agency*, Available at: <http://www.cna.com.tw/news/asoc/201509020206-1.aspx> [Accessed 03rd June 2015]
- Tsai, W.-C., Tsai, J.-L., & Shyu, Y.-I.L. (2008). Integrating the nurturer-trainer roles: Parental and behavior/symptom management processes for mothers of children with autism. *Social Science & Medicine*, 67, 1798-1806.

## Reference

- United Nations (UN) (1994) *The Standard Rules on the Equalisation of Opportunities for Persons with Disabilities*. New York: UN.
- United Nations Educational, Scientific and Cultural Organization (UNESCO) (1994). *The Salamanca statement and framework for action on special needs education*. Adopted by the world conference on special needs education: Access and equity. Paris: UNESCO.
- UNICEF (2010) *Advocacy Toolkit: A Guide to Influencing Decisions that Improve Children's Lives*. [Available at: [http://www.unicef.org/evaluation/files/Advocacy\\_Toolkit.pdf](http://www.unicef.org/evaluation/files/Advocacy_Toolkit.pdf)]
- Wakeford, N., & Cohen, K. (2008). Fieldnotes in public: using blogs for research. *The Sage handbook of online research methods*, 307-326. Sage: London.
- Walther, J. B. (2007). Selective self-presentation in computer-mediated communication: Hyperpersonal dimensions of technology, language, and cognition. *Computers in Human Behaviour*, 23, 2538–2557.
- Walther, J. B. (2011). Theories of computer-mediated communication and interpersonal relations. *The handbook of interpersonal communication*, 4, 443-479.
- Walther, J. B., Van Der Heide, B., Kim, S. Y., Westerman, D., & Tong, S. T. (2008). The role of friends' appearance and behaviour on evaluations of individuals on Facebook: Are we known by the company we keep?. *Human communication research*, 34(1), 28-49.
- Wang, K. Y. (2012). The care burden of families with members having intellectual and developmental disorder: a review of the recent literature. *Current opinion in psychiatry*, 25(5), 348-352.
- Wang, S.F (2008) *The Influence on the Parental Function of Developmental Delay Children's Parents in the Parent-Child Group*, Master Dissertation, National Taichung University of Education. (In Chinese)
- Wang, W. L. (2016) 'Don't use LINE as communication book.' *Parenting. CommonWealth*:<https://parentingcw.tumblr.com/post/149501174198/%E5%88%A5%E6%8A%8Aline%E7%BE%A4%E7%B5%84%E7%95%B6%E8%81%AF%E7%B5%A1%E7%B0%BF> [accessed 11 December 2016] (In Chinese)
- Warnock Report. (1978). *Special Educational Needs*, London: HMSO.
- Wasserman, S., & Faust, K. (1994). *Social network analysis: Methods and applications* (Vol. 8). Cambridge university press.
- Wellman, B. (2002). Little boxes, glocalization, and networked individualism. In Tanabe, M., van den Besselaar, P., & Ishida, T. (Eds.), *Digital cities II: Computational and sociological approaches* (pp. 10–25). Berlin: Springer-Verlag.

- Whittingham, K., Boyd, R. N., Sanders, M. R., & Colditz, P. (2014). Parenting and prematurity: Understanding parent experience and preferences for support. *Journal of Child and Family Studies*, 23(6), 1050.
- Wickenden, M., & Elphick, J. (2016). Don't forget us, we are here too! Listening to disabled children and their families living in poverty. In *Disability in the Global South* (pp. 167-185). Springer International Publishing.
- Wilson, R. E., Gosling, S. D., & Graham, L. T. (2012). A review of Facebook research in the social sciences. *Perspectives on psychological science*, 7(3), 203-220.
- Wolfendale, S. (1992). Empowering parents and teachers: working for children. London: Cassell.
- Wolfendale, S. (2013). Parents as key determinants in planning and delivering parenting education and support programme: an inclusive ideology. In Wolfendale, S., & Einzig, H. (eds.). *Parenting education and support: new opportunities*. (pp. 48-58). London: Routledge.
- Wong, H. S. W., Li, S. L., Fu, K., Tinsley, H., Chow, C., & Ip, P. (2015). The Importance of Online Resources for Parents of Children with Special Needs in Hong Kong: South China's Experience. *Journal of Health & Medical Informatics*, 6(192), 1-9.
- Wright, K., Golder, S., & Rodriguez-Lopez, R. (2014). Citation searching: a systematic review case study of multiple risk behaviour interventions. *BMC medical research methodology*, 14(1), 73-81.
- Wu, W. (2014) An Overview of Special Education in Taiwan (III): Challenges and Perspectives. *Special Education*, 132(1), 1-8. (In Chinese)
- Wu, Z. H. (2012) *Research of Sensationalism of Newspapers in Taiwan*. Master Dissertation. National Chengchi University.
- Yin, R. K. (2003). *Case study research, design and methods* (3rd ed.) Newbury Park: Sage Publications.
- Yin, R. K. (2009). *Case study research* (4th ed.). London: Sage Publications.
- Yu, C. P., Luo, Q. S., Lin, Y. G., & Wang, C. S. (2013). A Study of Inclusive Educational Policy in Taiwan. *Educational Policy Forum*, 16(2), 115-144. (in Chinese)
- Yu, T. H., & Wen, W. C. (2003). Crisis communication in Chinese culture: A case study in Taiwan. *Asian Journal of Communication*, 13(2), 50-64.
- Zand, D., Pierce, K., Thomson, N., Baig, M. W., Teodorescu, C., Nibras, S., & Maxim, R. (2014). Social Competence in Infants and Toddlers with Special

## Reference

- Health Care Needs: The Roles of Parental Knowledge, Expectations, Attunement, and Attitudes toward Child Independence. *Children*, 1(1), 5-20.
- Zickuhr, K., & Smith, A. (2012). *Digital Differences. Internet and AmericanLife Project*. <http://pewInternet.org/Reports/2012/Digital-differences.aspx>. Retrieved 26.04.12. [accessed 11 July 2014]
- Zong, U. (2016) Facebook global active users reached 1.65 billion. Taiwan 18 million. *The Epoch Times*. Available at: <http://www.epochtimes.com/b5/16/7/19/n8115301.htm> [accessed 30th June 2017]
- Zukhi, M. Z. B. M., Hussain, A., & Husni, H. (2017). A new model for cultural-based emoticon in distributed collective interaction via CMC. *Journal of Telecommunication, Electronic and Computer Engineering*, 9(2-12), 19-23.

## Appendix 1 Interview Schedules

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### 1. For parents

#### **Part 1: Basic information for internet usage:**

1. How often do you use internet for parenting purpose (hours a day/ week)? (How often do you view the information on the SNS pages for parents of children with SEN? How often do you use the internet to search for parenting knowledge? etc.)
2. What sort of activities you do on SNSs for parental purpose? (Do you look up for parenting information? Do you message other parents? Do you visit schools or teachers' SNS pages through internet in order to learn more about your children's learning? )

#### **Part 2: Further information of internet usage (continue from Part 1):**

(Experience of using SNS-based support for receiving or providing the three types of support)

1. Could you tell me about last time when you went online for parental support and the most useful thing within this experience? Is it typical?

\*\*Based on the experience of the types of support (emotional, informational, advocacy or others) the participant shared in the interview, follow up questions about the type of support.

- Why do you find it useful to share your parenting experience/ emotion/ advocacy activity information/ medical knowledge/ parenting knowledge in this experience?

or

- Could you tell me more about how you share your parenting experience/ emotion/ advocacy activity information/ medical knowledge/ parenting knowledge with other parents?

\*\* Follow up with other types of support that was not mentioned in the experience.

- If you have a chance to do so, will you find other parents or yourself sharing parenting experience/ emotion/ advocacy activity information/ medical knowledge/ parenting knowledge (only mention the types that wasn't mentioned in the interview) helpful? Why will you find it also being useful?
2. Is there a time when you found SNS unhelpful, and again, why was it not helpful to you? Why? Tell me about one of those experiences? Is it typical?

**Part 3: Information related to their expectation and relation with professionals:**

1. When is last time you interact with a professional (by professional I mean the page admin, teacher, social worker, doctors, etc. ) on the SNS page? Could you tell me about the experience? How do you think about this experience?

**\*\*Based on the experience of the types of support (emotional, informational, advocacy or others) the participant shared, follow up questions about the type of support.**

- Why do you find it helpful/ not helpful to interact/ discuss with a professional on the SNS pages about your parenting experience/ emotion/ advocacy activity information/ medical knowledge/ parenting knowledge?

**\*\* Follow up with other types of support that was not mentioned in the experience.**

- How about your experience sharing/ discussing your parenting experience/ emotion/ advocacy activity information/ medical knowledge/ parenting knowledge (only mention the types that wasn't mentioned in the interview) with a professionals on the SNS page?
- If you haven't have any of the experience in doing so, will you interact with a professional on SNS in the future? Why?

2. If you have a chance to change the interaction between you and the professionals on SNS pages, how will you change the way you interact?

**\*\* This question is about the expectation of the interaction between parents and professionals among the participants.**

## **2. For professionals**

### **Part 1: Basic information for internet usage:**

1. How often do you use internet for parental web-site management purpose (hours a day/ week) For example, how often do you post on the parental SNS? How often check and reply the comments?
2. How do you support parents through SNS? By supporting other parents, I meant actions such as sharing useful information to parents, commenting positively and supportively on posts which parents posted within the website, using chat room or sending private message to encourage the parents, etc.
3. What kind of parenting knowledge do you often shared for?
4. What is the purpose of this discussion group?

### **Part 2: Further information of internet usage (continue from Part 1):**

(Experience of using SNS-based support for receiving or providing the three types of support)

1. Could you tell me about last time when you successfully provided support/ or interacted with parents with children with SEN through SNS and the most useful thing within this experience? Is it typical?

**\*\*Based on the experience of the types of support (emotional, informational, advocacy or others) the participant shared in the interview, follow up questions about the type of support.**

- Why do you find it useful to provide support about parenting experience/ emotion/ advocacy activity information/ medical knowledge/ parenting knowledge in this experience?

or

- Could you tell me more about how you share parenting experience/ emotion/ advocacy activity information/ medical knowledge/ parenting knowledge with the parents?

**\*\* Follow up with other types of support that was not mentioned in the experience.**

- If you have a chance to do so, will you provide support about parenting experience/ emotion/ advocacy activity information/ medical knowledge/ parenting knowledge (only mention the types that wasn't mentioned in the interview)? Why and why not?
2. If you have a chance to change the interaction between you and the parents on SNS pages, how will you change the way you interact?



## Appendix 1

**\*\* This question is about the expectation of the interaction between parents and professionals among the participants.**

## Appendix 2. Information Sheet and Consent Form

---

### ***The Role of Social Network Sites (SNSs) in Providing Support for Parents of Children with Special Educational Needs (SEN) in Taiwan***

#### **Participant Information Sheet**

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

#### **Who will conduct the research?**

*I-Jung, Lu*

*Manchester Institute of Education (MIE), School of Environment, Education and Development, Ellen Wilkinson Building,  
The University of Manchester, Oxford Road  
Manchester, M13 9PL*

#### **Title of the Research**

*The Role of Social Network Sites (SNSs) in Providing Support for Parents of Children with Special Educational Needs (SEN) in Taiwan*

#### **What is the aim of the research?**

*The Study focuses on understanding the interaction of parents on SNSs for providing and receiving parents' support, the parents' reasons of using SNSs for support and the impact of SNSs on power relations between this group of parents and professionals.*

#### **Why have I been chosen?**

*You are chosen by your role as professionals who use social network site to support parents of children with SEN in Taiwan. You are regard as the representative of the professionals in this area.*

#### **What would I be asked to do if I took part?**

*You will be asked to conduct one face-to-face or Skype interview.*

#### **What happens to the data collected?**

*The data will be analyzed and used in the research to understand idea of parental support on SNS and internet.*

## Appendix 2

**How is confidentiality maintained?**

*All participants will be anonymous within the research, and audio record will be stored safely in my personal computer. The audio record will be destroyed if required after the research. If there is no requirement of destroying the audio record, it will be kept in my personal computer safely.*

**What happens if I do not want to take part or if I change my mind?**

*It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason.*

**Will I be paid for participating in the research?**

*No, you will not be paid.*

**What is the duration of the research?**

*one 1 hour interviews*

**Where will the research be conducted?**

*Public space in Taouyan, Taipei of Taiwan.*

**Will the outcomes of the research be published?**

*Yes, it will be published in my PhD thesis and other potential publications, such as academic journals.*

**Contact for further information**

*Email: [i-jung.lu@postgrad.manchester.ac.uk](mailto:i-jung.lu@postgrad.manchester.ac.uk)*

**What if something goes wrong?**

*Contact: Prof. Alan Dyson [[D.A.Dyson@manchester.ac.uk](mailto:D.A.Dyson@manchester.ac.uk)]*

*If there are any issues regarding this research that you would prefer not to discuss with members of the research team, please contact the Research Practice and Governance Co-ordinator by either writing to 'The Research Practice and Governance Co-ordinator, Research Office, Christie Building, The University of Manchester, Oxford Road, Manchester M13 9PL', by emailing: [Research-Governance@manchester.ac.uk](mailto:Research-Governance@manchester.ac.uk), or by telephoning 0161 275 7583 or 275 8093*

***The Role of Social Network Sites (SNSs) in Providing Support for  
Parents of Children with Special Educational Needs (SEN) in Taiwan***

**CONSENT FORM**

If you are happy to participate please complete and sign the consent form below

- |   | <b>Please<br/>Initial<br/>Box</b> |
|---|-----------------------------------|
| 1. I confirm that I have read the attached information sheet on the above study and have had the opportunity to consider the information and ask questions and had these answered satisfactorily. | <input type="text"/>              |
| 2. I understand that my participation in the study is voluntary and that I am free to withdraw at any time without giving a reason.   | <input type="text"/>              |
| 3. I understand that the interviews will be audio/video-recorded  | <input type="text"/>              |
| 4. I agree to the use of anonymous quotes   | <input type="text"/>              |
| 5. I agree that any data collected may be passed to other researchers   | <input type="text"/>              |
| 6. I agree that any data collected may be published in anonymous form in academic books or journals.  | <input type="text"/>              |

I agree to take part in the above project

_____	_____	_____
Name of participant	Date	Signature
_____	_____	_____
Name of person taking consent	Date	Signature
_____	_____	_____

## Appendix 3. Basic Settings of Facebook

---

The following section of this appendix will introduce the environment, Facebook, which is used to collect the data. These platforms of Facebook include Profile, Page, Groups, and the instant messaging function of Facebook. A virtual community called Facebook Sports, which includes Mark Zuckerberg, a public figure and also the founder of Facebook, as a member, will be used as the example in the following section to help introduce to the layout of a virtual community on Facebook.

### *Profile*

Before introducing the Facebook Sports community, I will introduce the settings and function of a Profile page, which is the most basic unit of Facebook and also a virtual community. All members of the virtual community own a Profile page which represents their identity and shares their personal information, such as their name, their photos and other information. Facebook users can share information with other users through posting information on their Profile page. They could also collect information through forwarding the post in another platform to their Profile page. The Profile page is similar to the 'home' of an individual in the traditional community.

The basic structure of a Profile page on Facebook is similar to the Profile page in other social network sites: the basic information of the page owner, the platform where they shared the information and interacts with other users, and a list of other users who have a connection with them on the internet. Figure A1. shows the Profile page of Mark Zuckerberg.

As can be seen in Figure A1., the introduction of Mark Zuckerberg is shown in the 'Intro' section on the left of the page. The Intro shows what the main focus is on his page and his personal information. In the middle of the Profile page shows the 'Timeline', which shows what the owner of the page posted in the past. The Timeline is the centre the Profile page where most of the interaction happens, including the receiving the comments and Likes given by Friends of the user and seeing how many of the posts were Shared by Friends. The owner of the page could also reply and click Like (the red circle) to the comments he or she received from others. For example in

### Appendix 3

Figure A1., Zuckerberg shared a post on 29<sup>th</sup> June 2017 about the speech he gave at the Harvard Commencement.

The image is a screenshot of Mark Zuckerberg's Facebook profile page. At the top, there's a cover photo featuring a blue world map with a network overlay. Below it is the profile picture of Mark Zuckerberg. The name 'Mark Zuckerberg' is displayed with a verified badge. Navigation tabs for 'Timeline', 'About', 'Friends', 'Photos', and 'More' are visible. A 'Follow' button and a 'Message' button are also present. Below the navigation tabs, a message says 'Follow Mark to get his public posts in your News Feed.' with a 'Follow' button. The 'About' section on the left lists his roles: 'Founder and CEO at Facebook', 'Works at Chan Zuckerberg Initiative', 'Studied Computer Science at Harvard University', 'Lives in Palo Alto, California', 'Married to Priscilla Chan', 'From Dobbs Ferry, New York', and 'Followed by 92,520,915 people'. The 'Photos' section shows a grid of images, including several of Mark Zuckerberg. The main post is dated '29 June at 16:14'. The text of the post reads: 'At Harvard Commencement, I shared the story of a young man I mentor whose parents brought him to America at a young age. He wasn't sure he'd get to go to college because he's undocumented. He wasn't sure they'd let him in, or that he could afford to go. Priscilla and I are providing 400 college scholarships to Dreamers in partnership with TheDream.US. This fall, 139 new scholars will be heading to colleges across the Bay Area. And we'll keep working to improve education and build stronger communities for everyone. We need a government that protects Dreamers. But for now, Priscilla and I hope these scholarships will help more young people pursue their purpose, contribute to society, and make our country stronger for all of us.' Below the text is a video of Mark Zuckerberg speaking at a podium. The post has '1.3M Views' and interaction buttons for 'Like', 'Comment', and 'Share'. The 'Like' button is circled in red, and the 'Share' button is circled in blue. Below the interaction buttons, it says 'Who liked this: 1.3M and 130k others'. The '8,603 shares' section shows a comment from 'Lumi lo Gardner' dated 'Yesterday at 01:19' with 580 likes.

Figure A1. Layout of a Profile

## Appendix 3

Under the content of the post shows '130k', which means 130 thousand others Like this post. The blue circle shows the Share icon. Under the Show icon shows '8,603 Shares', meaning 8,603 users clicked the Share icon and shared this post to their own virtual community. And finally under the number of Shares, is the comment made by other users on the content of the post. Under the first comment made by Lumi lo Gardner (see Figure A1.), 580 users clicked Like to the comment to provide their support or agreement.

The 'About' section of the Profile page (see Figure A1.) which the link is shown on the top of the page next to Timeline, is a similar section as 'Intro' section that introduced the owner of the page. Figure A2. showed the information which is shared in the About section. For example, it shows detailed information such as the places Mark Zuckerberg lived.



Figure A2. The About Section of a Profile page

Back to Figure A1., in the Profile page, on the top of the page showed the 'Photo' icon. It is a link to all the photos the owner of the page posted to his or her Profile page. It is also displayed under the 'Infor' section as can be seen in Figure A1. And



next to 'Photo' is the 'More' icon, which includes more links to other function of the Profile page, such as the link to the Note page, where the page owner write notes or articles he or she wants to share with all the Friends on Facebook. The profile photo of the person who owns the page, in this example the photo of Mark, is shown in the top left of the page (see Figure A1.) and a cover photo of the Profile, which most of the time are the decoration picture of the page, is shown on the top of the page (see Figure A1.).

The icon 'Friends' at the top of the Profile page of Mark Zuckerberg (Figure A1.) is the link to his list of Friends, who followed Mark Zuckerberg and have access to most of his information in his private spaces on Facebook. Through the list of Friends, you can contact the people who were listed on the Friend section directly through the instant messaging function shown at the right-hand side of the name (see Figure A3.).



Figure A3. The list of Friends on a Profile page

For general Facebook users, the left-hand side of the top of the Profile page is the 'Add Friend' icon and 'Message' icon where the other Facebook users could add the owners as friends or send private messages to the owners (see Figure A4.). However if the page owner is a public figure like Zuckerberg, or if the page owner represents a



company or organisation, then the 'Add Friend' and 'Message' icons will be replaced by 'Follow'.



Figure A4. Add Friend icon and Message icon on a Profile page

Besides the action of Like, there is also action of Tag (see Figure A5.). Tag is a action when a user typed in the name of another user and linked the name with the website or Profile of the users. The other users who read the name could then clicked directly on the name and be connect to the website of the person.

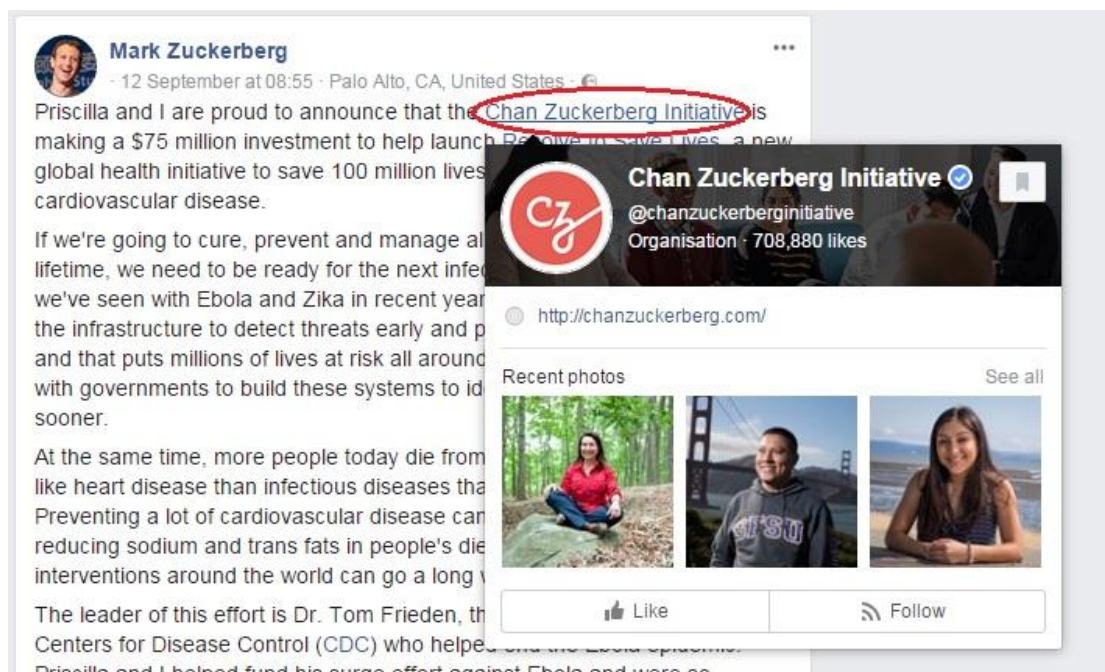


Figure A5. The function of Tag

For example, in Mark Zuckerberg's post, he linked the name Chan Zuckerberg Initiative to the website of the organisation. So when users saw his post, they could click on the name directly and linked to the Page of Chan Zuckerberg Initiative. However, since the process of Tagging other are more complicated than Like or Share, parental users were found to be less likely to use this function in the study.

## Page

After introducing the Profile page, I will introduce Page, which is the first platform of a virtual community on Facebook. The settings and function of Page were similar to a Profile page except for the privacy settings of Page were always public (See Figure A6. for the layout of a Page).

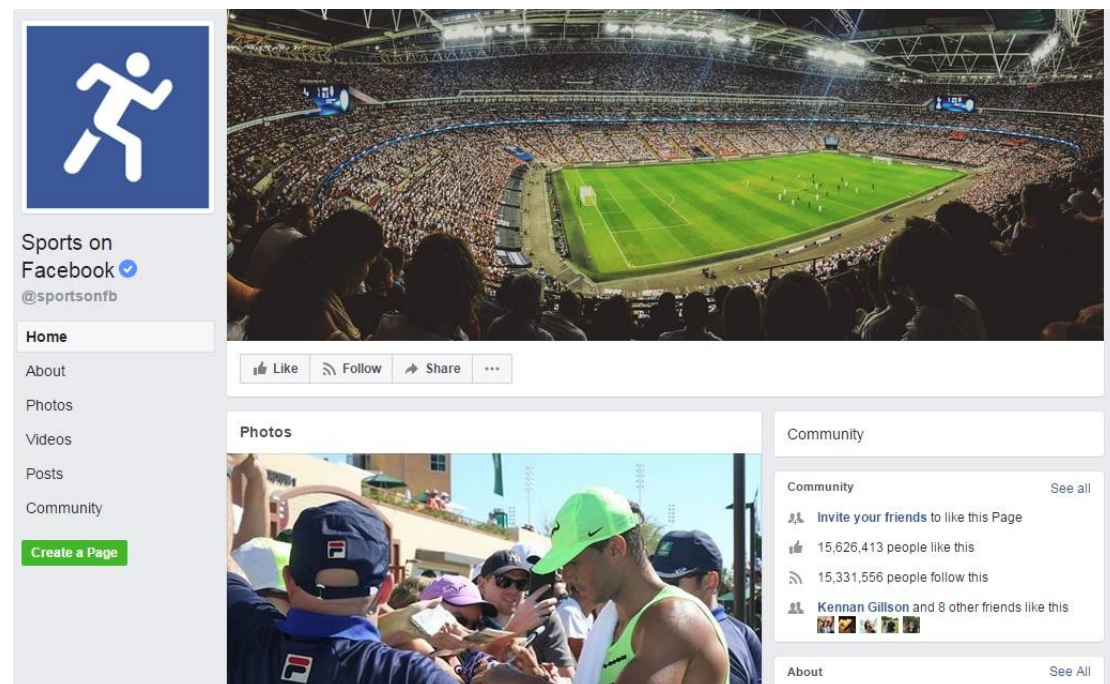


Figure A6. The layout of a Page

Facebook users do not need permission to access the information on a Page and only needs to 'Follow' or 'Like' the page to keep track on the information shared by the Page administrator, who organises the Page for an organisation or company that owns the Page (Facebook, 2017c). Facebook users can also see the number of Likes the Page received from the users and the lists of names and links to the users who Liked the page. If a Page is with a higher number of Likes, it tends to become more popular and attracts more users. Users who Liked the page also tend to comment and interact with other users through the Page if it is popular.

## Group

Most of the time the About section will introduce its Groups of the community which Facebook users who are interested in the Page could join. For example, under the

Page of Facebook Sport, a Closed Group named 'Facebook Sports Debate' was identified. (See Figure A7.)

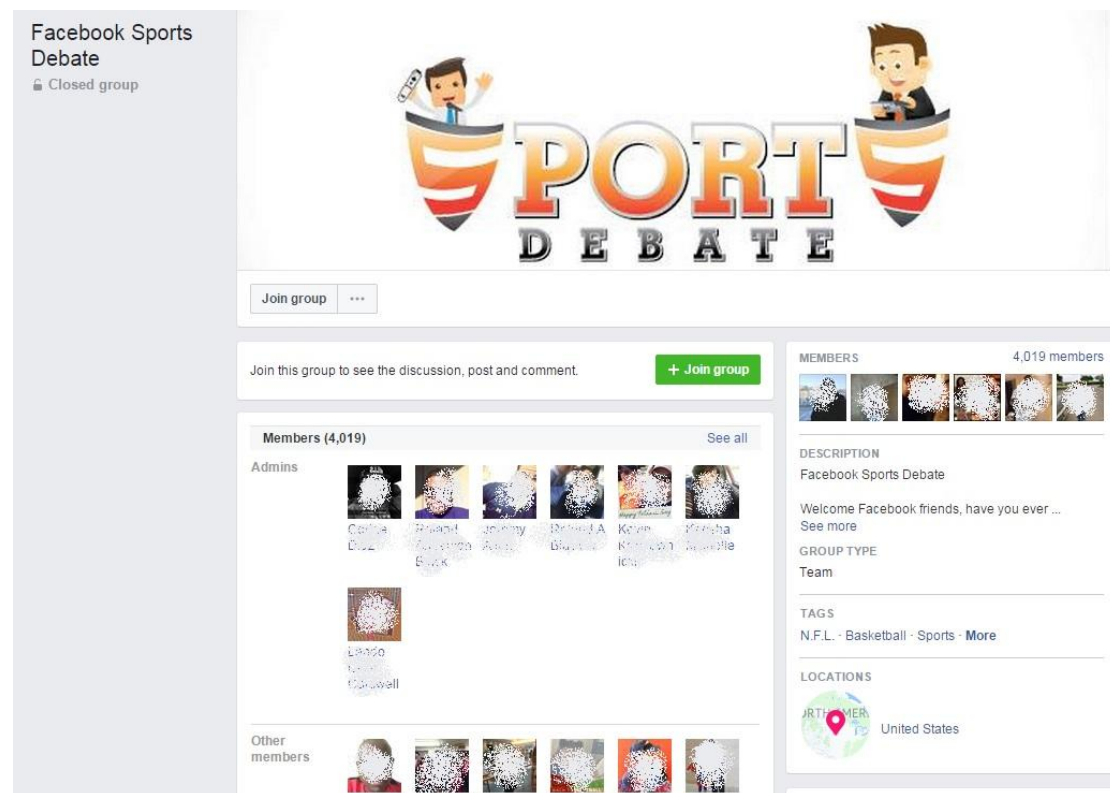


Figure A7. The layout of a private Group

A Group is a unique platform of Facebook. Different from Profile page or Page, which only allows the page administrators or owner to post and edit information on the Timeline, Group allows all members in the Group to post information, photo, video, and even create a poll for voting on its Timeline (Facebook, 2017c). A Group gives members of the virtual communities more authorities to discuss and debate issues. Since this is a private Group, members of the virtual community, in this example the Facebook Sports community, need to ask for permission to join the Group through clicking the 'Join Group' on the top middle of the Timeline. Before joining the private Group, the member can see the list of administrators and members who are already in the Group (see Figure A7.). Users can also see the short introduction in the 'Description' section of the Group which is shown on the right-hand side of Figure A7.

Privacy setting of Group on Facebook divided into three types, including public Group, closed Group, secret Group. Public Group is a Group which all Facebook users could access the information within. However, only members, who have admission to join the Group can post information and comments on the posts within the public Group (Facebook, 2015). As for closed Group, users who did not join the Group cannot see any of the information posted in the Group. They could only review the title, the introduction and description of the Group, and the member list of the Group (as shown in Figure A7.). Finally, for secret Group, users who are not invited to the Group cannot notice the existence of the Group. It is completely private and only users who are invited by the administrator or other members of the Group are allowed to join. In this research, both closed Group and secret Group were considered as private Groups.

Since all of the Groups under the Facebook Sports community were private Groups, in the following section I use a public Group Mark Zuckerberg created to introduce the layout of a public Group (see Figure A7.).

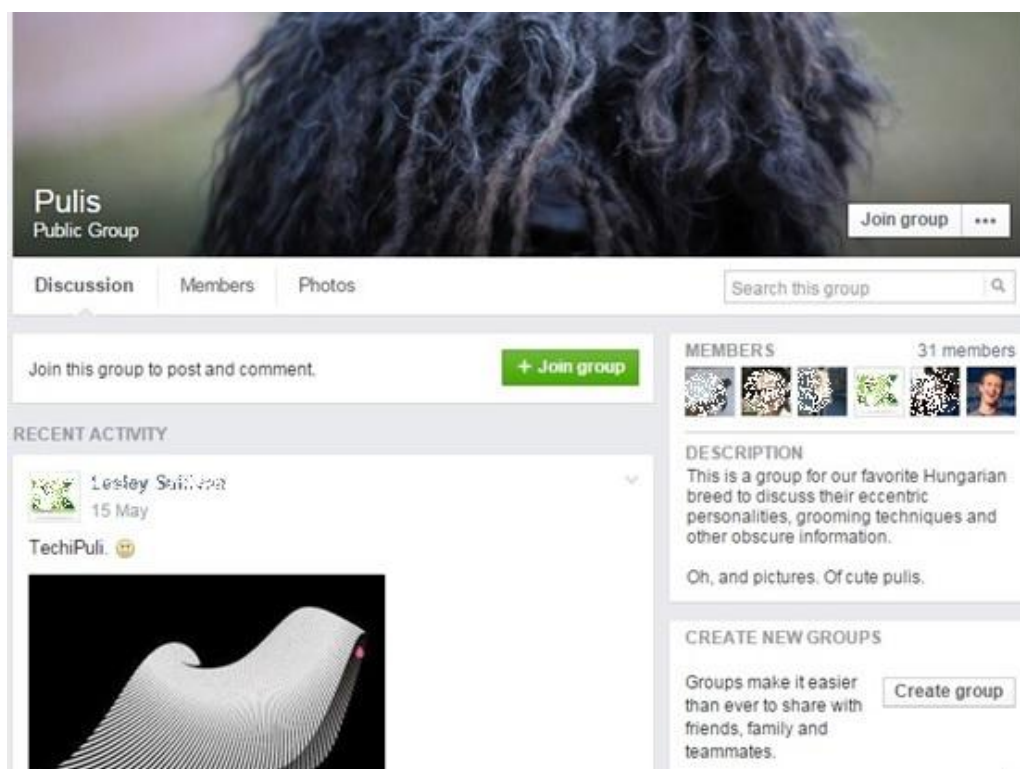


Figure A8. The layout of a Group

On the top of Group is also a cover photo, similar to the one in the Profile page. The title of the Group will be shown on the top of the Group. The title mainly shows the main purpose of the Group, for example, Figure A8. is a group of people who love Pulis dogs, so the title of the Group is Pulis. Under the title is the privacy setting status showing that the Group is 'Public' (see Figure A8.). Posts in Groups are similar to post on other platforms such as Page. For example, a member of the Group shared a photo of a Tech iPuli in the Group. Other members of the Group then replied through commenting on the post or clicked Like to the photo.

### *Message*

Finally, Message is an instant messaging tool inserted in all platforms of Facebook. Facebook users can contact other users by sending private messages through Message. The interactions between the users in Message are completely private, no other users can join the discussion unless the users are invited. The Message platform contains a dialogue box where users could type the message they want to send to the other users in the chat. The Message will then send a notification instantly to the users who are invited to the chat. The other users can then reply the message by typing in the same dialogue box. All conversation will be saved and displayed on the platform (see Figure A9.). Message and Secret Group are the two most private Facebook platforms comparing to the other platforms mentioned above.



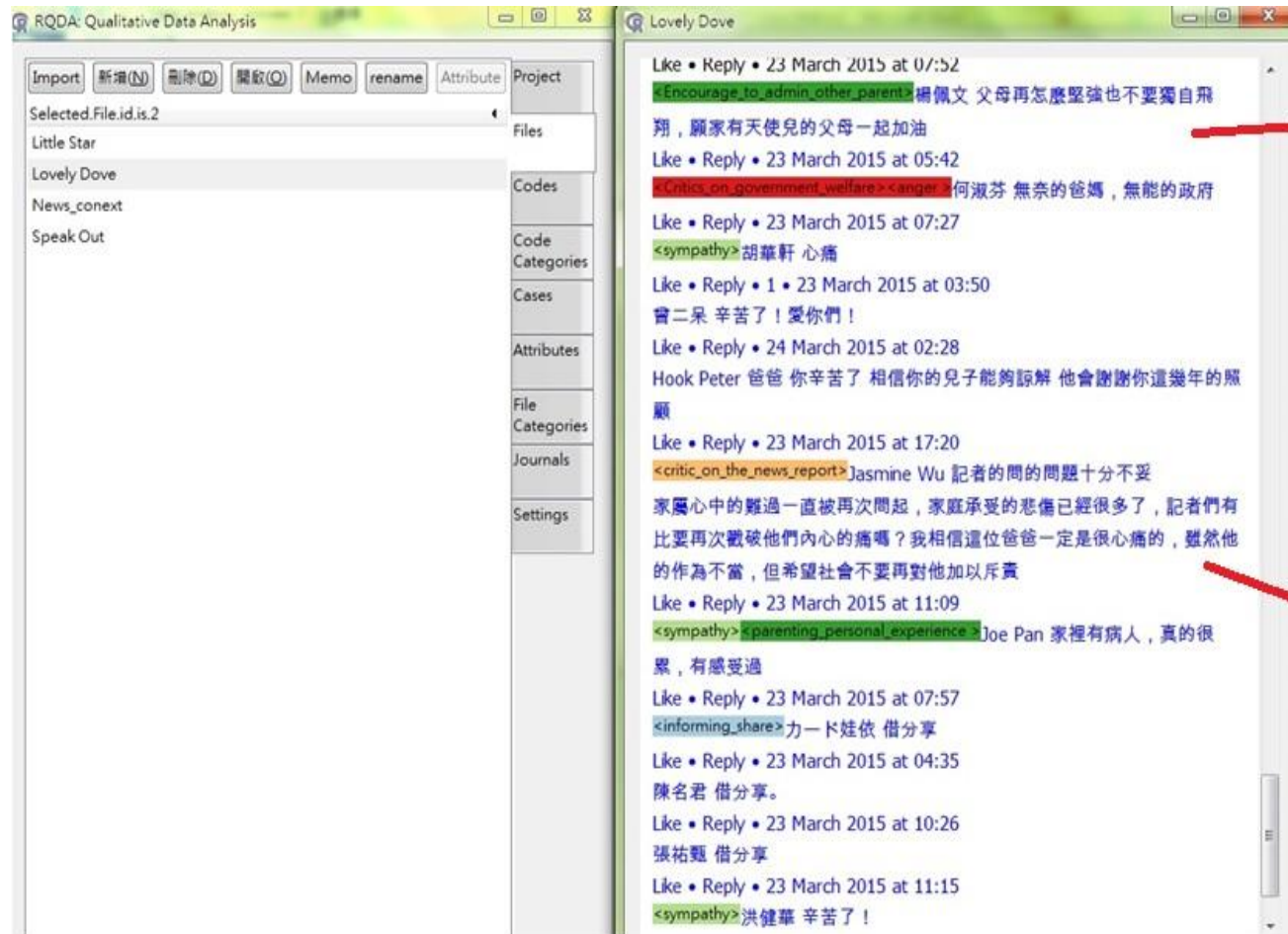


Figure A9. The layout of a Message platform in 2016

Even though Facebook users could use Message to contact more than one users, the function of Message is often used as one-to-one contact and communication. For example, when a parent hopes to contact the professional directly from Facebook, they could send a Message directly to the professional in private.

## Appendix 4 RQDA data collection and analysis process

Examples of platforms of RQDA.



## Appendix 4

**RQDA: Qualitative Data Analysis**

加入(A) 刪除(D) rename Memo

Anno Coding Unmark Mark

Selected.code.id.is.37\_1.codings

- Advo\_Diary\_Awareness
- Advo\_Educational\_Needs
- Advo\_having\_Face
- Em
- Em\_Encouragement
- Emo\_Offering\_Care\_Comfort
- Emo\_Relax\_entertainment
- Emo\_Solidarity
- Info\_Educational\_Placement**
  - Info\_child\_development
  - Info\_Communicating\_with\_teachers
  - Info\_Educational\_placement
  - Info\_Emo\_Entertainment
  - Info\_Formal\_Medical
  - Info\_informal\_medical
  - Info\_parenting skill
  - Info\_raising\_children\_and\_siblings
  - Info\_School\_life\_and\_activities
  - Info\_Welfare
- Tragic\_Advocacy
- Tragic\_emotional\_support
- Tragic\_Info
- Ways\_of\_Interaction

**Category**

**Sub-category**

**135 Retrieved codings: "Info\_parenting skill" from 25 files**

**IN\_MFp [1325:1445]Back**  
( 會有孩子的狀況和問題用FB聯絡嗎? )  
會, 因為如果說狀況蠻嚴重, 當自己沒有辦法掌控的時候, 我就會PO上去和社團聊, 那社團的有些家長可能也有這樣的經驗發生, 所以他就會去告訴我們。那我們就會去思考, 如果是我的話我會去怎麼處理。社工人員比較少。

**IN\_MFp [579:695]Back**  
( 那在那些與孩子相關的社團媽媽的互動通常是什麼? )  
通常我都是閱讀, 然後如果他有ADHD, 然後那個經驗相似的我就會回覆, 我就會分享說, 我如果以我的小朋友這樣, 我會怎麼做? 然後去看一下人家怎麼回應, 如果我是他們我也會想像一下我會怎麼做

**IN\_MFp [767:858]Back**  
都會回覆啦, 不過也會先觀看, 如果是說我家小朋友沒有這種狀況的話我也不會去回覆, 因為不敢有意見, 因為怕亂了他們的陣腳, 反正就是觀看這樣。如果是遇到跟我的小朋友有關的經驗, 我就會留言。

**IN\_MHp [316:523]Back**  
(也是幫助其他家長, 那您有跟其他家長透過這個去溝通嗎?)  
MHP: 之前有, 但是我後來發現, 因為你在分享的時候, 因為每個家長他看的, 切入的角度不同, 然後我會去看, 然後有些小孩他的分享, 是針對特殊孩子的該怎麼辦的時候, 我有時候會想回, 但是我如果看到有些人回覆的想法跟我一致的時候, 我就不再回了,

(所以你有會讀其他家長的回覆? 所以你會在你認同的家長回覆下按讚嗎?)  
MHP: 會,

**IN\_MHp [526:621]Back**  
加甲你覺得你可以幫忙的呢?

(Will you need to use Facebook to contact the professionals or other parents?)

Yes, if the situation is bad. When I cannot control the situation I will post my concern in our Group. Because other parents might have similar experience as mine. So they will tell me. We will think about their suggestions and solve the issue. Since there is not enough social workers.

(so you want to help other parents, did you also communicate with other parents through the community?)

I did. But I realised that when you share stuff in the Group, other parents will read it, and their interpretation will be different. So I will read about their children's situation, especially when they mentioned about their special needs. I will reply their questions, but if someone did it before me, I won't reply again.



## Appendix 4

The screenshot shows a qualitative data analysis software interface. On the left, there is a sidebar with a list of themes. The theme 'Info\_parenting skill' is highlighted in blue. The main area displays three text excerpts in Chinese, each with a red bracket indicating a specific theme. The excerpts are labeled with IDs like IN\_FNp [1099:1253] and IN\_FNp [1860:1931].

**Themes**

- Educational\_Provisions
- Face
- Leisure
- Medical\_Resource
- Parenting\_Skills
- Welfare

Selected.category.id.is.10

Selected.code.id.is.39\_135.codings

Advo\_Diary\_Awareness

Em\_Encouragement

Emo\_Solidarity

Info\_child\_development

**Info\_parenting skill**

Info\_raising\_children\_and\_siblings

**IN\_FNp [1099:1253]Back**

我們去分享我們照顧女兒的這一段, 所以我們去成立這樣的粉絲專頁, 但是還有很多人認識我但不見得認識我女兒的粉絲專頁, 我常常做的一個就是把他的連結分享到我的頁面上, 像我們有一些照片, 就是我跟女兒的照片, PO在粉絲專頁, 然後我在用連結的方式放到我的個人網頁, 那這樣, 因為瀏覽我的人多, 有三千多人,

**IN\_FNp [1860:1931]Back**

主動讓他在上面講說他的孩子是怎樣, 其實有點難度, 有些我們已經知道他是家長, 有些他們會在fb上報他們的孩子狀況, 那我們才會知道他們是家長

**IN\_FNp [1987:2049]Back**

那我在跟他們成為fb的朋友之後, 那他們在成為我的朋友後他們也很自然的成為渝綏的粉絲, 那我偶爾也會去看看他們照顧孩子的情況

**IN\_FNp [2054:2240]Back**

我覺得其他的家長會啦, 大部分還是隱性的, 隱性的在觀察, 看什麼情況, 那麼什麼情況他們才會問我呢, 就是說他們自己沒有辦法解決的情況, 一般的家長, 比如說他們在輔具的申請, 因為每個孩子狀況不一樣, 有的孩子是智能低下, 但他會走會跑會跳, 那他可能就沒有運動方面的問題, 有的可能是自閉症, 那光是孩子的障礙類別就有很多不同面向, 一般來說會問我們問題的其實真的不多

**IN\_FNp [5835:5991]Back**

我們最怕的就是什麼, 就是那些看到我們就要教我們的人, 就是看到我們就會說, 阿妳們的孩子, 這個就是缺鈣, 或者說肌肉無力, 吧啦啦, 三姑六婆, 家長其實都很想要把他們掐死, 他根本什麼都不懂, 他連腦性麻痺都不知道, 他還想要教我們怎麼教小來, 真的是蠢到家, 但現實生活中就是如此就是會有這樣熱心過頭的人

**IN\_FNp [6162:6419]Back**

We will share how we take care of our daughter, so this is the main reason why I set up this Fanpage. But a lot of people who know me might not know my daughter, so I shared her information in my personal Profile Page. For example, we got this photos, my daughter's photos, I will post it on the Fanpage, then I will link it to my Profile Page. Because I got more Friends. Around three thousands.

I think that most of the parents will share this information, but not all of them. most of them still chose to hide behind the screen. Since you need to check what is the situation. And how they hope to deal with this issue themselves. But normally, most parents, for example, when applying for assistive device for their children, children will have different situations and needs, some might be have lower IQ, some may not. So there are so many situations, so only few of them will really contact us directly.