Attachment in intellectual disabilities: A systematic review of parental reaction to diagnosis in the early years and a study into the contribution of attachment to challenging behaviour.

A thesis submitted to The University of Manchester for the degree of Doctorate in Clinical Psychology in the Faculty of Medical and Human Sciences

2013

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Abstract

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Attachment in intellectual disabilities: A systematic review of parental reaction to diagnosis in the early years and a study into the contribution of attachment to challenging behaviour

Lynsey Fulton
Doctorate in Clinical Psychology
University of Manchester, 2013

Abstract
This thesis explored attachment in individuals with intellectual disability (ID). It investigated the role attachment may have in presenting difficulties such as challenging behaviour, which is an area much researched within other populations. It also considered parental well-being in the early years following diagnosis and the implications this may have for attachment development.

Paper 1 describes a systematic review of the literature on parental response and adaptation to a child’s diagnosis of an ID in the early years. The news of a child’s diagnosis can be met with a range of intense emotions however, existing research reports conflicting outcomes regarding the nature of parental reactions and the psychological impact that may result. 12 studies were reviewed with one study demonstrating a strong methodology. The review found that the comparison groups used within studies had an important bearing on how effectual parental response and adaptation appeared. Due to the limited literature available and the methodological variation within the reviewed studies, no clear conclusions could be drawn.

Paper 2 describes an empirical study which investigated the contribution of attachment behaviour to engagement in challenging behaviour, whilst considering other variables, in adults with ID. 22 service staff completed assessment questionnaires which examined service user attachment behaviour, level of adaptive ability, challenging behaviour and other variables. The relationships between particular variables were analysed. Results showed that level of adaptive ability was significantly related to attachment behaviour and challenging behaviour. Attachment behaviour was also significantly related to challenging behaviour, particularly social withdrawal and lethargy. However, when adaptive behaviour was controlled for the significance of these relationships disappeared. Therefore attachment behaviour did appear to contribute to challenging behaviour but less significantly than level of adaptive ability. The nature of the interaction between these three key variables is unclear and requires further research. Findings support the implementation of effective attachment based interventions alongside evidence based behavioural strategies. This would be particularly important for those at high risk of attachment and behavioural difficulties, which current and previous findings suggest may be those with ASD and those with lower levels of ability.

Paper 3 describes the strengths and limitations of the systematic review and empirical paper. The research process, findings and clinical implications from each of the previous papers are discussed and reflected upon.
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Acknowledgements

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A Systematic Review of Parental Reaction to a Child’s Diagnosis of Intellectual Disability in the Early Years.

Prepared with a view to submit to the Journal of Applied Research in Intellectual Disabilities

2013

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Abstract

Background

A number of forms of Intellectual Disability (ID) can be diagnosed before or shortly after birth. A child’s diagnosis can be met with a range of intense emotions and research provides mixed reports about the nature and consequences of parental reaction and the process of adaptation.

Method

Embase, PsycINFO and Medline databases were searched, as well as manual screening to identify relevant literature. Articles were included if they were published in a peer reviewed journal and conducted empirical research into parental reaction to a child’s diagnosis in the early years (< 5 years old).

Results

12 papers were reviewed, one of which demonstrated strong methodology. Limited research indicated that parents of children with Down syndrome experience increased levels of stress or distress compared to parents of typically developing children. However this disparity is reduced when compared to parents of children with other difficulties. Levels of parental stress or distress may also vary at different stages of child development.

Conclusions

Due to the limited number of studies reviewed, conclusions regarding the reaction and adaptation of parents to a child’s diagnosis could not be drawn. Further research is required to develop a more comprehensive and reliable evidence base.

Keywords: Down syndrome, intellectual disability, diagnosis, parent, child, reaction, response
1.1 Introduction

1.1.1 Diagnosis of intellectual disability

The diagnosis of an intellectual disability (ID) can occur at many different stages of an individual’s life. In some cases, an ID may be diagnosed prenatally whilst in others it may not be detected or formally diagnosed until an individual has reached their preschool, adolescent or even adult years. Receiving a diagnosis has a significant impact on both the individual and their family (Falik, 1995; Heiman, 2002; Pieffer, Gerber & Reiff, 1989; Suton-Smith & Rosenberg, 1970). The disclosure and implications of such a diagnosis may result in a variety of emotional reactions and stages of adjustment. There are a number of conditions, including Down syndrome (DS), Cri du Chat syndrome and Phenylketonuria (PKU) that are diagnosable prior to and shortly after birth, which can be indicative of an intellectual disability. Thus it is possible for parents to be aware of a child’s diagnosis before they are born or in the days following their birth (Dykens, Hodapp & Finucane, 2000).

1.1.2 Parental reaction to diagnosis

The news of a child’s diagnosis can be met with intense emotions, amongst them shock (Wolfensberger, 1983), grief (Blacher, 1984) and chronic sorrow (Olshansky, 1962). Research has examined the emotional responses experienced by parents and family members, with variable conclusions being drawn regarding the nature of these emotions and the process of adaptation. There are varied reports about how parents and families react and adjust to the birth of a child with ID. Past research has predominantly reported negative parental reactions characterised by anger, guilt, sorrow and anxiety (Szymanski & Crocker, 1985). It is also assumed that parents are at higher risk of depression and psychological distress (Olsson & Hwang, 2001). Such assumptions are supported by evidence of higher rates of depression (Hoare, Harris, Jackson & Kerley, 1998; Veisson, 1999) and social isolation (Birnbaum, 1970; McAndrew, 1976) compared to controls. Lalvani (2008) reported that parents are met with a largely negative attitude towards disability by both society and professionals which is typified by perceptions of ‘loss’ and ‘devastation’.
However, an alternative perspective has emerged proposing that families generally adapt to such events in functional ways (Kazak & Marvin, 1984; Summers, Behr & Turnbull, 1989). Some researchers have criticised the pathological view of parental adaptation and highlight evidence of positive adjustment (Bennett, DeLuca & Allen, 1996). Ferguson, Gartner and Lipsky (2000) suggest that families do recover following an initial period of uncertainty and that despite increased demands and stress, families still report positive perceptions of their experiences (Goddard, Lehr & Lapadat, 2000). Thus, having a child with a disability may not be the only or even the most significant factor that shapes parental experience.

Some early studies have suggested that parental reaction and adaptation vary depending on the type of disability or diagnosis (Holroyd & McArthur, 1976) and that there may be significant diagnosis related factors that affect parental responses (Goldberg, Macrovitch, MacGregor & Lojkasek, 1986). Such aspects of a child’s diagnosis may include how severe, treatable or reversible it may be, the social stigma attached, whether the condition poses a threat to survival (Pelchat et al., 1999) and associated behavioural difficulties (Blacher & McIntyre, 2006). Differences across diagnostic groups have resulted in the emergence of concepts such as the ‘Down syndrome advantage’. This proposes that there is little difference in the experience of parents of children with DS and those with typically developing children (Gath, 1977; Gath & Gumley, 1984) given that mothers of children with DS report less depression, stress and burden compared to other types of developmental disability (Blacher & McIntyre, 2006; Seltzer, Krauss, & Tsunematsu, 1993).

1.1.3 Rationale

Literature reviews within this topic area, have primarily focussed on parental experiences in relation to behavioural and social difficulties that a child may present. Reviews have evaluated research that has included individuals across the life span, and focussed on factors affecting parental coping (Hassall & Rose, 2005). Furthermore, existing reviews have not been systematic and have not examined homogenous groups of intellectual disability (Shaprio, 1983; Yau & Li-Tsang, 1999). It is important to have accurate knowledge of potential reactions and adaptations to diagnosis, as these are likely to impact on parental well-being, the
socio-emotional development of the child and parent-child interactions (Hanson & Hanline, 1990).

1.1.4 Review aim

The current systematic review will identify existing literature on parental reaction to diagnoses and adjustment in the child’s early years and focus on studies that are specific to diagnoses that can be made either prenatally or shortly following birth. The quality of empirical studies will be assessed and parents’ psychological and emotional experiences relating to specific diagnoses will be reported.

1.2 Method

1.2.1 Search strategy

A systematic literature search was conducted of research papers published in the English language in peer-reviewed journals. The search was limited to primary studies that explored the reactions of parents to the diagnosis of their child’s ID, when this diagnosis could be made reliably soon after birth. The databases used in the search included Embase, (1974 - December 6th 2012), PsycINFO and Medline (1946 - December 2012). The search was conducted on 7th December 2012 and consisted of combinations of the terms outlined in Table 1.

Table 1. Search terms and limiting criteria

<table>
<thead>
<tr>
<th>All fields (one of)</th>
<th>All fields (one of)</th>
<th>All fields (one of)</th>
<th>All fields (one of)</th>
<th>Limits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent$ reaction</td>
<td>Baby</td>
<td>Diagnosis</td>
<td>Down$ syndrome</td>
<td>English language</td>
</tr>
<tr>
<td>Care$ reaction</td>
<td>Child</td>
<td></td>
<td>Cri du Chat</td>
<td>Primary study</td>
</tr>
<tr>
<td>Parent$ response</td>
<td>Newborn</td>
<td></td>
<td>Phenylketonuria</td>
<td>Peer-reviewed journal</td>
</tr>
<tr>
<td>Care$ response</td>
<td>Neonal</td>
<td>AND</td>
<td></td>
<td>study</td>
</tr>
<tr>
<td>Parent$ stress</td>
<td>Perinatal</td>
<td>AND</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Care$ stress</td>
<td>Prenatal</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Parent$ coping</td>
<td>Infant</td>
<td>AND</td>
<td>AND</td>
<td></td>
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<tr>
<td>Care$ coping</td>
<td>Toddler</td>
<td></td>
<td></td>
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<tr>
<td>Parent$ burden</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Care$ burden</td>
<td></td>
<td></td>
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</tbody>
</table>
1.2.2 Selection criteria

The criteria by which studies were included were 1) the study included a measure of the parental reaction to their child’s diagnosis of ID 2) when outcomes regarding parental reaction and/or comparison with other groups were reported.

Studies were excluded if 1) the age range of the diagnosis group exceeded 5 years, 2) if groups were heterogeneous i.e. not defined by diagnosis 3) if parental reaction measured was primarily related to behavioural difficulties, 4) if the study used qualitative methodology.

Edwards et al. (2002) recommends that two authors review the search results to prevent relevant articles being discarded. Due to restrictions on resources this was not possible, however if the inclusion or exclusion of a study was unclear, a second opinion was sought via supervision and a collaborative decision made.

1.2.3 Search results

The search produced 370 articles, which reduced to 356 once duplicates were removed. Following screening, 294 were removed by title and 45 by abstract, 21 potentially relevant articles were also identified by manually searching article reference lists. The remaining 38 articles were screened in full and an additional 3 articles were identified through manual searching, one of which could not be accessed. The article that could not be accessed was not available in the British Library and the author was unable to be contacted. Twelve articles were found to satisfy the inclusion/exclusion criteria. Figure 1 outlines details of the selection process.

1.2.4 Quality assessment

Due to the variability in methodology of the included studies, a meta-analysis was not appropriate (Higgins & Green, 2011). The quality of studies was evaluated using a quality assessment tool that was developed for this purpose, (see Appendix A). The quality assessment tool developed was based on quality indicators found in the Effective Public Health Practice Project Quality Assessment Tool for Quantitative Studies (EPHPP; Thomas, 2003) and the Critical Review Form for Quantitative Studies (Law et al., 1998) which included:
1. study design
2. confounders
3. data collection methods
4. participation rates
5. analyses.

The tool was adapted and other indicators were included based on their relevance to research in intellectual disabilities (method of ID assessment, Gersten et al., 2005; Smiley, 2005) and to the aims of the review (child sample age, parent sample and comparison group). Each quality indicator was awarded a value of ‘0’, ‘1’ or ‘2’. Studies which received a total rating of <11 of a potential total of 22, were considered to be ‘weak’ in quality as this would indicate an average rating of ‘1’ on all quality indicators. Please see Appendix B and C for copies of the Effective Public Health Practice Project (EPHPP) Quality Assessment Tool for Quantitative Studies and the Critical Review Form for Quantitative Studies. A selection of the studies was reviewed by an independent researcher (C.D). When outcomes were compared there was 80% agreement on overall study ratings and 85.5% agreement on individual indicators.
Figure 1. Flowchart of study selection process (based on Moher, Liberati, Tetzlaff & Altman, 2009)

Number of articles in search results = 370

Duplicates removed = 14

Number of articles screened = 356

Removed by title = 294

Number of titles imported into Microsoft office word = 62

Identified through references = 21

Number of articles removed:
- By abstract = 45

Number of full text articles reviewed = 38

Identified through manual search = 3

Exclusions and reasons
- Age of child sample = 18
- Parental responses specifically related to behaviour difficulties = 3
- Factors investigated not relevant = 2
- ID group not defined = 5
- Unable To access = 1

Number of articles reviewed = 12
### Table 2. Review of methodology and findings

<table>
<thead>
<tr>
<th>Author, year, Country</th>
<th>Study Purpose</th>
<th>Study design</th>
<th>Sample size</th>
<th>Child sample age range</th>
<th>Parent sample M/F</th>
<th>Compariso n groups P/DD/TD</th>
<th>Matched samples</th>
<th>Participation rates</th>
<th>ID assessment method</th>
<th>Assessment tools</th>
<th>Analysis</th>
<th>Relevant results.</th>
<th>Score; Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Most, Fidler, Booth-Laforce &amp; Kelly, 2006, USA</td>
<td>Compare patterns of stress in mothers of children with and without DS.</td>
<td>Longitudinal, questionnaire &amp; obs.</td>
<td>74</td>
<td>12-45 months</td>
<td>M</td>
<td>DD (1 grp)</td>
<td>Yes (BSID-II)</td>
<td>Not reported</td>
<td>Previous genetic test.</td>
<td>SQ, BSID-II, DAS, CDI, ITQ, CBC, PLS, PSI</td>
<td>Individual growth modeling</td>
<td>DS parental stress lower at Time 1 but greater increases later compared to DD parents. Diagnostic group predictor of stress level at time 3 (DS&gt;DD).</td>
<td>13; Moderate</td>
</tr>
<tr>
<td>2. Eisenhower, Baker &amp; Blacher, 2005, USA</td>
<td>Syndrome related differences in behavior and maternal well-being.</td>
<td>Longitudinal, questionnaire, interview and child ax.</td>
<td>215</td>
<td>30-40 months</td>
<td>M</td>
<td>DD(3 grps) TD (1 grp)</td>
<td>No</td>
<td>Not reported</td>
<td>Recruited from regional centers register. BSID-II, SBIS-IV</td>
<td>BSID-II (30-75=ID), SBIS-IV (&lt;85=ID), CBC, CES-D, PSQ</td>
<td>ANCOVA, Hierarchical Linear Regression</td>
<td>Sig less maternal negative impact in DS group at child age 3. Sig age X syndrome interaction – increase in negative impact at age 5 in DS group. Diagnosis group contributed to maternal stress after behaviour and cognitive ability controlled for.</td>
<td>14; Moderate</td>
</tr>
<tr>
<td>3. Roach, Osmond &amp; Barratt, 1999, USA</td>
<td>Perceptions of care giving stress of mothers and fathers.</td>
<td>Cross sectional, postal questionnaire</td>
<td>198</td>
<td>15-57 months</td>
<td>M&amp;F</td>
<td>TD (1 grp)</td>
<td>Yes (SES)</td>
<td>70%/46%</td>
<td>Not reported</td>
<td>CDC, PSI, DCS, CRTS, CSS</td>
<td>Repeated measures MANCOVA, Multiple Regression</td>
<td>Sig more parental stress associated with parental competence, health role restriction and depression in DS group. Sig diff in caregiving difficulties (DS&gt;TD). Diagnosis group predictor of stress for fathers but not for mothers.</td>
<td>13; Moderate</td>
</tr>
<tr>
<td>Study (Year, Location)</td>
<td>Topic</td>
<td>Study Design</td>
<td>Sample Size</td>
<td>Age</td>
<td>Gender</td>
<td>Grouping</td>
<td>Data Collection Methods</td>
<td>Instruments</td>
<td>Analysis</td>
<td>Key Findings</td>
<td></td>
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<tr>
<td>Pelchat et al., 1999, Canada</td>
<td>Adaptation of parents to infant in relation to type of disability.</td>
<td>Cross sectional, questionnaire</td>
<td>144</td>
<td>6 months</td>
<td>M&amp;F</td>
<td>P (2 grps) TD (1 grp)</td>
<td>No</td>
<td>66%/74%</td>
<td>Medical records SQ, SAM, PSI, PDI – QHS</td>
<td>Repeated Measures ANOVA, T-tests</td>
<td>Sig higher parental stress, stress appraisal and psychological distress in DS group compared to TD. Parental differences in reported stress (M&gt;F).</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Erickson &amp; Upshur, 1989, USA</td>
<td>Parental perceptions of care taking burden, involvement and satisfaction with social support.</td>
<td>Cross sectional, questionnaire &amp; child ax.</td>
<td>202</td>
<td>&lt;24 months</td>
<td>M</td>
<td>P (1 grp) DD (1 grp) TD (1 grp)</td>
<td>Yes (child age)</td>
<td>Not reported</td>
<td>Recruited from early intervention programme</td>
<td>SSS, FIRS, FSS – adapted SQ, BSID-II VABS</td>
<td>Data reduction techniques One way ANOVA with Scheffe tests, T-tests. No sig difference in caretaking burden across diagnostic groups. Sig diff in caretaking time across groups (DS&gt;comparison groups)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Krauss, 1993, USA</td>
<td>Parental differences in experience of stress.</td>
<td>Cross sectional, Interview, child ax &amp; questionnaire</td>
<td>121</td>
<td>1.7 – 21.8 months</td>
<td>M&amp;F</td>
<td>P (1grp) DD (1grp)</td>
<td>No</td>
<td>Not reported</td>
<td>Recruited from early intervention programme.</td>
<td>PSI, CILCS, PSS, FACES, BSID-II MDI BSID-II</td>
<td>MANOVA No sig diff between parents scores across groups. No sig diff in maternal and paternal stress.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Scott et al., 1997, Canada</td>
<td>Distress level of parents of children with and without DS.</td>
<td>Matched Cross sectional, postal questionnaire</td>
<td>216</td>
<td>&lt;24 months</td>
<td>M&amp;F</td>
<td>TD (1 grp)</td>
<td>Yes (SES)</td>
<td>60%</td>
<td>Recruited from specialized services.</td>
<td>BDI, POMS, IES – (Intrusion subscale). MANOVA and ANOVA. Estimated omega squares determined. Sig greater depression in DS group, but effect size small.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Atkinson et al., 1995, USA</td>
<td>Maternal cognitive coping style, affective state and sensitivity in mothers of children with DS.</td>
<td>Longitudinal, obs. and questionnaire</td>
<td>56</td>
<td>14-58 months</td>
<td>M</td>
<td>None</td>
<td>n/a</td>
<td>76%</td>
<td>Genetic test, BSID and VABS</td>
<td>AAS, MBSS, BIDR – (Self-deception subscale) IES, POMS, MBQS</td>
<td>Pearsons Correlations &amp; Multiple regression Approach coping sig more associated with mood disturbance than avoidance. Sig positive correlations between mood and maternal sensitivity.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Scott et al., 1993, USA</td>
<td>Parental perceptions of care taking burden, involvement and satisfaction with social support.</td>
<td>Cross sectional, questionnaire &amp; child ax.</td>
<td>202</td>
<td>&lt;24 months</td>
<td>M</td>
<td>P (1 grp) DD (1 grp) TD (1 grp)</td>
<td>Yes (child age)</td>
<td>Not reported</td>
<td>Recruited from early intervention programme</td>
<td>SSS, FIRS, FSS – adapted SQ, BSID-II VABS</td>
<td>Data reduction techniques One way ANOVA with Scheffe tests, T-tests. No sig difference in caretaking burden across diagnostic groups. Sig diff in caretaking time across groups (DS&gt;comparison groups)</td>
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144: Medical records
66%/74%: Parental differences in reported stress (M>F)
<table>
<thead>
<tr>
<th>Study</th>
<th>Title</th>
<th>Design</th>
<th>Participants</th>
<th>Measures</th>
<th>Analysis</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>9. Goldberg, Marcovitch, MacGregor &amp; Lojkasek, 1986, Canada.</td>
<td>Distress of parents of children with and without DS.</td>
<td>Cross sectional, questionnaire, interview, obs.</td>
<td>49</td>
<td>M&amp;F DD (2 grps)</td>
<td>No</td>
<td>Not reported</td>
</tr>
<tr>
<td>10. Hanson and Hanline, 1990, USA.</td>
<td>Parental stress and adaptation.</td>
<td>Longitudinal obs, clinical interview, questionnaire</td>
<td>35</td>
<td>M</td>
<td>P (1 grp) DD (1 grp)</td>
<td>No</td>
</tr>
<tr>
<td>11. Carr, J. 1988, UK.</td>
<td>Development of Children with DS. Effect on families.</td>
<td>Matched Longitudinal semi-structured interview.</td>
<td>108</td>
<td>M</td>
<td>TD (1 grp)</td>
<td>Yes (gender/age/social class)</td>
</tr>
<tr>
<td>12. Carr, J. 1970, UK.</td>
<td>Factors relating to disclosure of diagnosis</td>
<td>Part of longitudinal study</td>
<td>46</td>
<td>M</td>
<td>None</td>
<td>No</td>
</tr>
</tbody>
</table>

NB: All of the studies reviewed included a group of parents of children with Down syndrome to which outcomes of any comparison groups were compared.
Abbreviations: DS – Down Syndrome; DD-developmental Disorder; P-Physical disability/condition; TD – Typically Developing; ID – Intellectual Disability; M-Mothers; F-Fathers; sig – significant; diff – difference; behav obs – behavioural observations; obs – observations; ax - assessment

Assessments: SQ – Socio demographic questionnaire; BSID-II – Bayley Scales of Infant Development (MDI – Mental Developmental Index only); DAS – Differential Abilities Scale; CDI – MacArthur Communicative Development Inventory; ITQ – Infant Temperament Questionnaire; CBC – Child Behaviour Checklist; PLS – Pre-school Language Scale; PSI – Parenting Stress Index; SBIS-IV – Stanford Binet Intelligence Scale IV; CES-D – Centre for Epidemiological Studies Depression Scale; FIQ – Family Impact Questionnaire; CDC-Caregiving Difficulties Checklist; DCS – Daily Caregiving Scale; CRTS – Child Related Tasks Scale; CSS – Child Socialization Scale; SAM - Stress Appraisal Measure; PDI-QHS – Psychological Distress Index – part of the Quebec Health Survey; SSS - Social Support Scale; FIRS – Family-focused Intervention Rating Scales; FSS - Family Support Scale (adapted); VABS – Vineland Adaptive Behaviour Scale; CILCS - Child Improvement Locus of Control Scales; PSS – Parent Support Scale; FACES - Family Adaptability and Cohesion Evaluation Scales; BDI - Beck Depression Inventory; POMS – Profile of Mood States; IES – Impact of Events Scale; AAS - Approach-Avoidance Scale ; MBSS - Miller Behaviour Style Scale; BIDR - Balanced Inventory of Desirable Responding; MBQS -Maternal Behaviour Q-SET ; RTQ - Rutter Health Questionnaire; CSI - Coopersmith Self-Esteem Inventory; RIES - Rotters I-E Scale; FRQ - Family Relations Questionnaire; SS - Strange Situation ; IPE - Inventory of Parent Experiences; DASI-II - Developmental Activities Screening Inventory; K-ABC - Kaufman Assessment Battery for Children; NCAT - Nursing Child Assessment Scale: Teaching Task
1.3 Results

1.3.1 Study characteristics

Six studies explored parental stress, (1, 2, 3, 4, 6 & 10) two of which also assessed adaptation (4 & 10). Three studies measured distress (7, & 9 & 11), one of which also measured health (11), whilst one study enquired specifically about reactions of ‘shock’ (12). One study focused on parental perceptions of burden (5) and one on cognitive coping and sensitivity (8). Four studies also measured parental social support as a secondary factor (5, 6, 9 & 10).

Of the studies reviewed, six utilised a longitudinal design (1, 2, 8, 10, 11 & 12), but in the case of two studies (11 & 12), only part of the data was relevant due to the age range inclusion criteria. The remaining six studies used cross-sectional designs (3, 4, 5, 6, 7 & 9). Of all the studies reviewed, only one gained maximum ratings for the child age group of interest (< 12 months; 4). The comparison samples within studies varied with only one study using comparison groups of developmental and physical disabilities as well as a typically developing group (5). Two studies had no comparison group (8 & 12).

Six studies were conducted in the USA (1, 2, 3, 5, 6 & 10), four in Canada (4, 7, 8 & 9) and two in the United Kingdom (11 & 12), which were both part of the same longitudinal study. Seven samples were large (2, 3, 4, 5, 6, 7 & 11) and the diagnostic groups in seven studies were recruited from early interventions programmes (2, 4, 5, 6, 7, 8 & 10). Five studies obtained both maternal and paternal data (3, 4, 6, 7 & 9) and only one study gained maximum ratings for the methods by which the diagnosis was confirmed (8).

1.3.2 Parental stress

Six studies examined parental stress as the primary outcome. Of these, one was rated as strong in quality (4), three were rated as moderate (1, 2 & 3) and two as weak (6 & 10). Two of the moderately rated studies used a longitudinal design (1 & 2) and reported similar results. Each study (1 & 2) found significantly less parental stress and negative impact for DS parents at time point 1. However, increases in these variables over time resulted in higher or equal levels of negative impact and stress for DS parents compared to other groups at time point 3. Both studies reported diagnostic group membership to have an impact on outcome. A further
study, of cross sectional design (3), reported significantly greater DS parental stress and greater care giving difficulties when compared to a TD group. It also reported maternal and paternal differences, with diagnostic group predicting paternal stress, but not maternal stress. One study, rated as being of strong quality (4), reported significantly higher levels of stress in the DS parent group than the typically developing (TD) group, but not when compared to the physically disabled group (P). It also reported parental differences in stress, with mothers reporting higher levels of stress compared to fathers. Both studies rated as weak in quality (6 & 10) reported no significant differences in parental stress across groups.

1.3.3 Parental distress

There were four studies that investigated parental distress (7, 9, 11 & 12). Across the studies, factors measured related to mood, intrusive symptoms, self-esteem, locus of control and shock. One study was rated as being of moderate quality (7) and reported significantly higher rates of depression in the DS parental group compared to the TD group, but that the effect size was small. A similar trend was reported in another study (11), which found increased reports of depression from DS mothers compared to TD mothers and lower rates of maternal ‘good health’ in DS groups compared to TD groups, although neither of these differences were significant. A third study (9) also reported no significant differences in parental distress between groups. Each of the studies which reported no significant difference between DS parental groups and TD parental groups were rated as ‘weak’ in quality (9 & 11). A further study (12), which used the same sample cohort as study 11, was similarly rated as ‘weak’ and reported that 83% of mothers were ‘shocked’ when news of their child’s diagnosis was disclosed.

1.3.4 Parental perception of burden

One study measured parental perceptions of burden (5) and was rated to be of moderate quality. It was the only study to use TD, P and DD comparison groups. No significant differences in perceived care giving burden across groups were found, despite there being significant differences in the reported level of care taking time and demands.
1.3.5 Cognitive coping

One study examined maternal cognitive coping (8). This study did not use any comparison groups and suggested a significant relationship between maternal sensitivity and mood in parents of children with DS (i.e. those with lower mood are more likely to have reduced maternal sensitivity). It was also reported that approach coping styles had a stronger association with mood difficulties than avoidance coping styles.

1.4 Discussion

One study rated as strong in methodological quality (Pelchat et al., 1999) found that parents of children with DS had significantly higher levels of stress, stress appraisal and psychological distress than parents of TD children. However, when outcome measures were compared across diagnostic groups only (DS, Congenital heart disease (CHD) and Cleft Lip and Palate (CLP), the results varied. Parents of children with CHD and DS continued to have significantly higher levels of stress related to uncontrollability and perception of threat, compared to CLP parents. However, there were no significant differences between the three groups in levels of psychological distress. This highlights an important point with respect to the comparison groups used in studies, as findings relating to parental response and adaptation will be greatly affected by the groups to which they are compared. Comparison to TD groups is more likely to portray increased difficulties than comparison to groups of other types of disability. One limitation of this study was the lack of matched samples, thus confounding variables that may have affected parental stress and distress, e.g. annual income, SES, parental age, were not accounted or controlled for.

The next most highly rated study achieved a moderate rating (Scott, Atkinson, Minton & Bowman, 1997). Participants in this study were matched according to demographic variables, including income. A significant difference in the levels of depression in the DS parent group compared to a TD group was reported, but only when two separate samples were pooled and analysed as one large sample. Even when a statistically significant difference between groups in the large sample was found, this was relatively small. When differences in depression were investigated
further using clinical cut-offs, it was found that DS parents reported significantly higher levels of depression that would be considered ‘clinical depression’, when compared to the TD group. However, this was attributable to only 5.6% of the DS parents, whereas 80% showed minimal or no signs of depression.

A further five studies were rated as being of ‘moderate’ quality. Two of these studies adopted a longitudinal design and report similar results, (Most, Fidler, Booth-Laforce & Kelly, 2006; Eisenhower, Baker & Blacher, 2005). Results from both studies suggested that levels of stress and negative impact may initially be low for parents of children with DS, but may increase over time, whereas for comparison groups they may remain relatively stable over the same time period. Most et al. (2006) suggest that later increases in stress may be due to the emergence of cognitive delays, difficult behaviours and language delays as the child becomes older and these become more pronounced. However Eisenhower et al. (2005) found that even after behaviour and cognitive ability were controlled for, diagnostic group continued to contribute to maternal stress.

Two cross sectional studies rated as ‘moderate’ (Erickson & Upshur, 1989; Roach, Osmond & Barratt, 1999) found similar outcomes in relation to difficulties with caregiving. Roach et al. (1999) found that DS parents reported significantly more caregiving difficulties than those of TD children. Erickson and Upshur (1989) reported that DS parents spent significantly more time on caretaking tasks than comparison groups (DD, TD and P). Despite similarities in these findings, the two studies had contrasting reports regarding the impact of care giving difficulties on parental well-being. Roach et al. (1999) found significantly more parental stress in the DS group than TD group and that this was associated with parental competence, health, role restriction and depression. They also perceived more stress in relation to child acceptability, demandingness and children’s distractibility. However overall, very few DS parents scored within the ‘high’ range of parental stress according to the norms published by Abidin (1995). Erickson and Upshur (1989) however, reported no significant differences across groups in parental perception of caretaking burden. One reason for the variability in results may be the differences in measures used and the constructs measured. Each study also used different comparison groups with Roach et al. (1999) using a TD control group only, whilst Erickson and Upshur (1989) had comparison groups of both TD, DD and P. Roach et al. (1999) also used
samples matched on socio-economic status, therefore removing a potentially confounding variable.

A further moderately rated study (Atkinson et al., 1995) did not examine parental response or adaptation per se, but focussed on cognitive coping styles. The study looked specifically at approach and avoidance orientated coping and how these were related to maternal sensitivity and distress. They reported that approach orientated coping was more strongly associated with affective distress (mood) than avoidance coping. However, cognitive avoidance coping was more strongly correlated with maternal sensitivity suggesting that mothers who were more cognitively avoidant may also interact less sensitively with their children than less avoidant mothers. The findings showed that distress and sensitivity were correlated, with more distressed mothers tending to be less sensitive.

Five studies were rated as ‘weak’ in methodological quality (Carr, 1970; Carr, 1988; Goldberg et al., 1986; Hanson & Hanline, 1990; Krauss, 1993). Four studies (Carr, 1988; Goldberg et al., 1986; Hanson & Hanline, 1990; Krauss, 1993) concluded similar findings that there were no significant differences in parental response (stress or distress) between DS parental groups and comparison groups. Three of these studies (Goldberg et al., 1986; Hanson & Hanline, 1990; Krauss, 1993) did not use TD control groups, thus comparisons were only made between DS parents and parents of children with other physical and developmental disabilities. Carr (1988) did include a TD comparison group and although reported a trend of increased reports of depression and poorer physical health in the DS parental group compared to the TD parental groups, these differences were not significant. Such findings contrast with outcomes of other reviewed studies which did find differences between DS and TD groups to be significant (Pelchat et al., 1999; Roach et al., 1999; Scott et al., 1997). These differing outcomes may reflect the varied methodologies used and possibly differences related to the use of standardised and non-standardised measures to assess outcomes. Carr (1970) also reported that 83% of mothers were ‘shocked’ when news of their child’s diagnosis was disclosed, which has been echoed by other findings (e.g. Wolfensberger, 1983). Given the date of this study, all diagnoses within this sample were provided following birth and it would be interesting to compare parental responses to pre- and post-natal diagnoses of IDs and whether there are any implications for subsequent parental adaptation.
1.4.1 Parental differences

Pelchat et al. (1999) found significant differences in levels of stress and distress between mothers and fathers with mothers reporting more stress relating to role restriction and sense of threat as well as higher levels of psychological distress. These differences were found across all diagnostic groups, including the TD group, but despite differences being significant, they were reported to be ‘quite small’ (Pelchat et al., 1999, p.390). Such findings agree with previous research that has reported that a child’s disability has a greater impact on maternal wellbeing compared to paternal well-being (Beckman, 1991; Goldberg, Morris, Simmons, Fowler & Levison, 1990). Scott et al. (1997) also found significant gender differences in parental measures and that differences were present in both TD and DS group, with mothers reporting greater psychological distress than fathers. Further analyses showed that greater levels of distress were related to frequency of intrusive thoughts, depression and fatigue. Roach et al. (1999) found that diagnostic group did not predict levels of stress for mothers but did for fathers. They reported that a diagnosis of DS significantly predicted paternal stress level, which was related to perception of difficulties in parental competence and depression.

Goldberg et al. (1986) and Krauss (1993) were both rated as ‘weak’ studies and reported conflicting outcomes in relation to parental differences. Goldberg et al. (1986) found that mothers reported more symptoms of distress and lower locus of control yet higher levels of support than fathers. Krauss (1993) however, found there was no significant difference in maternal and paternal stress.

1.4.2 Social support

Four studies also included measures of social support as variables of interest (Erickson & Upshur, 1989; Goldberg et al., 1986; Hanson & Hanline, 1990; Krauss, 1993). Erickson and Upshur (1989), rated as moderate, found that DS parents reported significantly greater satisfaction with social support than comparison groups (P and TD). Sources of support included friends, family and community groups and satisfaction was not found to be related to the child’s severity of disability. The remaining three studies that measured social support were rated as ‘weak’ but reported similar findings to those of Erickson and Upshur (1989). Krauss (1993) found that parents of children with DS reported higher levels of helpfulness in
relation to social support. Both Goldberg et al. (1986) and Hanson and Hanline (1990) reported significantly higher levels of social support within DS groups than comparison groups. Such findings suggest that parents of children with DS experience adequate and satisfactory levels of social support at these early stages, however given the child sample age group, it would be important to understand if this continues to be the case over time.

1.4.3 **Methodological challenges**

Overall, the results of the reviewed studies appear inconsistent and difficult to synthesise in a coherent manner. Some of the reasons for this may lie in the variability and limitations of the methodologies applied.

1. **Comparison groups**

The studies reviewed used a range of groups to which outcomes for DS parents were compared. These ranged from having no comparison group to having TD, DD and P comparison groups. Roach et al. (1999) and Scott et al. (1997) highlight shortcomings in previous research with respect to comparison groups. A key finding from the review is that apparent DS parental response and adaptation to diagnosis is determined by the nature of the group to which they are compared. It appears that when compared to parents of TD children, measures of stress and distress are more likely to be elevated for DS parents. This is less so when compared to parents of children with other developmental or physical disabilities. Without a TD control group it is impossible to determine if having a child with an intellectual disability has any differential impact on the parent. Similarly, without DD or P comparison groups it is difficult to consider diagnostic group differences in parental responses and to further understanding of the factors which may contribute to variability in parental adaptation. Therefore it is important to consider the nature of comparison groups when interpreting results and forming conclusions. Only one of the 12 studies reviewed included comparison groups of DD, P and TD.

2. **Sampling procedures**

The processes through which participants were recruited for studies may also have had a bearing on the results obtained. Seven of the 12 studies recruited parents of children with DS from early intervention programmes and agencies therefore parents
were already in contact with and receiving input from services. These parents’ experiences of stress and distress may be significantly different to those who might be unable to access services or appropriate support. This sampling bias may also account in part for the levels of social support reported. Of the four studies that measured social support, three recruited parents in this manner, thus the positive reports of social support for DS parents may have been affected by existing involvement with services. A more representative view of parental experience may be obtained through recruiting beyond service groups. However, one study which did not recruit solely from early intervention programmes (Goldberg et al., 1986) maintained similar findings of enhanced levels of social support for DS parents.

Further sampling limitations were identified regarding the recruitment of parents within particular geographic areas, alongside group differences in socioeconomic status (SES), parental age and education level. Such factors are likely to affect parental knowledge, experience and financial stability. Previous research has highlighted the importance of variables that relate to parental SES. Ferguson and Watt (1980) found that SES contributed to parental distress levels and that SES was more important in predicting parental anxiety than the child’s level of disability. Cahill and Glidden (1996) examined the contribution of demographic factors to family functioning and found that when these were controlled for, all comparative advantages for DS parents disappeared. Stoneman (2007) reported similar results when parental income was specifically explored and it was found that parents of children with DS reported lower depression levels and higher levels of parental warmth than parents of children with other forms of ID., but these advantages failed to exist when income was controlled for. Consideration of such demographic variables is important in light of findings that parents of children with DS tend to be older and more affluent (Hodapp, 2002) and the reported associations between mental health, parenting and income of families who have children with disabilities (Emerson, 2003; Wang et al., 2004). Hence such demographic factors are liable to affect outcomes, however some studies that controlled for demographic factors also reported differences across diagnostic groups (Greenberg, Seltzer, Krauss, Chou & Hong, 2004; Hodapp, Ricci, Ly & Fidler, 2003). Although inconsistent, these findings nonetheless highlight the importance of considering demographic variables in order to control for confounding effects. Only three of the 12 studies matched
parental samples on SES (Carr, 1988; Roach et al., 1999; Scott et al., 1997). Two of these studies (Roach et al., 1999; Scott et al., 1997) reported significantly greater levels of stress and depression, respectively, for DS parental groups when compared to a TD control group. However, Carr (1988) found that differences in depression and physical well-being between DS mothers and TD mothers were not significant. This contrast in findings may be explained in part by the differences in quality in these studies or may reflect the varied methods of assessment used. Roach et al. (1999) and Scott et al. (1997) used standardised tools (Parenting Stress Index; Beck Depression Inventory and Profile of Mood States, respectively) whilst Carr (1988) used a semi-structured interview whereby participants were asked to rate if they were depressed and if they were in good health. Therefore, it is possible that the differences in findings are artefactual and related to the different research methodologies.

3. **Measures**

There was little consistency across studies in relation to the type and quality of measures used. The most commonly used measure was the Parenting Stress Index (PSI; Abidin, 1995) which was used in 5 out of the 12 studies. Apart from this there was large variability in the measures used and the constructs measured making comparison of the outcomes difficult. Glidden (1993) noted the lack of clarity around the concept of stress particularly with regard to the operationalization of ‘parental stress’. Hodapp et al. (2003) note that studies often claim to examine parental stress yet actually measure related constructs such as depression and malaise, yet the links between these constructs and experience of stress are unclear. Baker, Blacher and Olsson (2005) found that measures that were less related to child rearing e.g. measures of depression or marital adjustment, showed less impact on parental well-being. Therefore the measures used will have a significant impact on outcomes relating to parental experience.

4. **Age range**

During the initial selection process, many studies were excluded on the basis of the ‘age range’ criteria as they tended to contain samples which either spanned pre-school, adolescent and adult years or did not include children in the early years. Research in typically developing populations has highlighted the potential negative impact of parental stress and distress on children’s social, emotional and cognitive
development (Anthony et al. 2005; Murrary, Hipwell, Hooper, Stein & Cooper, 1996). Therefore, it is surprising that there is a paucity of research focusing on this acute stage of diagnosis and child development given the implications of parental difficulties. The failure to include families at this stage leads to inherent difficulties when examining responses to diagnosis given the retrospective nature of reports and reliance on recall rather than present experience. Of particular note are the findings of Most et al. (2006) and Eisenhower et al. (2005) who found a dramatic change in parental stress between two time points (3 years old and 5 years old). This implies that there would be variability in parental experience during different periods of their child’s development.

1.5 Future research

Response and adaptation to a child’s diagnosis of ID in the early years requires further rigorous research in order to draw firm conclusions regarding the impact of this on parents. Future studies should address the shortcomings of existing research. Homogeneous diagnostic groups of various aetiologies (P and DD) should be used and compared with TD groups. The use of such groups allows differential comparisons to be made regarding the impact of particular types of disability on parental outcomes. Future research should assess parental response at the stage of diagnosis in order to obtain information that is accurate and less confounded by retrospective recall or subsequent events and experiences. It would be valuable to follow up such assessments longitudinally given some of the variability in parental response across the life span. Parental samples should be matched on demographic factors (particularly age and SES) and standardised measures used that are appropriate to the construct(s) of interest. It may also be useful to routinely include measures that examine more positive parental attributes, such as resilience and self-efficacy. Studies which solely measure depression, stress, marital difficulties etc. may provide an overly pessimistic view of parental experience. Inclusion of measures of positive attributes and experiences may lead to a more balanced view and may also be useful in identifying what specific factors facilitate positive adaptation and coping, rather than which factors lead to reduced pathology.

The aims of the current review were to include literature from a number of conditions yet only those using DS groups met the inclusion criteria. This implies
that very little research has examined parental response in other disorders which are also diagnosable at birth such as PKU and Cri Du Chat. This is surprising given the impact these events may have on parental coping, attachment and child outcomes (Belsky & Isabella, 1988; Gunn & Berry, 1985; Izard, Haynes, Chisholm & Baak, 1991; Marvin & Pianta, 1996) and highlights a gap within existing research.

1.6 Clinical implications

A gradual shift in the findings of studies into having a child with ID has been reported (Ferguson, 2002; Hassell & Rose, 2005; Hodapp et al., 2003) with the trend moving from a perspective of parental pathology to stress and coping. Helff and Glidden (1998) describe the change in perspective as moving to a position of ‘less negative’ rather than ‘positive’. Krauss (1986) suggested that the greater availability of services and the promotion of inclusion of individuals ID in employment and educational systems may have contributed to this change. Scott et al. (1997) concur, proposing that the social context may have influenced a change in perception of both parents and professionals. If this were the case, it would be important to identify the factors which led to this change and continue to implement interventions at a community level that aim to reduce stigmatization and promote inclusion and integration.

Research into the responses and experiences of parents in relation to specific diagnostic groups should increase understanding of the difficulties they may encounter. This should in turn, inform clinical practice regarding the most appropriate, timely and effective interventions and supports. Given the trend of differences between maternal and paternal experiences and of potential paternal marginalisation in services/roles (Carpenter & Towers, 2008; FPLD, 2005), it is important to consider the value of fathers’ role within future supports and interventions. The findings reported by Most et al. (2006) and Eisenhower et al. (2005) may also be important in considering the stages when services and input may be necessary and the longevity of support that may be required. Most et al. (2006) and Eisenhower et al. (2005) report trends of increasing parental stress across a child’s early years. Moss et al. (2006) suggested this may be due to the child’s emerging cognitive and language delays or behavioural difficulties. The realisation of the reality of these issues alone may be distressing for parents, with the trajectory
of their child’s development and level of their difficulties becoming apparent and increasingly obvious in comparison to peers. Other factors that may contribute to this trend of increasing stress may be experience of stigma as the child becomes more present in society. There may also be the added difficulty for parents of others’ reactions to their child’s difficulties. Ryan (2005) suggested that young children with ID are more likely to elicit sympathetic responses from the public, however, as children grow older, the nature of response changes to disapproval which can have a significant impact on mothers, contributing to experiences of stress, distress and weariness. The continuation of the reported high levels of social support for parents, (Erickson & Upshur, 1989; Goldberg et al., 1986; Hanson & Hanline, 1990; Krauss, 1993) beyond the acute stage of diagnosis and early years is of importance in this regard. Should this not be maintained, parents’ experience of stress and coping may be affected by the decline of a protective resource. It would be important to further examine this trend and identify the factors that may influence changes and fluctuations in parental stress and distress. This would be useful to inform interventions aimed at alleviating parental distress and promoting coping skills. Further knowledge of parents’ long term experiences may also serve to identify if there are key stages at which support and interventions are most necessary.

1.7 Conclusions

Of the limited existing literature on parental reaction to child diagnosis in the early years, only one of the 12 studies showed strong methodological quality. Variability and limitations with regard to methodology prevent any sound conclusions being made. The impact a child's diagnosis may have on parents and the process of adaptation therefore remains unclear and further high quality research that utilises more rigorous methodologies is required in this area in order to address the limitations within existing research. Further clarity around the experiences of parents would assist in identifying contributing factors in relation to risk and resilience. It would assist in the development of a reliable evidence base to inform the most effective interventions and appropriate supports for parents and families.

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## References


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Abstract

Background

An attachment based perspective is fundamental to understanding individuals’ experiences and presenting difficulties. However, knowledge of the development and impact of attachment within the ID population is limited and under researched. This study examined the relationship between attachment behaviour and challenging behaviour along with relevant variables.

Method

22 staff participants completed measures about service users’ attachment, behaviour and abilities. The relationships between key variables were analysed and their relative contribution to challenging behaviour was explored.

Results

Level of adaptive ability was significantly related to both attachment behaviour and challenging behaviour. A significant relationship was found between attachment and challenging behaviour, particularly social withdrawal and lethargic behaviour. When level of adaptive ability was controlled for, the significance of these relationships disappeared. The nature of the relationship between adaptive ability, attachment and challenging behaviour was discussed.

Conclusions

Findings support the implementation of attachment-based interventions alongside behavioural strategies. Continued research is required to further the understanding of the relationship between level of ability, attachment and challenging behaviour which would inform the most effective approaches to intervention.

Keywords: Attachment, intellectual disability, challenging behaviour, adaptive behaviour
2.1 Introduction

2.1.1 Challenging behaviour

Challenging behaviour is defined as:

\[\text{culturally abnormal behaviour(s) of such intensity, frequency or duration that the physical safety of the person or others is placed in serious jeopardy, or behaviour which is likely to seriously limit or deny access to the use of ordinary community facilities (Emerson, 2001 p.3).}\]

Forms of challenging behaviour can include:
1. *Physically aggressive behaviour*
2. *Destruction of environment*
3. *Self-injury*
4. *Sexually inappropriate behaviour*
5. *Offending type behaviour (arson, stealing, other crime).*
6. *Other (may include behaviour problems as varied as ripping clothes, eating non-edible objects, mannerisms or bizarre rituals)*

(Royal College of Psychiatrists, 2001)

Challenging behaviour is one of the most common difficulties facing both individuals with an intellectual disability and services that provide support to them. Prevalence figures vary, with estimates of between 30% and 60% (Deb, Thomas & Bright, 2001) to 6.1% in the community and 40% among those in long stay hospitals (Emerson, 2001). Much research has been conducted with the aim of understanding the origins of challenging behaviour and the factors which contribute to its onset and maintenance. This has provided an evidence base from which to develop effective preventative and/or management strategies and thus alleviate the impact it can have on an individual’s quality of life. Research has identified factors that contribute to engagement in challenging behaviour, which include intra-personal factors, such mental-ill health, (Smiley *et al.*, 2007), level of ability (Emerson *et al.*, 2001; Janssen, Schuengel & Stolk, 2002), specific genetic conditions (Skuse, 2002) and specific developmental difficulties, particularly autistic spectrum disorder (ASD) (Rojahn, Matson, Naglieri & Mayville, 2004; Rutgers, Bakermans-Kranenburg, van IJzendoorn & van Berckelaer-Onnes, 2004). Thus, individuals who experience
mental health difficulties have reduced cognitive and adaptive skills or who have particular genetic or developmental conditions may be more likely to engage in challenging behaviour. In addition, environmental factors (Emerson & Bromley, 1995) and interpersonal factors also affect challenging behaviour. These include sensory and social elements, (RCP, 2007) as well as communication factors (Desrochers, Hile & Williams-Moseley, 1997; Durand & Carr, 1991). Despite current understanding of challenging behaviour and the effective management approaches that have been developed, intervention-resistant challenging behaviour can be found (Janssen et al., 2002). Additionally, despite physical aggression being the most common form of challenging behaviour, it is associated with the lowest treatment response (Didden, Ducker & Korzilius, 1997; Scotti, Evans, Myer & Walker, 1991). Thus further research is required in order to gain a comprehensive understanding of the additional factors which contribute to and maintain engagement in challenging behaviour.

2.1.2 Attachment

Attachment is a protean concept but a common feature of definitions is that attachment is a pre-requisite for typical human development (Malekpour, 2007). Bowlby (1977) defines attachment as an enduring emotional bond which an individual forms with another person, whilst Papalia, Olds and Feldman (1999) emphasise that an attachment relationship is reciprocal and enduring, with both infant and caregiver contributing to the quality of the relationship. Attachment can therefore be taken as the emotional bond that develops between a child and caregiver over the course of infancy. The attachment relationship acts a vehicle for a range of developmental tasks. Bowlby (1973, 1980) proposed that a child’s experience of attachment with a caregiver leads to the development of ‘Internal Working Models’ (IWM). An IWM is a representation of the child’s beliefs and expectations about themselves, the world, other people and relationships and, based on the IWM, a child can predict the likely behaviour of the attachment figure and plan their own responses. The concept of the intergenerational transmission of attachment patterns was also proposed by Bowlby (1973) which suggests the initial attachment relationship and resulting IWM has an impact on future relationships and the way the individual will relate to and interact with others. A further function of the attachment relationship is that of emotional regulation. Initially, a child is fully
dependent on their caregiver to regulate their emotions through soothing and stimulation. In this way, the caregiver fulfills the role of an external regulation system. However, as the child experiences being effectively soothed, they gradually acquire the ability to conduct this task independently and can engage in appropriate self-soothing. Given the important tasks mastered via the early attachment relationship and the impact it can have on future development, the establishment of an attachment that effectively facilitates these tasks is essential.

Ainsworth, Blehar, Waters and Wall (1978) identified individual differences in patterns of infant attachment and proposed that attachments could be secure or insecure, with three distinct sub-types of insecure attachment identified, with a fourth subsequently proposed by Main and Solomon (1990). A secure attachment is characterised by a caregiver who is sensitive and responsive to the needs of the child which results in the child developing an IWM of the world and others as safe, trustworthy and reliable (Furnivall, McKenna, McFarlane & Grant, 2012). Secure attachment relationships have been found to be associated with later psychological well-being, effective stress management (Thompson, 2000) and the ability to self-regulate recognised emotions (Schore, 2001), whilst insecure attachments are linked to future externalising behavioural difficulties (De Mulder, Denham, Schmidt & Mitchell, 2000; Keil & Price, 2006; Milan & Pinderhughes, 2000; Munson, McMahon & Spieker, 2001; Speltz, Greenberg & DeKlyen, 1990; Sroufe, Egeland, Carlson & Collins, 2005; van Ijzendoorn, Schuengel & Bakernams-Kranenburg, 1999), internalising behavioural difficulties (Howes & Ritchie, 1999; Madigan, Atkinson, Laurin, Benoit, 2013), relationship difficulties (Gearity, 2005), depression and anxiety (Thompson, 2000; Waters & Cummings, 2000), and a reduced ability to manage stress (Furnivall et al., 2012).

One factor found to influence attachment is the experience of trauma. Existing literature on the experience of trauma within ID populations suggests that those with ID are more likely to experience traumatic events than those without ID (Balogh et al., 2002; McCarthy, 2001; Spencer et al., 2005; Sullivan & Kunston, 2000). Experience of early trauma has been found to have an impact on attachment in typical populations (Barnett, Ganiban, & Cicchetti, 1997; Cook et al., 2005; Crittenden & Ainsworth, 1989; Furnivall et al., 2012). There is a paucity of research addressing whether this pattern is reflected within ID populations but initial studies
indicate that adverse life events are related to attachment disorder behaviours, even after level of ability is considered (Minnis, Flemming & Cooper, 2010).

2.1.3 Attachment in ID

Patterns of attachment behaviours have been examined in children with ID with some indication that they were more likely to display insecure attachment behaviour (Atkinson et al., 1999; Ganiban, Barnett & Cicchetti, 2000; Muris & Maas, 2004; Schuengel & Janssen, 2006), with this risk increased further for those with ASD (Bakermans-Kranenburg, Rutgers, Willemsen-Winkels & van Ijzendoorn, 2003; Spencer, 1993). Research also suggests that these attachment patterns continue into adulthood (Fraley, 2002; Hanzan & Shaver, 1987; Main, Kaplan & Cassidy, 1985), thus attachment remains relevant throughout the lifespan.

A number of hypotheses have been suggested regarding the processes which account for attachment differences between those with and without ID, which include both individual and caregiver factors. It is thought that the development of secure attachments are more difficult due to increased stress appraisals/experiences by those with ID (Janssen et al., 2002; Schuengel & Janssen, 2006;), atypical attachment signals which are more difficult for care-givers to interpret (Vaughn et al., 1994; Janssen et al., 2002) and increased parental stress which may disrupt the caregiving system (Marvin & Pianta, 1996). It is proposed that such difficulties may result in reduced secure base interactions for the individual and that heightened caregiver sensitivity may be required in order to overcome these challenges (Schuengel & Janssen, 2006). The impact of difficulties with reciprocal aspects of the attachment relationship may provide some insight into findings of increased insecure attachment behaviours in individuals with autism and those with increased impairment levels (Larson, Alim & Tsakanikos, 2011; Naber et al., 2007; Rutgers et al., 2004).

Conversely, several studies have found that the proportion of individuals with ID and/or ASD displaying secure attachment behaviours was not significantly lower than comparison samples (Rogers & Dilalla, 1990; Rogers, Ozonoff & Maslin-Cole, 1991; Willemsen-Swinkels, Bakermans-Kraenburg, Buitelaar, van IJzendoorn & van Engeland, 2000). One factor contributing to ambiguity in findings is the absence of an assessment tool that is valid for the ID population. To this end, a measure of secure attachment behaviour for individuals with ID has been developed in the
Manchester Attachment Scale – Third Party (MAST) (Hare et al., 2011), which has demonstrated reliability and validity in ID populations.

As previously discussed, research indicates an association between insecure attachments and externalising/internalising behaviour problems in typically developing children. Looked-after children, who often have difficult attachment experiences, have been found to be more at risk of conduct disorder, emotional disorders, self-harm and behavioural difficulties (Meltzer, Gatward, Corbin, Goodman & Ford, 2003) and are over-represented in the youth justice system (NARCO, 2003). Thus it must be considered whether parallels can be seen in ID populations and if challenging behaviour can be understood from an attachment perspective.

2.1.4 Attachment and challenging behaviour in ID

Preliminary research indicates that attachment behaviour and challenging behaviour are correlated and a stress-attachment model of challenging behaviour has been proposed by Janssen et al. (2002). According to this model, securely attached individuals will seek security and comfort appropriately at times of stress. Those with insecure attachments may have to utilise secondary strategies, such as minimising or maximising attachment behaviour (Main, 1990) in order to modulate anxiety and stress. It was hypothesised that individuals with ID are at increased risk of:

- Encountering stressful events
- appraising events as stressful
- appraising resources to cope as absent or inadequate.

This results in increased experiences of stress, anxiety and potentially learned helplessness (Olson & Schober, 1993) which, taken with the elevated likelihood of insecure attachments in ID populations, provides a rationale for the models’ proposal that challenging behaviour can be understood as a ‘maladaptive response to perceived stress’ (Janssen et al., 2002, p.447). The stress-attachment model is supported by De Schipper & Schuengel’s (2010) finding that secure attachment behaviours were associated with reduced irritability, lethargy, hyperactivity and
stereotypic behaviour, which was interpreted as evidence that limited emotional security can lead to emotional distress and dysregulated behaviour.

Alternative explanations of the link between attachment and challenging behaviour are that challenging behaviour is a form of separation protest (Clegg & Landsdall-Welfare, 1995). Other researchers have argued that the role of attachment is less significant, not least because of existing evidence of secure attachment behaviours in ID populations, (Dissanayake & Crossley, 1997; Rutgers et al., 2004; Sigman & Mundy, 1989) and proposals that the links between attachment and challenging behaviour can be explained by mediating factors of poor social skills, (Clegg & Sheard, 2002) verbal skills or cognitive ability (Atkinson et al., 1999).

The aim of the current research is to delineate the contribution of attachment to challenging behaviour, in adults with ID, when other contributing factors are controlled for and using a valid measure of attachment for this population.

2.1.5 Hypotheses

1. Reduced levels of secure attachment behaviours, as measured by the MAST, will be significantly related to higher levels of challenging behaviour, as measured by the ABC and BPI.

2. Reduced levels of secure attachment behaviours, as measured by the MAST, will be significantly associated with higher levels of particular types of challenging behaviour, as measured by sub scales of the ABC and BPI.

3. Increased levels of experience of potentially traumatic events will be significantly associated with lower levels of secure attachment behaviour, as measured by the MAST.

2.2 Method

2.2.1 Ethical approval

The study received ethical approval from the University of Manchester Psychological Sciences Ethics Committee and National Research Ethics Committee North West - Greater Manchester East, (see Appendix D and E, respectively, for documentation). The relevant Research and Development approval for each trust was also obtained (see Appendix F).
Participants

Participants were adults with an ID who were service users. Data were provided through the completion of questionnaires by staff who had supported service users for a minimum of three months.

Power calculation

For the proposed primary analysis of multiple linear regression, a sample size of N=50-70 would be sufficient for assessing a number of independent predictors using the general 10:1 rule of participants to predictors. For correlational analyses with the current sample size of 22, the empirical study has an estimated 80% power to detect correlation coefficients (r) of 0.57 or greater.

2.2.2 Recruitment

Staff and service users were recruited from ID services within Newcastle Tyne and Wear NHS Trust, Calderstones Partnership NHS Foundation Trust and City Care Partnership. Information about the study was provided to service managers through a presentation by the researcher and information sheets disseminated. Potential staff participants were informed of the research by the researcher or their line manager and provided with written information about the study (see Appendix G), following which they were invited to participate. Service users were provided with information about the research informally and then, following agreement on their behalf, met with the researcher who provided further information on what the study would involve. Service users were provided with an information sheet (see Appendix H) and given a verbal explanation.

Both staff and service users were given time to consider if they wished to provide consent to participate in the research. Consent from staff participants was provided by signing a consent form (see Appendix I) and service users provided consent either in written form (see Appendix J) or verbally. For those who provided consent, questionnaire packs (see Appendix K) were provided for staff participants to complete. The researchers contact details were provided so that staff and service users could contact them with any questions or for further information. The researcher returned a minimum of two weeks later to collect the completed questionnaires.
Consent

If concerns were raised regarding a service user’s capacity to consent, a comprehensive capacity assessment was completed by a Clinical Psychologist (A.F), (See Appendix L for assessment template). If the individual was found to lack capacity to consent, a ‘consultee’ was identified by service staff. Research information was provided to the consultee either verbally or in written form, (see Appendix M). The consultee could agree to the completion of questionnaires if they judged that the individual would not have objected to the process, had they had capacity to consent. The consultee could then sign a declaration form (see Appendix N).

Response rates

Of the 29 questionnaire packs provided for staff participants, 22 completed packs were returned (response rate = 76%).

2.2.3 Materials

1. Manchester Attachment Scale-Third Party (Hare et al., 2011)

The MAST requires an informant to rate observable attachment behaviour and make inferences about the internalised states, needs and feelings of individuals with an ID. The MAST is a 16 item assessment, scored on a five point likert scale. The MAST has adequate internal consistency (α = 0.750) with no evidence of multi-collinearity. MAST total scores are reliable overtime and have convergent reliability with total frequency scores on an existing self-report measure of secure attachment in adults with ID ( Self Report Assessment of Attachment Security; SRAAS, Smith & McCarthy, 1996; r_s = .504; p = 0.033), taken as a large effect size (> 0.5, Cohen, 1988) (Penketh, Walker, Flood, Hendy & Hare, 2013). The inter-rater reliability of the MAST has not yet been examined, however this did not have a bearing on the current study as only one staff member completed all measures. Positively stated MAST items were reverse scored thus higher MAST scores were indicative of more secure attachment behaviours. Positively stated MAST items were reverse scored thus higher MAST scores were indicative of more secure attachment behaviours.
The MAST was used due to its’ reliability and validity as demonstrated within adult ID populations (Penketh, Walker, Flood, Hendy & Hare, 2013). Measures of adult attachment such as the Adult Attachment Interview (Main & Goldwyn, 1984) or the Adult Attachment Styles Scales (Hazan & Shaver, 1987) have been developed with typical population samples and so were not appropriate for use with the current sample. These measures also require extensive training, are time consuming to administer and rely on an adequate language ability and ability to reflect on past and current events and relationships. Other measures that were available and may have been appropriate to use with ID populations were limited but included the Self Report Assessment of Attachment Scale (Smith & McCarthy, 1996). However, the authors of this measure report a number of shortcomings in that the measure focuses solely on comfort seeking and proximity seeking behavior, and thus does not specifically measure attachment relationship behaviour. It also relies on individuals with ID having an adequate level of receptive and expressive verbal ability, which results in difficulties in using this measure with individuals across the full range of ID. Therefore, the MAST was deemed to be most appropriate for the current study sample due to both its established reliability and validity and its third-party format that ensured participants with lower levels of ability would not necessarily be excluded.


The ABC is a widely used behaviour rating scale comprising 58 items, each scored on a four-point scale, which relate to five factors Irritability, agitation and crying/lethargy and social withdrawal/stereotypic behaviour/hyperactivity and non-compliance/inappropriate speech. The ABC demonstrates ‘fair to excellent’ internal consistency with a mean coefficient α across subscales of .87 (Rojahn, Rowe, Kasdan, Moore & van Ingen, 2011). Several studies (Aman et al., 1985; Bihm & Pointdexter, 1991; Rojahn & Helsel, 1991) have confirmed the reliability and validity of the ABC. Scores for each subscale were summed along with an overall ‘total’ score, with higher scores indicating higher levels of behaviour.

3. Behaviour Problem Inventory (Rojahn, Matson, Lott, Esbensen & Smalls, 2001)
The BPI is a measure of challenging behaviour, consisting of fifty-two items across three subscales self-injury, stereotypy and destructive/aggressive behaviours, with Cronbach’s α values of .652, .466, and .812 respectively, (Sturmey, Fink & Sevin, 1993). A frequency and severity score was calculated for each subscale apart from stereotypy which has only a frequency scale. Higher scores indicated a higher level of behaviour.

The ABC and BPI were selected due to their established reliability and validity when used with ID populations. It was also important that the items in each assessment allowed for the measurement of specific sub types of challenging behaviour. This facilitated the measurement of overall levels of challenging behaviour as well as particular types of behaviour which ensured that both hypothesis one and two could be investigated.

4. *Adaptive Behaviour Assessment Schedule-II (Harrison & Oakland, 2003).*

The ABAS-II is a comprehensive norm-referenced assessment of adaptive skills from birth to 89 years across ten adaptive skill areas, covering three domains (conceptual, social and practical skills), which encompass the practical, everyday skills required to function, meet environmental demands, care for oneself, and interact with others effectively and independently. The ABAS-II shows strong reliability (.97-.99) for total scores and skill areas across age groups (.85-.97). Interrater reliability for total scores was also strong both with and without ‘work’ (.90-.93). The ABAS total score correlates with the *Vineland Adaptive Behavior Scales-Classroom Edition* (VABS) Adaptive Behavior Composite at .82.

The ABAS was included as level of ability and communication skills are related to engagement in challenging behaviour, (Emerson *et al.*, 2001; Janssen, Schuengel & Stolk, 2002; Durand & Carr, 1991). Due to the time required to conduct an assessment of cognitive ability, an informant rated measure of adaptive ability was deemed to be more suitable. The functional aspect of challenging behaviour would suggest that an individuals’ level of adaptive skill may have some bearing on engagement in challenging behaviour, thus a measure of adaptive behaviour was relevant to the current research question.
5. *Glasgow Depression Scale-Learning Disability, Carer Supplement (Cuthill, Espie and Cooper 2003)*

The GDS-LD carer supplement measures depressive symptom levels across a 1-week period. It consists of sixteen items and takes approximately five to ten minutes to complete. The GDS-LD differentiates depression and non-depression groups, is correlated with the Beck Depression Inventory-II \((r=0.88)\), and has good test-retest reliability \((r=0.97)\) and internal consistency \((\alpha=0.90)\). The Carer Supplement was also reliable \((r=0.98; \alpha=0.88)\), correlating with the GDS—LD \((r=0.93)\) (Cuthill et al., 2003).

As mood has been found to influence challenging behaviour (Smiley et al., 2007), the GDS-LD was selected as it has been developed specifically for individuals with ID. The supplement section was used due to it being informant rated, thus assessments of mood could be conducted for all participants regardless of level of ability which may have influenced the completion of the self-report section.

6. *Trauma Index*

This was developed for the purposes of the current study to assess life events the client has experienced that may have been traumatic. The index is based on items contained on already existing measures of trauma, including the Traumatic Events Screening Inventory (TESI-C) (Ghosh-Ippen et al., 2002) and the Lifetime Incidence of Traumatic Events (Greenwald & Rubin, 1999).

Experience of trauma has been found to affect both attachment and behaviour within typical populations (Barnett, Ganiban, & Cicchetti, 1997; Cook et al., 2005; Crittenden & Ainsworth, 1989; Furnivall et al., 2012) and these findings require replication with the ID populations. Recent research has identified a lack of valid and reliable measures of trauma for use with people with ID (Wigham, Hatton & Taylor, 2011) and therefore a basic index of potentially traumatic events was developed for the present study and allowed for the investigation of hypothesis three.
2.3 Statistical analysis

All data were analysed using Statistical Package for the Social Sciences (SPSS) version 20. The data were screened for normality using the Kolmogorov-Smirnov test and histograms. When analysing data of normal distribution, parametric tests were used and non-parametric tests were used when data was skewed from normal distribution. Correlational analyses were carried out to examine relationships between continuous variables. Partial correlations were conducted to analyse significant relationships further by controlling for additional variables. Analyses of variance were used to examine differences between groups with post-hoc t-tests with Bonferroni corrections conducted.

2.4 Results

2.4.1 Demographical data

The demographic data relating to the service user sample is shown in Table 1.
Most service users were male (77.3%). The age of service users ranged from 18 years to 72 years old with an average of 40.14 years. The most common diagnosis of service users was ASD (22.7%) although most service users did not have any specific diagnosis (45.5%). Staff reported that 72.2% of service users did not have any diagnosed medical conditions. Of the mental health difficulties reported, service users most commonly had difficulties with low mood (27.3%), psychosis (18.2%), anxiety (13.6%) and personality difficulties (13.6%). Just over half of the sample (54.5%) reported one or more mental health difficulty.

### 2.4.2 Assessment data

Assessment data from standardised measures completed by staff relating to the service user sample can be found in Table 2. Data were not collected in relation to...
the staff member completing assessments. The staff member would have been part of the service users direct care team and would have known the service user for at least 3 months, however information was not collected on the exact nature of the staff members role e.g. support worker, key worker, team leader etc.

Table 2. Summary of scores on standardised measures

<table>
<thead>
<tr>
<th>Measure</th>
<th>Minimum – maximum (range)</th>
<th>Median</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>MAST</td>
<td>36-57 (21)</td>
<td>46.5</td>
<td>6.44</td>
</tr>
<tr>
<td>ABC (total)</td>
<td>0-60 (60)</td>
<td>13.5</td>
<td>16.87</td>
</tr>
<tr>
<td>ABC (Irritability/agitation/cry)</td>
<td>0-18 (18)</td>
<td>5.5</td>
<td>4.45</td>
</tr>
<tr>
<td>ABC (Lethargy/social withdrawal)</td>
<td>0-15 (15)</td>
<td>4</td>
<td>4.34</td>
</tr>
<tr>
<td>ABC (Stereotypy)</td>
<td>0-11 (11)</td>
<td>0</td>
<td>3.13</td>
</tr>
<tr>
<td>ABC (Hyper/non-compliance)</td>
<td>0-21 (21)</td>
<td>3</td>
<td>6.37</td>
</tr>
<tr>
<td>ABC (Inappropriate speech)</td>
<td>0-8 (8)</td>
<td>0</td>
<td>2.1</td>
</tr>
<tr>
<td>BPI (self-injury severity)</td>
<td>0-9 (9)</td>
<td>0</td>
<td>2.18</td>
</tr>
<tr>
<td>BPI (self-injury frequency)</td>
<td>0-8 (8)</td>
<td>0</td>
<td>2.08</td>
</tr>
<tr>
<td>BPI (aggression severity)</td>
<td>0-19 (19)</td>
<td>1</td>
<td>4.5</td>
</tr>
<tr>
<td>BPI (aggression frequency)</td>
<td>0-9 (9)</td>
<td>1</td>
<td>2.7</td>
</tr>
<tr>
<td>BPI (stereotypy frequency)</td>
<td>0-15 (15)</td>
<td>1.5</td>
<td>4.84</td>
</tr>
<tr>
<td>ABAS (GAC)</td>
<td>17-90 (73)</td>
<td>61.0</td>
<td>17.07</td>
</tr>
<tr>
<td>GDS</td>
<td>0-17 (17)</td>
<td>10.5</td>
<td>4.49</td>
</tr>
</tbody>
</table>

Within the service user sample, scores on standardised measures showed a wide range of both adaptive skill level (17-90), as measured by the ABAS, and level of challenging behaviour, as measured by the ABC and BPI subscales. The distribution of scores on the MAST was less varied, with a high median score (46.5 of a possible 64). Scores on the GDS yielded a median score of 10.5 of a possible 32, with lower scores on the GDS indicating fewer difficulties with low mood.

2.4.3 Statistical analyses

T-tests were conducted to investigate whether there were any gender differences in outcomes. A significant difference was found on GDS scores ($t = -2.140, p = .001$). Descriptive statistics showed that females scored significantly higher on the GDS indicating more difficulties with low mood.
A one-way ANOVA was conducted to examine if there were any differences in MAST scores across the three services that were used in recruitment. There was no significant difference in MAST scores across service groups, (F = .333, p = .721).

A Spearman’s correlation coefficient was conducted to assess the relationship between MAST scores and total scores on the ABC. There was a significant negative correlation between MAST scores and ABC total scores (r = -.38, p = .041). Therefore as MAST scores increase, scores on the ABC decrease. This suggests that as secure attachment behaviour increases, challenging behaviour levels decrease. There was a medium effect size (> .3, Field, 2005) and R² = .14 suggesting that scores on the MAST accounted for 14% variance of scores on the ABC. The relationship between these variables is shown in Figure 1.

**Figure 1. Graph showing the relationship between MAST and ABC total scores**

A Spearman’s correlation coefficient was conducted to examine the relationship between MAST scores and frequency and severity scores for each BPI subscale. No significant relationships between MAST scores and BPI frequency or severity scores were found.

A Pearson’s correlation coefficient was carried out to examine the relationship between MAST scores and ABASGAC scores. A significant positive correlation was found (r = .668, p = .000). This suggests that as level of adaptive behaviour
increases, secure attachment behaviours also increase. A large effect size (> .6, Field, 2005) was found and $R^2 = .44$ indicating the ABASGAC and MAST share 44% variance. A Spearman’s correlation coefficient identified a significant negative correlation between ABASGAC scores and ABC total scores ($r_s = -.489$, $p = .012$) suggesting that as adaptive behaviour increases the level of challenging behaviour decreases. $R^2 = .24$ suggesting that adaptive ability explains 24% variance in challenging behaviour and vice versa. The relationships between these variables are depicted in Figure 2.

Figure 2. Graphs showing relationships of ABASGAC scores with MAST and ABC scores

A partial correlation was conducted to examine the relationship between MAST scores and total ABC scores when ABASGAC was controlled for. This found that the significant relationship between the MAST and ABC disappeared when ABASGAC was controlled for ($r = .078$, $p = .372$). The partial correlation showed that when adaptive ability is controlled for, attachment behaviour accounts for .6% of variance in challenging behaviour ($R^2 = .006$).

A significant negative correlation was found between the MAST scores and scores on the ABC ‘social withdrawal/lethargy’ behaviour subscale, ($r_s = -.435$, $p = .021$). This suggests that as secure attachment behaviours increased, levels of social withdrawal and lethargy decreased. This demonstrated a medium effect size (> .3, Field, 2005) and suggests that MAST scores account for 19% of variance in ABC social withdrawal/lethargy scores ($R^2 = .19$). MAST scores were not significantly correlated with any other ABC subscale.
A further partial correlation was conducted to determine if the relationship between the MAST and ABC social withdrawal and lethargy remained significant when ABAS GAC was controlled for. The results show that the significant relationship between MAST scores and ABC social withdrawal and lethargy disappeared when ABASGAC is controlled for ($r = -.181, p = .223$). $R^2 = .03$, indicating that when ABASGAC is controlled for, the MAST accounts for 3% of variance in social withdrawal and lethargy behaviour.

Scores on the ABC social withdrawal /lethargy subscale were significantly positively correlated with scores on the GDS ($r_s = .459, p = .016$), suggesting that social withdrawal and lethargy increased as symptoms of depression increased.

Over half of individuals in the sample had experienced or been witness to a potentially traumatic event (Table 3).

**Table 3. Frequency of potentially traumatic event experienced/witnessed**

<table>
<thead>
<tr>
<th>Event experienced</th>
<th>Event witnessed</th>
<th>Neither experienced or witnessed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frequency / %</td>
<td></td>
<td></td>
</tr>
<tr>
<td>19 / 86.4</td>
<td>10 / 45.5</td>
<td>3 / 13.6</td>
</tr>
</tbody>
</table>

The frequency of service users reported to have experienced or witnessed potentially traumatic events are represented in Table 4. A Graph representing this data can be found in Appendix O.
Table 4. Frequency of each potentially traumatic event experienced/witnessed

<table>
<thead>
<tr>
<th>Event</th>
<th>Experienced</th>
<th>Witnessed</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Natural disaster</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Fire or explosion</td>
<td>0</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Transportation accident</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Physical assault (e.g. being attacked)</td>
<td>10</td>
<td>7</td>
<td>17</td>
</tr>
<tr>
<td>Serious accident at home, work etc.</td>
<td>3</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Exposure to toxic substance</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Assault with a weapon</td>
<td>2</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Sexual assault</td>
<td>5</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Any other uncomfortable sexual experience</td>
<td>4</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Combat or exposure to war zone</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Captivity (hostage, kidnapped)</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Life threatening injury or illness</td>
<td>4</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Sudden, unexpected death of someone close</td>
<td>11</td>
<td>3</td>
<td>14</td>
</tr>
<tr>
<td>Serious injury, harm or death caused by you</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Hospitalized due to injury/illness</td>
<td>11</td>
<td>1</td>
<td>12</td>
</tr>
<tr>
<td>Family discord</td>
<td>12</td>
<td>4</td>
<td>16</td>
</tr>
<tr>
<td>Other stressful event</td>
<td>8</td>
<td>1</td>
<td>9</td>
</tr>
</tbody>
</table>

Taking the total frequencies of experienced and witnessed events, the most common was found to be ‘physical assault’ (17), followed by ‘family discord’ (16), ‘sudden, unexpected death of someone close’ (14) and ‘hospitalisation due to injury/illness’ (12). There were positive but non-significant correlations between ‘trauma experienced’, ‘trauma witnessed’, ‘total trauma’ and MAST scores. Additionally, no significant relationships were found between the trauma scale and other variables in the current study.

Analyses were conducted to examine if there were any differences in outcomes between those diagnosed with ASD and those who had no developmental diagnosis.

A one way ANOVA showed there were no significant differences in MAST scores across developmental diagnosis groups (F= 2.103, p = .128). Descriptive statistics showed that, on average, those with ASD had the lowest MAST scores (Median (Mdn) = 38), with the no developmental diagnosis group having the highest (Mdn = 47.5). A one way ANOVA found there was no significant difference in ABASGAC scores across developmental diagnosis groups (F = 2.410, p = .095).
However those with ASD were found to have the lowest level of adaptive ability ($Mdn = 40$) and those with no developmental diagnosis to have the highest ($Mdn = 72$). A Kruskal-Wallis test showed there was a significant difference between ‘ASD’, ‘AS’ and ‘no developmental diagnosis’ groups in ABC scores ($H (2) = 5.383, p = .050$). Post Hoc Mann-Whitney U tests were conducted and Bonferroni corrections were applied ($p < .0167$). A significant difference in ABC scores was found between those who had ASD and those who had ‘no developmental diagnosis’, ($U = 4.000, z = -2.574, p = .004, r = .67$).

A further series of Mann-Whitney U tests were conducted to examine which types of behaviours were significantly different in those with ASD and those without a developmental diagnosis (Table 5).

**Table 5. Difference in sub types of behaviour between ASD and No diagnosis group**

<table>
<thead>
<tr>
<th>ASD vs. No diagnosis</th>
<th>Scale</th>
<th>U</th>
<th>z</th>
<th>p</th>
<th>r</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABC scores</td>
<td>Total</td>
<td>4.000</td>
<td>-2.574</td>
<td>.010</td>
<td>.66</td>
</tr>
<tr>
<td></td>
<td>Irritability/crying</td>
<td>9.500</td>
<td>-1.905</td>
<td>.057</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Social withdrawal/lethargy</td>
<td>10.000</td>
<td>-1.850</td>
<td>.064</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Stereotypy</td>
<td>5.000</td>
<td>-3.144*</td>
<td>.004*</td>
<td>.81</td>
</tr>
<tr>
<td></td>
<td>Hyper/non-compliant</td>
<td>12.500</td>
<td>-1.550</td>
<td>.121</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Inappropriate speech</td>
<td>23.000</td>
<td>-0.414</td>
<td>.679</td>
<td></td>
</tr>
</tbody>
</table>

*P < .0083 (using Bonferroni corrections)
A significant difference was found in stereotypy scores between those with ASD and those with no diagnosis. Mean scores show that those with ASD scored significantly higher on the stereotypy subscale than those with no diagnosis.

2.5 Discussion

The significance and relevance of an attachment perspective has been under researched within the ID population. It is essential that the role of attachment be explored more comprehensively to further understand the impact it may have on presenting difficulties and thus inform the development of effective intervention approaches.

With regard to the first aim of the study, the current findings support hypothesis one, that security of attachment will be significantly related to level of challenging behaviour. This was found to be true for the ABC but not the BPI. Results showed that lower levels of secure attachment behaviours were significantly related to higher levels of challenging behaviour measured by the ABC. However attachment and challenging behaviour were also significantly correlated with adaptive ability. Once the effect of adaptive ability was controlled for, the significant relationship between attachment and challenging behaviour disappeared. Therefore it appeared that adaptive ability made a more significant contribution to challenging behaviour than attachment. This is not surprising given that adaptive ability encompasses communication, social and self-care skills, thus it is likely that level of adaptive ability will influence: 1) development of attachment; which is demonstrated further by the level of shared variance between the MAST and ABASGAC, and 2) engagement in challenging behaviour. Previous research reported similar results in finding that as level of cognitive and adaptive ability decreased, engagement in challenging behaviour increased (Emerson et al., 2001; Janssen et al., 2002). Additionally, findings have indicated that as level of ability decreases, secure attachment behaviours also decrease (Larson et al., 2011; Naber et al., 2007; Rutgers et al., 2004). Further statistical analyses would be required in order to explore the relationship between this triad of variables and to determine direction, causality and predictability.
Current findings indicated a significant relationship between attachment behaviour and social withdrawal and lethargy challenging behaviour, which would support hypothesis two; attachment behaviour will be significantly related to particular types of challenging behaviour. Such findings mirror De Shipper and Schuengel (2010) who also found that insecure attachment behaviour was related to social withdrawal and lethargic challenging behaviour as well as aggression/irritability and stereotypic behaviour. Further, research within ID and typically developing populations suggests that poor attachment styles are associated with externalising and internalising behavioural difficulties, (De Mulder et al., 2000; Janssen et al., 2002; Howes & Ritchie, 1999; Keil & Price, 2006; Madigan et al., 2013; Milan & Pinderhughes, 2000; Munson et al., 2001; Speltz et al., 1990; Sroufe et al., 2005; van Ijzendoorn et al., 1999), which can be taken as illustrating the role of attachment and its potential contribution to the development and maintenance of difficulties in individuals with ID. Such findings raise questions as to how these behaviours are affected by attachment. Proposed explanations suggest that challenging behaviour represents inappropriate attempts to cope and regulate distress in the absence of secure attachment behaviours or informed strategies (Bradley, 2000; De Schipper & Schuengel, 2010; Janssen et al., 2002) or are examples of ‘minimizing’ or ‘maximising’ attachment signals (Main, 1990).

The direction of causality between attachment and social withdrawal and lethargy cannot be determined by the present study. Therefore it is unclear if less secure attachment behaviours result in more social withdrawal and lethargy or if increased withdrawal and lethargy hampers the development of secure attachment behaviours. When level of adaptive behaviour was controlled for, the significant relationship between attachment and social withdrawal and lethargy disappeared. This indicates that level of adaptive behaviour explains more variance in social withdrawal and lethargy than attachment. However, when De Schipper and Schuengel (2010) controlled for developmental age, the significant relationship between attachment and particular types of challenging behaviour remained. There are a number of reasons why different outcomes were obtained including varying sample sizes, methods of assessment of attachment and the nature of ability assessed.

From the present findings it appears that adaptive ability will influence both attachment behaviour and levels of challenging behaviour, perhaps more
specifically, behaviours with an emotional component such as social withdrawal (De Schipper & Schuengel, 2010).

The third aim of the study was to examine the relationship between trauma and attachment. The present study did not find a significant relationship between experience and/or witness of potentially traumatic events and attachment behaviour, thus hypothesis three was not supported. Descriptive analysis showed that, only three participants (13.6%) had no report of experiencing or witnessing any traumatic events, thus the remaining 86.4% had either experienced and/or been witness to a potentially traumatic event. These figures are not dissimilar to the findings in other studies which have found between 50-90% of sample participants having experienced at least one traumatic event in the previous 3-6 months (Stavrakaki, 1997) or within their life (Ryan, 1994). Therefore, the present findings concur with reports that individuals with ID are at increased risk of experiencing traumatic events than those without ID, (Balogh et al., 2002; McCarthy, 2001; Spencer et al., 2005; Sullivan & Kunston, 2000). Current results indicate that the most common potentially traumatic event experienced and/or witnessed was ‘physical assault’. This may not be surprising given that the sample consisted of services users who may be residing with others who engage in behaviour that challenges. Therefore, inter-personal environment may have had a bearing on this outcome. However similar findings were reported by Emerson et al. (2012) who, in a national review, found the most commonly reported type of abuse was physical abuse. The higher incidence of trauma within ID groups has been attributed to a number of factors such as ‘deficiencies of sexual knowledge, physical and emotional dependence on caregivers, multiple care-giving, limited communication skills and behavioural difficulties’ (McGee, Garavan, de Barra, Byrne & Conroy, 2002 p.244), as well as difficulties with disclosure and less exposure to sexual health education (National Disability Authority, 2008).

Additional analyses showed a gender difference in symptoms of depressed mood, suggesting that females within the sample had more difficulties with low mood than males. This is a trend that has been found within the general population (Piccinelli & Wilkinson, 2000), however preliminary research within ID has shown mixed outcomes (Dagnan & Sandhu, 1999; Lunsky 2003; Lunsky & Benson, 2001).
Contrasting outcomes may be attributed to differences in methodology and measures used, particularly self-report versus informant methods, with gender differences more consistently found with self-report measures. The factors which may contribute to increased mood difficulties in females include increased stress, reduced coping skills and more severe abuse histories (Lunsky, 2003). However further research within ID populations is required to clarify these gender trends and the variables which may account for them.

2.5.1 Developmental disorder

When MAST scores were compared, no significant difference in attachment was found for those with and without an ASD diagnosis. This contrasted with previous research that reported increased attachment difficulties with ASD groups in comparison those without ASD (Bakermans-Kranenburg et al., 2003; Naber et al., 2007; Rutgers et al., 2004; Spencer, 1993).

A significant difference was found in levels of challenging behaviour between the ASD/ no diagnosis groups with regard to stereotypic behaviour. This is not surprising as stereotypic behaviour is one aspect of ‘repetitive behaviour’ which is a defining feature of ASD (DSM-IV-TR, American Psychiatric Association, 2000). Hypotheses regarding the cause or function of stereotyped behaviour suggest this behaviour serves as a means to avoid an anxiety provoking social world (Baren-Cohen, 1989) or as a strategy to regulate arousal (Hutt & Hutt, 1965, 1970; Hutt, Hutt, Lee & Ounsted, 1964). Each of these hypotheses would have clear implications for attachment, with stereotyped behaviour potentially acting as a precursor to and/or a consequence of, poor attachment. Thus it is considered whether the ASD groups’ engagement in high rates of stereotyped behaviours in the present study may be related to their comparatively lower scores on the MAST. Although this may be a possibility, such links are tentative and should be treated with caution. Additional explanations of stereotyped behaviours also exist (Frith & Happ, 1994; Lovaas, Newsom, & Hickman, 1987) and stereotyped behaviour is not exclusive to those with ASD (De Schipper & Schuengel, 2010).
2.5.2 *Understanding relationships between variables*

When all of the current findings are considered, it appears that an individuals’ level of adaptive ability plays a central role in contributing to both attachment behaviour and challenging behaviour. The directionality of the complex interaction of these variables remains unclear from the present results. However, existing research that has addressed specific dyads within this model, may increase understanding of this interaction. The relationship between adaptive ability and challenging behaviour, with levels of challenging behaviour increasing as ability decreases, is largely understood through a functional approach and is supported by a large evidence base, (LaVigna & Wills, 1995; Sturmey, 2006). There has been extensive research with typically developing populations into the relationship between attachment security and behavioural difficulties (De Mulder et al., 2000; Keil & Price, 2006; Meltzer et al., 2003; NARCO, 2003; van Ijzendoorn et al., 1999). Similar patterns of increasing challenging behaviour with decreasing attachment security have emerged in preliminary research in ID populations (De Schipper & Schuengel, 2010; Janssen et al., 2002). When existing research that does provide evidence for the directionality between particular variables is considered, it may be possible to propose the potential nature of interaction between the triad of variables. It is plausible that whilst level of ability may directly affect challenging behaviour, attachment behavior may also act as a mediating variable. Thus, some of the variance in challenging behaviour may be mediated by attachment security. Such a proposal is necessarily tentative and is based on the limited data available from the present study. However further exploration with a larger sample size may clarify how much, if any, variance in challenging behavior is mediated by attachment behavior. Such future research is important as it may provide a rationale for attachment based interventions and a basis for understanding their demonstrated effectiveness (Damen, Kef, Worm, Janssen & Schuengel, 2011; Sterkenburg, Janssen & Schuengel, 2008; van Wouwe, 2012). Current findings, although based on a sample which was under power, may also provide a preliminary framework from which to understand findings of increased effectiveness when behavioural and attachment based interventions are implemented together (Sterkenburg et al., 2008). A model of the potential interaction between these variables and underlying
processes involved is proposed in Figure 3. This model requires further examination in order to determine the nature and direction of the proposed relationships.

*Figure 3. Diagram depicting potential interaction of key variables*

2.6 Limitations

The current study had a limited sample size (N = 22) due to a number of difficulties relating to the research governance and recruitment processes. The research governance requirements stipulated that service user consent had to be obtained for staff to complete assessments. This restricted recruitment to service users who could provide informed consent and thus had an adequate level of ability to do so. Within the services involved in the current study, there were a limited number of service users for whom staff raised no concerns regarding capacity thus it appeared that the majority of those in receipt of services had lower levels of ability. In order to include those who were judged to not have the capacity to consent to participate in
the study, a full capacity assessment was required with the subsequent appointment of a ‘consultee’. This was a time and resource demanding process, however it did allow for the addition of a small number of participants who did not have capacity to consent and facilitated the representation of this group within the study. Given the higher rate of behaviour that challenges with those who have lower levels of ability (Moss et al., 2000), it was this specific group whom it was hoped the research may potentially benefit, thus it was important for the sample to be representative of the range of ability levels in the population of people with ID.

The sample size meant that non-parametric analyses were mostly used. Such analyses tend to be conservative and thus increase the risk of Type II error, which may be reflected in the non-significant results obtained in the current study. Although the sample size was small, it is comparable with other empirical studies within the area (Ganiban et al., 2000; Rogers et al., 1991; Sterkenburg et al., 2008). However, a larger sample size would have allowed for parametric statistical tests and for further analyses to be conducted. Regression analyses would have been beneficial to clarify the interaction between variables and the contributions made by various factors. However these were not possible as the tests would have lacked power whilst increasing the risk of Type I error. The correlational nature of present analyses allowed for identification of significant relationships, however conclusions about causality and directionality between variables could not be drawn.

### 2.7 Implications for future research and practice

The current findings suggest links between level of adaptive ability, attachment behaviour and level of challenging behaviour. Further research is required, with increased sample sizes, to clarify the nature of this relationship and the relative contribution each variable may make. Additionally, research into the experience of trauma and any bearing this may have on attachment and presentation within this population would be extremely valuable, particularly with the use of valid measures.

Given that attachment has been shown to make a, albeit modest, contribution to challenging behaviour, it is important to consider the implications for practice and service provision. When the potential role of attachment is considered, the importance of interpersonal relationships and particularly support staff, is highlighted with regards the relationship that is developed with service users.
Residential, day care and support services, which often suffer from low staff ratios and high staff turnover (Buntinx, 2008), do not provide an interpersonal environment conducive to developing optimal attachments (De Schipper & Schunegel, 2010). It is important to consider service design, structure and the management of transition through services to determine how these can best meet the attachment needs of service users. Evidence is emerging which demonstrates the effectiveness of attachment based interventions which have been direct and therapeutic (Sterkenburg, et al., 2008) and systemic, involving training and education for staff and carers (Damen et al., 2011). Promising results are also reported in relation to attachment based interventions increasing the effectiveness of concurrent behavioural interventions (Sterkenburg et al., 2008). Future research should examine further the potential mediating role of attachment behaviours to challenging behaviour, thus determining if attachment based interventions for ID populations are applicable and efficacious. This would be particularly important for those who may be at heightened risk of both attachment and behaviour difficulties, which previous and present findings would suggest are those with lower levels of ability and who have co-morbid difficulties, such as ASD.

2.8 Conclusions

The current findings demonstrate links between adaptive ability, attachment behaviour and engagement in challenging behaviour. Outcomes indicate that these three variables interact in a complex manner to effect an individual’s presentation. This provides support for further investigation into the role of attachment and provides a rationale for examining how significant a contribution attachment may make to engagement in challenging behaviour. Continued research within this area will contribute to the development of the evidence base and facilitate understanding of both the role of attachment in ID and the applicability and efficacy of attachment based interventions with this population.

Acknowledgements

With sincere thanks to Dr Andrea Flood for the time and effort dedicated to conducting capacity assessments; this was an invaluable contribution to the study.
References


Critical Reflection

Word count: 6,658
3.1 Context of thesis

The role of attachment in ID is the focus of increasing interest in clinical and research contexts, thus the current research is both relevant and appropriate. Within child focused research and services, an attachment perspective has long been central to understanding presenting difficulties and informed approaches taken to intervention. However, it has only been in the last decade that research into attachment in ID populations has begun to emerge (Schuengel, De Shipper, Sterkenburg & Kef, 2013). Research focused on the development of valid attachment assessments (De Shipper & Schuengel, 2006, Hare et al. 2011), therapeutic interventions (Sterkenburg, Janssen & Schuengel, 2008) and systemic interventions (Damen, Kef, Worm, Janssen & Schuengel, 2011), marks acknowledgement of the relevance of an attachment perspective within ID populations.

A number of studies have demonstrated the effectiveness of attachment based interventions within ID populations (Sterkenburg et al., 2008; Schuengel, Sterkenburg, Jeczynski, Janssen & Jongbloed, 2009; Damen et al. 2011; Van Wouwe, 2012) therefore this thesis is also clinically relevant. With aims of investigating how attachment behaviours may contribute to the presentations that often challenge services, it is hoped the findings will promote an attachment perspective in how these challenges are understood and approached.

The researcher chose this particular area of research due to both professional and personal experiences. The researcher was aware of the increasing literature base on attachment in intellectual disabilities and yet the historically reduced priority of this perspective within practice. Having worked for a number of years within ID services prior to training, the researcher had a personal interest in this area and particularly in behaviour that challenges. Increasing understanding of challenging behaviour holds many clinical implications and increases the potential for effective interventions. Such outcomes have potentially invaluable consequences for service user and carer quality of life. The researcher felt that this would not only be a valuable piece of research that would be clinically relevant but that it would also be a topic which would hold their personal interest and therefore would be more likely to maintain their motivation and enthusiasm throughout the challenges of the research process.
The choice of topic for literature review was due to interest in the development of attachment between parents and children with intellectual disability and the factors that influence this process. Findings indicate that individuals with an ID were more likely to be assessed as having insecure attachment than those within the general population (Ganiban, Barnett & Cicchetti, 2000; Muris & Maas, 2004; Schuengel & Janssen, 2006). Therefore it was of interest to explore the factors that may affect attachment development in the early years when this process is fundamental.

Knowledge of research on the effect of parental difficulties and pathology on attachment within typically developing populations (Scott, Doolan, Beckett, Harry & Cartwright, 2010; Campbell et al. 2004; Goodman & Gotlib, 2002; Toth, Cicchetti, Rogosch, Sturge-Apple, 2009) and awareness of a predominantly negative view of parental reaction following their child’s diagnosis (Blacher, 1984; Marvin and Pianta, 1996; Falik, 1995), led the researcher to consider the links between these threads of research. The findings of existing research regarding parental reactions to diagnosis were of interest and whether the nature or severity of parental response had any implications for the development of attachment and bonding with their child.

3.2 Systematic literature review

3.2.1 Topic area

The initial aims of the review were to identify literature which explored parental reaction to a child’s diagnosis in the weeks and months following birth. This demanded the search be limited to types of ID that can be diagnosed before or just after birth. However, following a number of preliminary searches it became apparent that there was a paucity of research exploring parental reaction at these early stages. Studies that had explored this area tended to be largely retrospective in nature, often measuring parental reaction many years after diagnosis (Lord, Wastell & Ungerer 2005; Van Riper, Ryff & Pridham, 1992). Therefore it was necessary to adjust the parameters of the search in relation to child sample age; this was increased initially from 0-1 years to 0-3 years and then finally to 0-5 years. This was not ideal as the researcher was aware that even during these pre-school years other factors such as behavioural difficulties or realisations around the child’s developmental trajectory could impact on parental responses. However in order to obtain enough literature to review, this was required. The researcher attempted to reduce the
impact of confounding variables within studies by excluding any which appeared to measure parental reaction/stress/distress solely in relation to behaviour difficulties.

Time was taken to consider the search terms that should be applied. The decision was made to exclude the term 'intellectual disability' and derivatives of this as this appeared to lead to overly inclusive results. In order to make the search more specific, the terms 'Down syndrome' 'Phenylketonuria' and ‘Cri du Chat’ were used due to the ability to provide these diagnoses at or before birth and because they are indicative of an ID. Using such terms would lead to a more specific search providing results that were relevant to the aims of the review. The researcher was aware that this may reduce the sensitivity of the search as there is often a trade-off between specificity and sensitivity, (Pettriew & Roberts, 2006). However given the time and resources available, it was considered that ensuring specificity would be a priority. The researcher also engaged in manual searching of reference lists to facilitate inclusion of studies that may not have been identified within the parameters of the specific search.

3.2.2 Limitations

The variability within the research and lack of consistency in methodology, coupled with limited studies which met the inclusion/exclusion criteria, meant that no firm conclusions could be drawn from the review. However, it was striking that only one study which met criteria was considered methodologically ‘strong’. This suggests that in relation to the criteria by which methodology was evaluated, the included studies were not sufficient in quality. Some of the indicators included in the tool were derived from existing tools designed to evaluate medical and health research. Therefore these variables would relate to aspects of the ‘gold standard’ of research; Randomized Controlled Trials (RCT’s). Historically a diagnosis of ID constituted exclusion from RCT’s therefore past ID research would always fall short of this gold standard. This has however improved, with a recent review showing that people with ID were included in 27% of 100 RCT’s reviewed (Scheifes, Stolker, Egberts, Nijman & Herrdink, 2011). However, despite their inclusion, the definition of an ID was unclear within these trials and there were no agreed methods of assessing participants ID, thus sub group comparisons were not possible. Therefore research with ID populations appears to be progressing, but further developments are required...
to increase the methodological quality of research and thus the reliability, validity and generalisability of outcomes. The question remains as to whether progression should be towards meeting RCT driven quality goals or a criteria that is more specific and relevant to ID research.

3.2.3 Quality assessment tool

One of the challenges in conducting the review was the lack of quality assessment tools that were available to specifically evaluate research in ID populations. There were many that have been developed to evaluate research in other clinical areas and particularly for medical/health studies or RCT’s e.g. Effective Public Health Practice Project (EPHPP; Thomas, 2003) Quality Assessment Tool for Quantitative Studies and the Cochrane Collaboration Risk of Bias Tool (CCRBT). Therefore it was necessary to develop a tool that was appropriate for the review of research in ID. Attempts were made to identify the indicators that were both relevant to the research question and common within more established tools. The relevant indicators from the EPHPP provided a basis for the assessment tool, further items were then included on the basis of applicability to ID research (Smiley, 2005) and the research question. The researcher was aware of the limitations of developing a novel tool, however efforts were made to increase the validity of ratings through having another researcher (C.D) rate a percentage of the reviewed papers. When ratings were compared they showed 80% agreement in overall study ratings and 85.5% agreement on ratings of individual indicators. The researchers had the chance to discuss and review discrepancies which found that items in the assessment tool which were more open to interpretation, for example items 10 and 11, led to increasingly subjective evaluations and thus had more chance of disagreement. There is evidence that an element of subjectivity remains even when using a structured, standardised assessment tool. With well-established tools such as the EPHPP and CCRBT, findings of only ‘fair’ and ‘slight’ inter-rater reliability have been found (Armijo-Olivo, Stiles, Hagen, Binondo & Cummings, 2012; Hartling et al., 2009). Armijo et al. (2012) also found there was no agreement between the ratings provided by each measure when used to review the same studies, despite claims that they both measure the ‘quality’ of evidence. Armijo-Olivo et al. (2012) acknowledge the subjective nature of such tools and suggest the need for clearer user guidelines in order to improve consistency.
3.2.4 Strengths

This review was focussed and specific in attempting to examine parental experience solely in relation to diagnosis. Limitations within this area of research have been previously noted including the use of heterogeneous diagnostic groups within studies (Pelchat, et al., 1999) and lack of control for demographic factors (Roach, Osmond & Barratt, 1999); the current review was limited due to the former point and findings supported the latter. The outcome of the review was useful in highlighting that despite some limitations being acknowledged in previous literature, subsequent research has not appropriately addressed these. The review indicates that the existing literature falls within the ‘weak’ to ‘moderate’ range, therefore future research must employ higher quality methods.

A further strength of the review is that it has also emphasised the lack of research which explores parental experience at the acute stage of diagnosis. It was this paucity of literature that led to increasing child sample age range. It stands to reason that to gain accurate information regarding an individuals’ response to an event, proximity to the event will be an important factor. It is likely that reports of parental reaction in terms of stress or psychological difficulties many years after the diagnosis, will be confounded by retrospective recall or variables such as behavioural difficulties. Thus the review served to identify a gap in the existing literature that demands attention and further investigation.

3.3 Empirical paper

3.3.1 Research governance

The research governance process was a daunting experience for the researcher, as it was the first time this had been undertaken. On reflection, it was one of the most difficult periods throughout the project which was due to a mixture of submission processes being unclear, a lack of clarity around amendment procedures and the subsequent delays to starting the recruitment process. Having now had experience of this, there are various things that would be conducted differently in the future. This would include submitting the proposal to a committee who were familiar with research projects in ID and, being more aware of the potential delays, beginning processes even earlier. For example the researcher waited until ethical approval was
given before contacting the relevant Research and Development departments, however this could have been initiated earlier with agreements made pending the approval of the study.

### 3.3.2 Capacity and service user recruitment

One of the difficulties presented with the research governance process was around obtaining consent from service users for their permission for staff to complete anonymous measures that asked about service user behaviour and presentation. The researcher understood the need to include service users as far as possible, but this requirement had a significant impact on recruitment and raised a number of issues. Supporting service users to understand what they were consenting to was difficult. The task involved explaining that service users were giving permission for staff to complete a questionnaire, about them, but that they did not need to participate any further in the research process. This was a complicated concept about which even service staff and managers required additional clarification, thus communicating this in an accessible manner and supporting service users to comprehend the concept was a challenge. The research governance requirements also meant that individuals who may not have capacity to consent could not be included unless a full capacity assessment was completed and a consultee appointed. Ethically, the researcher wanted to ensure that those without capacity were not excluded, which so often happens, as it was felt important that the sample should represent individuals with varying levels of ability and portray their experiences. However given the resources required to conduct capacity assessments for individuals, it was not within the remit of the project and thus the research had to proceed with recruitment limited to service users who had capacity to consent.

A number of difficulties with recruitment were encountered. Service and team leaders were met initially to begin recruitment and it became clear that service users considered to have capacity to consent were a minority in services. For example, it was hoped that approximately 15-20 participants could be recruited from each service, however the first service suggested there would only be approximately 8-10 service users who would have capacity. A similar message was obtained from the second and third services meaning that only half of the anticipated sample would possibly be recruited. It became apparent that within the services involved, those
most likely to be accessing support were perhaps those who had lower levels of ability and thus were less likely to have capacity to consent. A further challenge was ensuring that staff making judgements on those who may not have capacity fully understood the concept of capacity in line with the Mental Capacity Act (2005). The researcher emphasised the decision-specific nature of capacity and the information that would need to be understood, retained, considered and communicated in order for a service user to provide informed consent. It was important to ensure that service users were not denied the opportunity to partake in the research based on potentially inappropriate assumptions of lack of capacity. On reflection, it may have been helpful to contact services earlier in the process to gauge how many service users would potentially have capacity to consent. These estimates could have guided whether additional services should be approached for recruitment or could have been presented to the ethics committee to inform decisions made.

Later in the recruitment process, a field supervisor (A.F) working within one of the recruitment services kindly offered to carry out capacity assessments for potential participants within that service. It was only through achieving this added resource that those without capacity could be represented in a meaningful way within the project. This occurred at a later stage in the research process and a further ethical amendment was submitted that required a full panel review. Thus, these time limitations meant only a small number of participants who did not have capacity to consent were able to be recruited as this involved a capacity assessment being conducted, contacting a suitable consultee, gaining consultee consent, gaining staff consent and completion of measures. The inclusion of individuals who lacked capacity was limited but valuable nonetheless. The researcher reflected on how difficult a process this had been and how the challenges posed to including those without capacity may contribute to their lack of representation within research. The research governance process proved to be a double edged sword, on the one hand acting to protect those who may not have capacity but on the other, presenting barriers to their inclusion. Given the higher rate of behaviour that challenges with those who have lower levels of ability (Moss et al., 2000), it was this specific group whom it was hoped the research may potentially benefit. Therefore it was disappointing that more participants who lacked capacity could not be included and
frustrating that this was due to requirements made that were viewed as being in their best interests.

### 3.3.3 Staff recruitment

There was a variety of responses to the research from staff both within and across services, which was to be expected. The researcher was aware that participation would involve time on the part of staff to complete questionnaires and thus attempted to be as flexible as possible. It seemed that there were a number of hurdles to jump regarding participation in that service managers would agree to recruitment, which then involved meeting with team leaders and only following this were support staff and service users met. Therefore there were a number of levels of staff to meet with and gain agreement from before even making contact with those who may participate. Stalker (1998) notes a similar experience in conducting research within ID services and reports that the hierarchical structure of services resulted in three levels of consultation, with service users being the third. However, once potential participants were met, staff appeared generally happy to take part which was encouraging.

The researcher was aware of the issue of acquiescence and that this could potentially affect decisions around providing consent. At times it seemed difficult for staff to achieve a balance of supporting the service user to understand the nature of the study but yet remain impartial, particularly when asked direct questions by service users about their opinion on participation. The researcher reflected that perhaps in settings where service users have a reduced degree of autonomy and increased reliance on staff, making and communicating an informed decision independently could be unnerving. In light of this, a conscious effort was made to emphasise to staff that service users should not be encouraged to provide consent and additionally that consent should not be assumed.

The return of data proved to be a testing and frustrating issue. Some difficulties with this part of the process had been anticipated which led to a decision to return in person to collect data rather than have it returned by post. Despite arranging dates and times for collection, it was extremely difficult to obtain completed data. This tended to be due to staff changes, miscommunication about where data was or forms having not been completed. The researcher spent a significant amount of time
travelling to the numerous services and in some cases travelling to the same facility several times for the same data set. The difficulties with obtaining data led to delays in analysis and write up which was anxiety provoking. It was found that obtaining data from services was more efficient when a key contact person was identified, such as an onsite team leader, whom communication could be maintained with and who could disseminate information.

A further issue with recruitment was the time involved. The services involved in recruitment were mostly supported housing facilities. Thus only one or two service users who were eligible resided in one house meaning multiple facilities and staff teams had to be visited along the course of recruitment. Due to the course of recruitment the researcher had to make three visits to the facility per service user recruited; one to provide information to staff and service user, a second one week later to gain consent from service users and staff and a third to collect completed questionnaires. Logistically this was difficult due to staff shift changes and service user schedules and when the difficulties with obtaining completed data are considered, often more than three visits were required. The time demands around recruitment may have been reduced by having staff post completed questionnaires back, however given the difficulties with postal questionnaires in relation to low participation (Edwards et al. 2002) and missing data (Parker & Dewey, 2000) it was decided that collection of questionnaires would provide higher levels of data.

3.3.4 Missing data

When data was returned it was found that answers were not provided for some items in several questionnaires. At times this appeared to be simply an oversight by staff, however for one questionnaire, the MAST, a printing error resulted in a rating scale not being provided alongside a statement. Some staff rectified this by simply scoring it as they had done the other items, however others did not rate this item. This raised a challenge in terms of how to obtain a total score for this measure. The researcher was aware that the MAST had an adequate internal consistency ($\alpha = 0.750$) and that Cronbach’s $\alpha$ if item deleted ranged from 0.711 to 0.764 (Penketh, Walker, Flood, & Hare (2013). The Cronbach’s $\alpha$ if deleted value suggested that even if an item was missing this would not significantly affect total scores. However, given that the majority of the MAST questionnaires did not have missing
items and in order to be consistent within the data set, it was decided along with the research supervisor to pro-rate the item. The internal consistency findings suggest that the expected value of the missing item would correlate with the scores on other items, thus a modal pro-rating system was thought to be most appropriate. Given the findings of Penketh et al. (2013), it was not expected that this would significantly confound the scoring.

It was noted that the one questionnaire that was the source of most of the missing data was the demographic questionnaire. The demographic questionnaire contained 8 items and 22 questionnaires were completed. Of the total 176 items, 16 were missing. This does not represent a large proportion of missing items however it was noted that often questions regarding the service users’ assessment of ID, developmental disorders or mental health difficulties were left unanswered. There were also a number of instances where information was provided in an inappropriate section, for example, under an item asking about mental health difficulties, ‘limited communication’, or ‘learning disability’ had been entered. It was considered if these omissions reflected staff knowledge of service user history and current difficulties and whether such information is communicated to or made available for support staff. Drawing from personal experience, the researcher was aware that supporting service users can be a very practical and active role and time is not always made for staff to review notes or to provide them with historical information. It may also have been a reflection of staff time constraints and that this did not allow for checking notes or files to verify information, thus items were left unanswered. Perhaps the questionnaire could have been adjusted to facilitate more accurate information, such as providing a ‘tick box’ system for each question. This may have increased clarity around the type of information that items were requesting. The researchers email address was provided on information sheets and staff were encouraged to use this if they had any queries or concerns about completing the questionnaires, however staff did not seem to avail of this. On reflection, completing questionnaires with staff may been a more efficient use of time and may also have reduced instances of missing data. However, this may have been difficult to organise due to the unpredictable nature of events within services and given staff would be ‘on duty’ at the time.
3.3.5 Staff and consultee feedback

Staff and consultee participants provided valuable feedback and ideas about the process of the research. On several occasions staff noted that contrasting responses may be provided to questions by different staff which might depend on their interpretation of questions, their understanding of service users’ behaviour or their level of training and experience. It was also suggested that a number of staff could complete the questionnaires together, thus reducing the workload and counter-acting some element of subjectivity. Given the aims of the project, time and resources it was not possible to pursue these ideas and suggestions, however it raised interesting questions about staff interpretations of behaviour and the factors which may affect these. The researcher attempted to address these by ensuring that it was the staff member ‘who knew the service user best’ who completed the questionnaires as this may be more likely to provide the most accurate responses. On meeting a parent of a service user who was to act as a consultee, it was suggested that it would have been beneficial to also have a family member complete the MAST measure. The researcher agreed that this would have been a valuable addition to the data set and that comparing responses from staff and family would have been an interesting analysis. A further point was made by staff in relation to the behavioural measures used. They suggested that particular service users, who had higher levels of ability and capacity to consent, often presented with challenges which were not captured by the behaviour measures used. Examples given included ‘threats of self-harm’, ‘substance abuse’ or if challenging behaviour did present it may be extremely severe but infrequent. Thus if such events were not captured by questionnaires it may potentially appear that levels of challenging behaviour within the higher ability group would be reduced. This may have contributed to the patterns of findings obtained in the current research, however this has consistently been found in previous research also (Emerson et al., 2001; Janssen, Schuengel & Stolk, 2002). Therefore it should be considered if this difficulty is a historic one and highlights the need to explicitly operationalize what is being measured as ‘challenging behaviour’. It also raises the longstanding dilemma of differentiating environmentally driven behaviours from those which may be conflated with mental health difficulties (Emerson, Moss & Kiernan, 1999) and the potential for diagnostic (Lowry 1997) and behavioural over-shadowing (Palucka, Nyhus & Lunsky, 2003). The researcher
reflected that given the aims and scope of the current study it may not have been feasible to include further measures relating to mental health difficulties. However, a question about additional challenges may have facilitated the reporting of behaviours not included in the measures, but which nonetheless posed challenges to services and staff.

3.3.6 Sample size

Given the difficulties with the research governance process, recruitment and the time demands involved, a smaller than desired sample size of twenty-two was recruited. The researcher was pleased about this given the efforts required to obtain such a sample size. However, the reduced sample size influenced the nature and extent of analyses that could be conducted. Non-parametric tests were largely used which can increase the chances of Type II error which can often lead to false negative outcomes (Button et al., 2013). This may have contributed to the number of non-significant associations between variables within the current study. Once the data analysis process began, it became apparent that certain statistical analyses were not possible due to the study being under powered and the increased risk of Type II error. Ideally, regression analyses would have been conducted to examine the predictive power of the variables measured. It was disappointing to be unable conduct more sophisticated analyses but it was important to be aware of the increased risks and reduced usefulness of conducting under power analyses.

Despite the size of the current sample, findings from demographic data suggested it may reflect some characteristics of a representative sample. There was a male majority within the current service user sample (77.3%; 22.7%) which mirrors Emerson et al. (2012) who found an increased frequency of males diagnosed with ID compared to females and subsequently rates of males known to ID services were higher. Therefore the current sample may be a reflection of the gender disparity within the population. The researcher considered if the male majority within the sample may influence the nature of behaviours reported however there were no gender differences found in behavioural or attachment behaviour measures.

A large proportion of the sample (54.5%) experienced one or more mental health difficulty. This is notably higher than the expected prevalence rate within the general population (one in four (25%); Singleton, Bumpstead, O’Brien, Lee &
Meltzer, 2001). The current finding is consistent with evidence suggesting that individuals with ID are at increased risk of mental health difficulties and that prevalence rates are higher compared to the general population, (Cooper, Smiley, Morrison, Williamson & Allan, 2007; Smiley, 2005). However it should be noted that the present sample consisted of participants in receipt of services and thus may present elevated rates of mental health difficulties compared to a population sample.

3.3.7 Researcher role

One of the challenges of conducting the project was assuming the role of researcher rather than clinician. The researcher was aware that this was something they would have to be mindful of and that explicitly explaining their role within services and remaining boundaried would be essential. Although the researcher had anticipated some difficulties with this, they were surprised by how much they encountered staff seeking advice or feedback regarding service user behaviour. Given the nature of difficulties that the sample service user group may be presenting with, it was understandable that staff may be feeling more stressed or challenged. Thus they may be more likely to seek out advice and support from all avenues. The researcher was careful to acknowledge that staff may be finding managing particular behaviours difficult and empathised with this. However they encouraged staff to pass on any concerns to line managers and team leaders so that appropriate actions could be considered and pursued. When meeting with service users the researcher encountered challenges in relation to balancing building rapport alongside being clear about their limited involvement and the nature of their role. Often service users with ID may have more restricted social networks (Walker, Ryan & Walker, 1993) and therefore may place more significance on the contact than would be expected (Booth & Booth, 1994). They may have also have expectations of continued contact, particularly if they had input from psychological or other services in the past. Thus a conscious effort was required to attempt to maintain an appropriate balance of engagement with both staff and service users and to be mindful of the boundaries of the researcher role.
3.4 Findings and future research

3.4.1 Related variables

The findings of the empirical study suggest that level of adaptive ability and attachment behaviour may interact to play a role in engagement in challenging behaviour. It is proposed that each of these may directly affect challenging behaviour but also that attachment at times may act as a moderating variable between level of ability and challenging behaviour. If such a process does underlie some instances of challenging behaviour, this would suggest that behavioural interventions alone may not prove most effective. This would correspond with preliminary findings of improved effectiveness of intervention when attachment and behavioural based interventions were implemented concurrently (Sterkenburg et al., 2008). It may also be considered whether such a process adds to understanding the ways in which attachment and other variables may contribute to behaviour which is considered ‘resistant’ (Janssen et al., 2002) to behavioural interventions. The model of potential interaction between variables, proposed in figure 3 of Paper Two, provides a basis from which to explore the relationship between these variables and possibly test this model using a larger sample.

3.4.2 Trauma

The findings of the empirical study suggested that experiencing or witnessing potentially traumatic events was not related to attachment behaviours or challenging behaviours. This was unexpected given existing research findings that demonstrate such links in typically developing (Barnett, Ganiban, & Cicchetti, 1997; Cook et al., 2005; Crittenden & Ainsworth, 1989; Furnivall, McKenna, McFarlane & Grant, 2012) and ID populations (Minnis, Flemming & Cooper, 2010). The researcher was aware that the contrasting findings from this study may have been influenced by the measure developed to measure potential traumatic experience. Additional factors which may have had an effect include staff knowledge of historical events, service user ability to report or communicate these and more generally, insight into service users subjective experience of such events. The latter point highlights the difficulties around substantiating whether an individual finds an event traumatic as their interpretation of events and experience of them may not always be possible to ascertain. Likewise, an event which may not be objectively considered traumatic
may be experienced as such. This issue has been previously highlighted in relation to stress (Janssen et al. 2002; Bramston & Fogerty, 2000) with the stress-attachment model of challenging behaviour emphasising that those with ID are more likely to appraise events as stressful. This would have significant implications for the subjective experience of trauma and the subsequent impact this may have. Further research into the experience of trauma in ID populations would be beneficial, particularly with measures that are appropriate and reliable within this group. It would be valuable to use both self-report and informant methods in order to consider whether there may be discrepancies or agreement between these.

3.4.3 Developmental diagnosis

Current findings which suggested more difficulties with attachment behaviour for those with ASD were not unexpected given the trends that have emerged in previous literature (Rojahn, Matson, Naglieri & Mayville, 2004; Rutgers, Bakermans-Kranenburg, van IJzendoorn & Berckelaer-Onnes, 2004). It was also observed that those with ASD had the highest rates of stereotypic behaviour which raised the question as to whether there may be links between this particular behaviour and attachment behaviour. Conclusions could not be drawn from the current study, however this highlighted an area for further research. It would be important to explore if such links exist, particularly when repetitive behaviours are a defining feature of ASD (DSM-IV-TR, American Psychiatric Association, 2000). Further research could also examine the nature of such links in determining whether stereotypic behaviour may act to affect the development of attachment by allowing the individual to avoid the social world (Baron-Cohen, 1989), or if this behaviour develops as a result of difficult attachment and so serves as a substitute regulatory strategy (Hutt & Hutt, 1965, 1970). Understanding the nature the relationship between these variables would be helpful to inform intervention.

3.4.5 Participant samples

Further research with larger sample sizes would be beneficial to establish the directionality and predictability of key variables on challenging behaviour. This research identified those which may play a significant role and that an interaction amongst them exists, however this could be clarified with larger samples and regression analyses. Understanding this relationship more fully would assist in
differentiating the contribution of each variable and thus the most effective approaches to intervention. It may also be of benefit to have more individuals who do not have capacity to consent included in samples, this would increase the generalisability of outcomes and may also facilitate a comparison between different levels of ability. This may allow exploration of whether particular variables contribute more significantly within groups of differing levels of ability.

3.5 Clinical implications

As outlined previously, the current empirical findings provide support for attachment based interventions that have showed positive outcomes (Sterkenburg et al., 2008; Damen et al., 2011). Of particular note are findings by Sterkenburg et al. (2008) that providing attachment and behavioural based interventions alongside each other improved outcomes, which would appear to agree with the proposal from the current findings that attachment may play a mediating role in challenging behaviour. This would suggest that providing attachment based interventions, whether they be direct or systemic, alongside behavioural approaches may lead to more effective outcomes. Although the present findings may indicate that attachment behaviour plays a modest role in challenging behaviour, when this is considered in relation to an individuals’ quality of life, level of distress or the impact on families and carers, a potentially modest improvement through attachment based approaches may be regarded as invaluable.

It is important to consider the current empirical findings alongside findings from the systematic review in paper one and the studies included. From the review, firm conclusions could not be made regarding parental reaction to diagnosis, however the most strongly rated study (Pelchat et al., 1999) indicated that parents of children with ID (Down Syndrome) had higher levels of stress and psychological distress compared to parents of typically developing children. Parental experience of elevated levels of stress and distress during this early stage of development may have implications for attachment, along with the additional difficulties that may affect the development of attachment with a child with ID (Janssen et al., 2002; Schuengel & Janssen, 2006; Vaughn et al., 1994; Marvin & Pianta, 1996). Therefore it should be considered whether the supports and services available to parents and carers at this early stage, can incorporate attachment based elements into the education and
interventions they may provide. This may serve to highlight the issue of attachment and provide support to facilitate its development as well as embracing an increasingly proactive approach. Similarly, parenting interventions which have been developed for parents of children with ID, such as ‘Stepping Stones Triple P’, are largely behaviourally based although certain aspects such as encouraging positive relationships between parent and child and developing safe and interesting learning environments (Sanders, Mazzucchelli, & Studman, 2003) may promote secure attachment development. The current findings would suggest that it may be beneficial to enhance the attachment focused elements of these interventions through psychoeducation and potentially incorporating aspects of attachment based interventions found to be effective. The Stepping Stones Triple P programme also includes a focus on parental adaptation to a child’s diagnosis and disability, thus, given the findings of the review discussed, would appear to be beneficial for families of children with Down syndrome and potentially those with physical difficulties such as Congenital Heart Disease. Although such parenting programmes may be directed towards families of children with ID, as the current findings show, the issue of attachment continues to be relevant throughout the lifespan and thus attachment based interventions are also applicable within the adult population. Findings from intervention research in adult groups (Sterkenburg et al., 2008, Damen et al., 2011) appear to focus on staff and professional carers, however many adults with ID in services continue to have family involvement and it should be considered whether interventions could be helpful for this group also.

A further aspect that should be considered is the structure of services and how well these embrace or facilitate the development and maintenance of positive attachment relationships. As discussed in Paper Two, services often have high staff turnover rates and low staff ratios which results in short term staff teams who may have less time to dedicate to the service users they support and less opportunity to be sensitive to service users attachment needs. The transitions between services can often be difficult and frequent, with changes occurring between child and adult services as well as between residential and day care settings. Ironically, these transitions are likely to be even more frequent for those who present most challenges to services and so will experience even more change in personnel and increased disruptions to relationships. It would be important for services to consider the ways in which the
structure of the service might meet the attachment needs of individuals within a person centred framework.

The current empirical findings also indicate that those who may have most difficulty with attachment relationships may be those with lower levels of ability and with ASD. If these are the individuals who may be at higher risk of poor attachment relationships, it would suggest that attachment based interventions may be most applicable and effective with these groups. The MAST could potentially be used to identify those who might benefit most from attachment based interventions as an adjunct to behavioural strategies. Therefore it would be important to ensure that these groups are included in future research and are ensured access to the appropriate services and interventions.

3.6 Dissemination to services

A number of sessions will be offered to provide services involved in recruitment with feedback from the project. Service managers, staff, service users and consultees will be invited to the presentations and it is hoped that the dissemination of results and implications may be helpful to those who attend.

3.7 Submission for publication

The systematic literature review (Paper 1) will be submitted to the Journal of Intellectual Disability Research. The empirical study (Paper 2) will be submitted to the Journal of Applied Research in Intellectual Disabilities.
References


Penketh, V., Walker, S., Flood, A., Hendy, S. & Hare, D. J. (2013). Attachment in adults with intellectual disabilities; The examination of the psychometric properties
of the Manchester Attachment Scale- Third Party Observational Measure (MAST)

Accepted for publication in Journal of Applied Research in Intellectual Disabilities.


**Appendix A**

Adapted Quality Assessment Tool

1. **Research question focus**
   1. Main focus on measuring psychosocial factors with parents of children with DS. (0)
   2. Main focus on comparison of psychosocial measures of parents of children with DS and those with other physical or developmental conditions OR typically developing children. (1)
   3. Main focus on comparison of psychosocial measures of parents of children with DS, with other physical or developmental conditions AND typically developing children. (2)

2. **Design/method**
   1. Postal parental questionnaire/survey (0)
   2. Questionnaire/measure completed with researcher/assistant. (1)
   3. Questionnaire completed with researcher along with additional interview or behaviour observations. (2)

3. **Sample size**
   1. Small sample size, n=29 (central limit theorem) (0)
   2. Medium sample size, n=30-99) (1)
   3. Large sample size, n=100+ (2)

Central limit theorem states that as samples get larger than 30, the sampling distribution tends to be normally distributed (Field, 2011).

4. **Method of diagnosis of ID.**
   1. Physical features (e.g. with DS) or lack of meeting milestones (0).
   2. Genetic testing/prenatal diagnosis OR other developmental assessment OR recruited from agency which has previously diagnosed disorder (1).
   3. Genetic testing/prenatal diagnosis or other developmental testing AND cognitive functioning testing. (2).

5. **Child sample age range**
   1. 37-60 months (0).
   2. 13-36 months (1).
   3. 0-12 months (2).

6. **Parent sample**
   1. One parent participating (1)
   2. Both parents participating (2)
7. Matched samples
   1. Not reported/no (0).
   2. Matched on child characteristics (age/gender/level of ability etc.) or parent characteristics (SES/age/income).
   3. Matched on both child and parent characteristics.

8. Participation rates (selection bias)
   1. Not reported, below 30% (0)
   2. 30 to 65% participation (1)
   3. Above 65% participation (2)

Nakash et al. (2006) reported average return rate for postal questionnaires was 65%. If ID and TD participation rates differed, then the ID rating was used overall.

9. Assessment tools used
   1. Non-standardized assessment tools/not reported (0)
   2. Acceptable psychometric properties (0.8>.7) (1)
   3. Good or excellent psychometric properties (≥.8) (2).

Categories based on commonly accepted rule of thumb for describing internal consistency using Cronbach’s alpha (George and Mallery, 1999). If one tool was moderate and one tool was strong, the total was rated as moderate. If one tool was weak and one tool was strong the total was rated as moderate. If one tool was weak and one was moderate, the total was rated as weak.

10. Analysis, is it appropriate to research question?
   1. No/uncertain (0).
   2. Yes, probably (1).
   3. Yes definitely (2).

11. Findings
   1. Outcome of interest is not clear or not reported (0).
   2. Reports outcome of interest briefly (1).
   3. Reports outcome of interest clearly and in detail (2).
Appendix B – EPHPP quality assessment tool

QUALITY ASSESSMENT TOOL FOR QUANTITATIVE STUDIES

COMPONENT RATINGS

A) SELECTION BIAS

Q1. Are the individuals selected to participate in the study likely to be representative of the target population?
   1. Very likely
   2. Somewhat likely
   3. Not likely
   4. Can’t tell

Q2. What percentage of selected individuals agreed to participate?
   1. 99% to 100% agreement
   2. 91% to 99% agreement
   3. less than 90% agreement
   4. Not applicable
   5. Can’t tell

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B) STUDY DESIGN

Indicate the study design
1. Randomized controlled trial
2. Controlled clinical trial
3. Cohort analytic (two group pre + post)
4. Case-control
5. Cohort (one group pre + post; before and after)
6. Interrupted time series
7. Other specify
   ____________________________________________________________________________
8. Can’t tell

Was the study described as randomized? If NO, go to Component C.
   No                      Yes

If Yes, was the method of randomization described? (See dictionary)
   No                      Yes

If Yes, was the method appropriate? (See dictionary)
   No                      Yes

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C) CONFOUNDERS

(01) Were there important differences between groups prior to the intervention?

1. Yes
2. No
3. Can’t tell

The following are examples of confounders:
1. Race
2. Sex
3. Marital status/family
4. Age
5. SES (income or class)
6. Education
7. Health status
8. Pre-intervention score on outcome measure

(02) If yes, indicate the percentage of relevant confounders that were controlled (either in the design (e.g., stratification, matching) or analysis)?

1. 80–100% (excellent)
2. 60–79% (some)
3. Less than 60% (few or none)
4. Can’t tell

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D) BLINDING

(01) Were (were) the outcome assessor(s) aware of the intervention or exposure status of participants?

1. Yes
2. No
3. Can’t tell

(02) Were the study participants aware of the research question?

1. Yes
2. No
3. Can’t tell

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E) DATA COLLECTION METHODS

(01) Were data collection tools shown to be valid?

1. Yes
2. No
3. Can’t tell

(02) Were data collection tools shown to be reliable?

1. Yes
2. No
3. Can’t tell

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F) WITHDRAWALS AND DROP-OUTS

(01) Were withdrawals and drop-outs reported in terms of numbers and/or reasons per group?
   1 Yes
   2 No
   3 Can't tell
   4 Not Applicable (i.e. one time surveys or interviews)

(02) Indicate the percentage of participants completing the study. (If the percentage differs by groups, record the lowest)
   1 80 - 100%
   2 60 - 79%
   3 less than 60%
   4 Can't tell
   5 Not Applicable (i.e. Retrospective case-control)

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G) INTERVENTION INTEGRITY

(01) What percentage of participants received the allocated intervention or exposure of interest?
   1 80 - 100%
   2 60 - 79%
   3 less than 60%
   4 Can't tell

(02) Was the consistency of the intervention measured?
   1 Yes
   2 No
   3 Can't tell

(03) Is it likely that subjects received an unintended intervention (contamination or co-intervention) that may influence the results?
   4 Yes
   5 No
   6 Can't tell

H) ANALYSES

(01) Indicate the unit of allocation (circle one)
   community organization/institution practice/office individual

(02) Indicate the unit of analysis (circle one)
   community organization/institution practice/office individual

(03) Are the statistical methods appropriate for the study design?
   1 Yes
   2 No
   3 Can't tell

(04) Is the analysis performed by intervention allocation status (i.e. intention to treat) rather than the actual intervention received?
   1 Yes
   2 No
   3 Can't tell
GLOBAL RATING

COMPONENT RATINGS
Please transcribe the information from the gray boxes on pages 1-4 onto this page. See dictionary as how to rate this section.

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GLOBAL RATING FOR THIS PAPER (circle one):
1. STRONG
2. MODERATE
3. WEAK

With both reviewers discussing the ratings:

Is there a discrepancy between the two reviewers with respect to the component A-F ratings?
- No
- Yes

If yes, indicate the reason for the discrepancy:
1. Oversight
2. Differences in interpretation of criteria
3. Differences in interpretation of study

Final decision of both reviewers (circle one):
1. STRONG
2. MODERATE
3. WEAK
## Appendix C

**Critical Review Form – Quantitative Studies**

©Law, M., Stewart, D., Pollock, N., Letts, L. Bosch, J., & Westmorland, M.

*McMaster University*

- Adapted Word Version Used with Permission –

*The EB Group would like to thank Dr. Craig Scanlan, University of Medicine and Dentistry of NJ, for providing this Word version of the quantitative review form.*

### Instructions

Use tab or arrow keys to move between fields, mouse or spacebar to check/uncheck boxes.

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<td>Outline the purpose of the study. How does the study apply to your research question?</td>
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<td>Specify any biases that may have been operating and the direction of their influence on the results:</td>
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<thead>
<tr>
<th>SAMPLE</th>
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<tr>
<td>Sampling (who; characteristics; how many; how was sampling done?) If more than one group, was there similarity between the groups?:</td>
<td>Describe ethics procedures. Was informed consent obtained?:</td>
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<tr>
<td>N =</td>
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<tr>
<td>Was the sample described in detail?</td>
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<td>□ Yes</td>
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<td>Was sample size justified?</td>
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<td>□ Yes</td>
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<tr>
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<td>OUTCOMES</td>
<td>Specify the frequency of outcome measurement (i.e., pre, post, follow-up):</td>
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<tr>
<td>------------------------------</td>
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</table>
| Were the outcome measures reliable? | □ Yes  
□ No  
□ Not addressed |
| Were the outcome measures valid? | □ Yes  
□ No  
□ Not addressed |

<table>
<thead>
<tr>
<th>INTERVENTION</th>
<th>Provide a short description of the intervention (focus, who delivered it, how often, setting). Could the intervention be replicated in practice?</th>
</tr>
</thead>
</table>
| Intervention was described in detail? | □ Yes  
□ No  
□ Not addressed |
| Contamination was avoided? | □ Yes  
□ No  
□ Not addressed  
□ N/A |
<table>
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<tr>
<th>Cointervention was avoided?</th>
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<tr>
<td>□ Yes</td>
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<tr>
<td>□ No</td>
<td></td>
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<tr>
<td>□ Not addressed</td>
<td></td>
</tr>
<tr>
<td>□ N/A</td>
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<thead>
<tr>
<th>RESULTS</th>
<th></th>
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</table>

**RESULTS**

Results were reported in terms of statistical significance?

□ Yes
□ No
□ N/A
□ Not addressed

Were the analysis method(s) appropriate?

□ Yes
□ No
□ Not addressed

What were the results? Were they statistically significant (i.e., p < 0.05)? If not statistically significant, was study big enough to show an important difference if it should occur? If there were multiple outcomes, was that taken into account for the statistical analysis?

What was the clinical importance of the results? Were differences between groups clinically meaningful? (if applicable)

Clinical importance was reported?

□ Yes
□ No

**Clinical importance was reported?**
<table>
<thead>
<tr>
<th>Drop-outs were reported?</th>
<th>Did any participants drop out from the study? Why? (Were reasons given and were drop-outs handled appropriately?)</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Yes □ No</td>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>CONCLUSIONS AND IMPlications</th>
<th>What did the study conclude? What are the implications of these results for practice? What were the main limitations or biases in the study?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conclusions were appropriate given study methods and results</td>
<td></td>
</tr>
<tr>
<td>☐ Yes ☐ No</td>
<td></td>
</tr>
</tbody>
</table>
Appendix D – University of Manchester Psychological Sciences Ethics
Subcommittee approval letter

Ms Lynsey Fulton
21st December

Dear Lynsey

Feedback from Research Subcommittee 19th December 2011

Thank you for your revised research proposal which was considered by the Research Subcommittee Meeting on 19th December 2011. The committee were satisfied that the revisions made were appropriate and in accordance with the feedback from the meeting of 21st November 2011 and you may now proceed with your research as set out in your proposal. In doing so, you are strongly recommended to seek independent advice regarding the ethics of accessing participants’ case-notes in order to inform your completion of the IRAS documentation.

For the purposes of ethical scrutiny by relevant NHS and/or University bodies, this letter may be taken as confirmation that your research proposal has been independently reviewed and that it is considered to meet necessary scientific and methodological standards.

On behalf of the Research Subcommittee, we wish you good luck with your research work.

Yours sincerely

Dr Dougal Julian Hare
Research Director
Panel Chair, Research Sub-Committee

cc Supervisor, Field Supervisor (if applicable), Clinical Tutor
Appendix E  - NREC approval letters

NRES Committee North West  - Greater Manchester East
3rd Floor, Barlow House
4 Minshull Street
Manchester
M1 3DZ

01 October 2012

Miss Lynsey Fulton
Division of Clinical Psychology
University of Manchester
2nd Floor, Zachonis Building
Brunswick Street
Manchester
M13 9PL

Dear Miss Fulton

Study title: Attachment in Intellectual Disabilities: Investigating the contribution of attachment security to challenging behaviour.
REC reference: 12NW/0791
IRAS project no: 114966

The Research Ethics Committee reviewed the above application at the meeting held on 18 September 2012. Thank you for attending the meeting with Dr Hare to discuss the study.

Discussion

You were congratulated on the improved quality of the application.

You were asked about the race/ethnicity categories in the ABAS form, since some of these are of little relevance to the local population. You advised that this information will not be collected.

The familiarity of staff with the MAST questionnaire was raised. You advised that this will be limited since the questionnaire is not yet published though it has been copyrighted. However, staff will be provided with a full set of documentation and you will explain the questionnaire to staff before use. Staff will have an opportunity to ask questions about it and will be given your contact details to use in the event of any queries. You confirmed that you are confident that staff will be able to use the questionnaire properly

You were advised of minor amendments required to the study documentation.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.
Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see “Conditions of the favourable opinion” below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission (“R&D approval”) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rcforum.nhs.uk.

Where a NHS organisation’s role in the study is limited to identifying and referring potential participants to research sites (“participant identification centre”), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Additional conditions

Service user information sheet

i. Under the heading ‘What is the research study about?’, the last sentence does not make sense as it stands and needs to be corrected.

ii. Under the heading ‘Risks of participating in the study’, the third sentence of the third paragraph should be amended to read ‘The researcher will always ask your permission...’ since it is essential to obtain consent.

iii. Under the heading ‘Will my personal details be confidential?’, a statement needs to be included to provide information about when it would be necessary to breach confidentiality and what would happen in such circumstances.

iv. Under the heading ‘What happens to the information collected when the study finishes?’, it should say that a summary of the research will be presented to staff and service users in line with the answer to question A53 of the application form. The phrase ‘in scientific journals’ should be added to the last sentence.

Staff information sheet

i. Under the heading ‘Why have I been asked to take part?’, the last sentence does not make sense as it stands and needs to be rewritten.
ii. Under 'What happens if I take part?', the phrase 'and who has given consent for the study' after 'an individual with an intellectual disability who you are supporting'.

iii. Under the heading 'What happens to the information collected?', it should say that a summary of the research will be presented to staff and service users in line with the answer to question A53 of the application form.

**Consent forms**

i. The service user consent form needs the phrase 'my medical care and' to be inserted before 'my legal rights' in point 2.

ii. The staff consent form needs the phrase 'my medical care and' to be deleted before 'my legal rights' in point 2.

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You must notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

**Approved documents**

The documents reviewed and approved at the meeting were:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
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<td>Evidence of insurance or indemnity</td>
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<td>14 June 2012</td>
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<td>Investigator CV</td>
<td>Lynsey Futton</td>
<td></td>
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<tr>
<td>Investigator CV</td>
<td>Dougal Hare</td>
<td></td>
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<tr>
<td>Investigator CV</td>
<td>Andrea Flood</td>
<td></td>
</tr>
<tr>
<td>Investigator CV</td>
<td>Melanie Chapman</td>
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<td>Other: Unfavourable opinion letter</td>
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<td>Other: Letter addressing points</td>
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<td>Participant Consent Form: Part consent form 1</td>
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<tr>
<td>Protocol</td>
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<tr>
<td>Questionnaire: Adaptive Behaviour Assessment System</td>
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<tr>
<td>Questionnaire: Aberrant Behaviour Checklist</td>
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<tr>
<td>Questionnaire: Manchester Attachment Scale: Third Party</td>
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<tr>
<td>Questionnaire: Behaviour Problems Inventory: Short form</td>
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<td>Questionnaire: Glasgow Depression Scale-Learning Disability (Career Supplement)</td>
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<td>Questionnaire: Trauma checklist</td>
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<td>Questionnaire: Demographic Information</td>
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<td>REC application</td>
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</table>
Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

12/NW/0701 Please quote this number on all correspondence

With the Committee’s best wishes for the success of this project

Yours sincerely

[Signature]

Mr Francis Chan
Chair

Email: nreascommittee.northwest-gmca@nhs.net
Enclosures: List of names and professions of members present at the meeting

"After ethical review – guidance for researchers"

Copy to: Lynne McCrae, R&D, University of Manchester

Lynne Webster, R&D, Central Manchester NHS Foundation Trust

Dr Dougal Hare
21 March 2013

Miss Lynsey Fulton
Division of Clinical Psychology,
University of Manchester
2nd Floor, Zochonis Building
Brunswick Street
Manchester
M13 9PL

Dear Miss Fulton

Study title: Attachment in Intellectual Disabilities: Investigating the contribution of attachment security to challenging behaviour.

REC reference: 12/NW/0701

At the meeting held on 19 March 2013 the Research Ethics Committee reviewed a supplementary application for approval of the above research study under Section 30 of the Mental Capacity Act. Thank you for attending the meeting with Dr Hare to discuss the amendment.

Favourable Opinion

Discussion:

The Committee agreed that the research is connected with a condition which could impair capacity, namely intellectual disability. It agreed that the research could not be conducted as effectively if it were confined to participants able to give consent as it would skew the study and it would be unjust to exclude adults lacking capacity.

The research was found to be of potential benefit to participants in the group lacking capacity and to have the potential to provide knowledge which would assist the care of such people without imposing a disproportionate burden.

The arrangements for appointing a personal consultant were found to be in order, but further information was sought with regard to the arrangements for appointing a nominated consultant with no connection with the project where this was required.

You assured the Committee that any nominated consultant appointed would be independent of the study; the staff complement was sufficiently large to ensure this. Nominated consultants would be appointed by team leaders.
It was explained that the consultees could not consent to take part in the study but would need to sign a declaration to advise that they considered the adult concerned would wish to take part in the study, and the form therefore needed to be amended accordingly.

The Committee therefore gave a favourable opinion of the amendment, subject to the amendment of the consent form.

Mental Capacity Act 2006

The members of the Committee present approved the supplementary application on the basis described in the documentation submitted. I confirm that the Committee has approved this research project for the purposes of the Mental Capacity Act 2005. The Committee is satisfied that the requirements of section 31 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

Confirmation of ethical opinion

The research continues to have a favourable opinion from this committee. It should continue to be conducted on the basis previously approved by the committee, as amended by this supplementary application. The conditions of approval issued with the committee's original favourable opinion continue to apply.

Approved documents

The documents reviewed and approved at the meeting were:

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<tr>
<th>Document</th>
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<td>11 January 2012</td>
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<td>Protocol</td>
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<td>Substantial amendment 1</td>
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Membership of the Committee

The members of the Ethics Committee present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

Feedback on the application process

Now that you have completed the application process you are invited to give your view of the service you received from the National Research Ethics Service. If you wish to make your views known please use the feedback form available on the NRES website at:

https://www.nationsres.org.uk/AppForm/Modules/Feedback/EthicalReview.aspx
We value your views and comments and will use them to inform the operational process and further improve our service.

12/11/07/01 Please quote this number on all correspondence

With the Committee’s best wishes for the success of this project.

Yours sincerely

[Signature]

Mr Francis Chan
Chair

E-mail: nroscommittee.northwest-grsou@rhe.net

Enclosure: List of names and professions of members who were present at the meeting

Copy to: Mrs Catherine Darow, University of Manchester
          Dr Lynne Webster, Central Manchester University Hospitals NHS Foundation Trust
Appendix F – Research and Development approval letters

Northumberland, Tyne and Wear NHS Foundation Trust

Our ref: MM110N

Workforce and Organisational Development
Directorate
Old Appleby Ward
St. Nicholas Hospital
Jubilee Road
Gosforth
Newcastle upon Tyne
NE3 3XT

14 December 2012

Private & Confidential
Miss L. Fulton
39 Norview Drive
Didsbury
Manchester
M20 5QF

Tel (0191) 223 28593
Fax (0191) 223 2361
Email: michelle.molloy@nwy.nhs.uk

Dear Miss Fulton,

Observer Status

I am writing to confirm the award to you by Northumberland, Tyne and Wear NHS Trust of Observer Status for the period 14 December 2012 to 30 April 2013, during your attachment to project ‘Attachment and Challenging behaviour in Adults with Intellectual Disability’.

You will be afforded access to such clinical facilities and professional activities in the Department or the Trust’s hospitals, health centres and clinics as may be determined by the Trust on advice of your supervising consultant. The award of Observer Status does not confer upon you any other privileges or entitlements unless given to you in writing nor does it imply formal recognition of any status in respect of any particular grade unless separate application has been submitted on your behalf and approved by the appropriate awarding body.

The Trust bears financial responsibility for the negligent acts of its staff in the course of the bona fide activities and this cover extends to those individuals who have been granted formal Observer Status.

Although not an employee of the Trust you will be required to be bound by the policies and procedures of the Trust in so far as they are applicable to someone who is not a Trust employee. You will also be required to follow any local rules of the Department to which you are attached and these will be brought to your attention by your supervisor Dr Barry Ingham.

In case of carrying out research, you must comply with all reporting requirements, systems and duties of action put in place by the Trust to deliver research governance.

G:\HumanResources\VCHRecruitment\Honorary Contracts4. Contract Templates\2. Clinical Observer Access
If you follow all the various policies, procedures, rules, instructions and guidance, you will be protecting yourself should any mishap occur. If you are unsure about any policies, procedures or rules, you should raise these with your supervisor Dr Barry Ingham or the Directorate Support Team.

Please ensure you familiarise yourself with relevant policies. All of our policies can be found on the Trust intranet.

I should be grateful if you would confirm in writing your acceptance of the arrangements described above. A copy of this letter has been sent to your supervising consultant.

Yours Sincerely

Michelle Moley
Directorate Support Team Coordinator

CC: Dr Barry Ingham
    Laura Frisby
Dear Lynsey,

Project 2012-14: Attachment in Intellectual Disabilities: Investigating the contribution of attachment security to challenging behaviour.

R&D reference: 12/NW/0701

Following the approval by Greater Manchester East Research Ethics Committee and Calderstones Partnership NHS Foundation Trust Research Approval Committee, I am pleased to confirm that your proposed research study within Calderstones can proceed.

I would bring your attention to the responsibilities of researchers and principal investigator required by this Trust in accordance with the Department of Health’s Research Governance Framework. All research conducted within this Trust must comply with the full requirements of the Research Governance Framework for Health and Social Care (www.dh.gov.uk) and fully adhere to the submitted protocol approved by Calderstones Partnership NHS Foundation Trust and the relevant Research Ethics Committee.
This letter provides proof that the relevant Trust committees have formally reviewed your project and that the R&D Lead has formally approved your project. Members of staff from Caldicot NHS Partnership Trust are fully entitled to ask to see your formal letter of approval before they agree to allow you to access a ward or have any contact with other members of staff or service users or carers from the Trust.

A representative from the Research Department will contact you to monitor the progress of your research within Caldicot NHS Partnership Trust. Please inform the department immediately of any proposed changes, amendments to or deviations from the ethics committee and research governance approved protocol. On completion of the research, you will be requested to forward a copy of your final report and complete any relevant feedback and necessary information as required by the Trust and specific directors involved in funding your research. In the dissemination of the research, the Trust may request you to present your research study and findings.

Best wishes for your research and I look forward to finding out more about the progress and outcomes. Please contact Rachel Lloydhouse 01254 821289 or Paula Johnson 01254 824916 in the Research and Development Department if you require any further information and guidance at any stage of the research study.

Yours sincerely,

Rachel Lloydhouse
Research Governance Coordinator
Appendix G – Staff participant information sheet

Full title: Attachment in Intellectual Disabilities: Investigating the contribution of attachment security

Information sheet 1 – Information for staff participants/services (Version 3)

16/10/12

Short title of study: Attachment and challenging behaviour in adults with Intellectual Disabilities

I am a Trainee Clinical Psychologist, based at the University of Manchester. As part of my training I am conducting a research study. I would like to invite you to take part in the study. Before you decide I would like you to understand why the research is being done and what it would involve for you. I will go through the information sheet with you and answer any questions you have. This should take about 10 minutes. Please feel free to talk to others about the study if you wish and ask me if there is anything that is not clear. There is also a research protocol that you can look at that provides more detailed information.

Aim of the research study
The study aims to use a new measure of secure attachment, called the Manchester Attachment Scale—Third party observational measure (MAST). The MAST is for staff to use with individuals with Intellectual Disabilities. The study also hopes to discover how much of an impact attachment has on a person’s engagement in challenging behaviour when other contributing factors are controlled for.

Reason for the study
Infants develop an affectional bond with their main caregiver during the first year of life called ‘attachment’. This attachment relationship helps us develop ways to cope with our emotions. We know a lot about attachment in children and adults, but our knowledge of attachment in adults with Intellectual Disabilities is limited.

There is increasingly more research examining Intellectual Disabilities and attachment. For example, some studies suggests that challenging behaviour presented by people with Intellectual Disabilities may be associated with attachment difficulties. Developing a greater understanding of attachment is crucial, as this will help plan future interventions and improve outcomes for individuals with Intellectual Disabilities.

Due to the lack of research in this area, there are considerable potential research benefits to others gained from the results of the study. A greater understanding of Intellectual Disabilities, attachment and challenging behaviour will help plan services to meet the needs of individuals with Intellectual Disabilities.

Who is organising and funding the study?
The University of Manchester. The study has been reviewed by the University of Manchester Research Ethics Sub-committee and by the National Research Ethics Service Committee North West – Greater Manchester East.

Why have I been asked to take part?
You have been asked to take part in the study due to your experience of working with individuals with Intellectual Disabilities. The aim is to recruit 70 staff participants who can complete measures about the service users they support.
Do I have to take part in the study?
No, participation is voluntary. If you do agree to participate, you can leave the study at any time without giving any reasons; this will not impact upon you or your job role.

What happens if I take part?
You will be asked to complete a number of questionnaires:
- The MAST
- The Adaptive Behaviour Assessment Schedule
- The Problem Behaviour Inventory
- The Aberrant Behaviour Checklist
- The Glasgow Depression Scale – Learning Disability
(Copies of the questionnaires are attached to this sheet). You will be asked to complete the above questionnaires based upon the knowledge you have of an individual you are supporting with an Intellectual Disability, who has given consent for the study. The individual does not have to be present when you fill out the questionnaires. It will take approximately 90 minutes to complete all the questionnaires.

How long will the study last?
You will be asked to complete questionnaires within a 2 week period. This can be done at your own convenience and I will then return to collect them. I am aware that many staff may have used the questionnaires before as they are widely used in services. However, my contact details are below and I will be available should you have any questions or queries about the questionnaires.

Risks of participating in the study
Risks - There is low risk of negative consequences resulting from participating in the study. As the questionnaires take 90 minutes to complete it may be difficult to have the time to complete them. Following completion of questionnaires, you will be offered the opportunity to have a debriefing session with the researcher, to answer any questions or concerns. In the unlikely event you become distressed during participation, you will be withdrawn from the study and the researcher will provide you with support.

Will my personal details be confidential?
All records will be kept confidential. Names will not be recorded on any of the questionnaires that you complete, so that your identity will be anonymous and private throughout the study. If you decide to take part, you will be asked to complete a consent form which will have your name on it. This will be separated from the questionnaires, so that participants can not be identified from their responses on the questionnaires. Only I and my research supervisors will see the completed questionnaires.

What happens to the information collected and when the study finishes?
All staff and service user participants will be invited to a feedback session. During this session the existing research regarding attachment theory will be presented, as well as a summary of the key findings from this study. The results of the study will form part of a report that will be submitted to the University of Manchester and examined as part of my training course. Once the report has been examined the findings will be published in a peer reviewed journal. In light of the questionnaires being confidential, I will be unable to give individual feedback regarding the questionnaires completed concerning people with Intellectual Disabilities.
What if I have a problem about the study?

Complaints
Please speak to me about any concerns you may have about this study. I will do my best to answer your questions. If I am unable to help, or you wish to make a complaint about the study, please contact a member of the University research team on 0161 2757583 or 0161 2750093 or by email to research-agreement@manchester.ac.uk.

Harm
In the event that something does go wrong and you are harmed during the research you may have grounds for a legal action for compensation against The University of Manchester but you may have to pay your legal costs. The normal National Health Service complaints method will still be available to you.

The University of Manchester has cover for no fault compensation for bodily injury, mental injury or death where the injury resulted from a procedure as part of the study. This would be subject to policy terms and conditions.

Any payment would be without legal commitment. (Please ask if you wish more information on this).

The University would not be bound to pay this compensation where the harm resulted from a procedure when the study protocol was not followed.

How do I get involved with the study?
I will visit your service to tell you more about the study and answer any questions. You will then have a minimum of 24 hours to consider whether you wish to support the research and participate in the study.

When you and your service have decided whether they would like to participate, you will be asked a number of questions to check you are fully aware of what the study involves, and will be asked to sign a consent form.

Who can I contact for further information?
Lynsey Fulton
Trainee Clinical Psychologist
University of Manchester
Division of Clinical Psychology
Second Floor, Zochonis Building
Brunswick Street
Manchester
M13 9PL
Tel: 0161 306 0400
Email: lynsey.fulton@postgrad.manchester.ac.uk

Please do not hesitate to contact me if you have any questions.

Thank you for taking the time to read this information sheet.
Information sheet 2 - Information for participants (version 3)

18/10/12

Full title: Attachment in Intellectual Disabilities: Investigating the contribution of attachment security to challenging behaviour

Short title of study: Attachment and challenging behaviour in adults with Intellectual Disabilities

Please read this sheet carefully. (NB to be read aloud if the person has any literacy difficulties)

I am a Trainee Clinical Psychologist from the University of Manchester. As part of my training I am doing some research. I would like to invite you to take part in the study.

To help you decide, it is important that you understand why the research is being done and what it would involve for you. I will go through an information sheet with you and answer any questions you have. This should take about 10 minutes. Please talk to others about the study if you wish. Please ask me if there is anything that is not clear.

We are asking people to take part in a study about how people with Intellectual Disabilities cope with different feelings.

What is the research study about?
The study aims to help understand how a person’s relationships can affect how they cope with emotions. By improving our understanding of this, we can then find ways to help people who have difficulties managing emotions.

Version 3, 18th October 2012
Reason for the study
Young children develop a relationship with their main caregiver in the first year of life called 'attachment'. This 'attachment' helps us find ways to cope with our emotions. We know a lot about attachment in children and adults, but less is known about attachment in adults with Intellectual Disabilities.

The study will help us understand more about attachment and how it affects the ways people with Intellectual Disabilities cope with their feelings. This will help us find the best ways to support people with Intellectual Disabilities.

Who is organising and funding the study?
The University of Manchester: The study has been reviewed by:
- The University of Manchester Research Ethics Subcommittee
- The National Research Ethics Service Committee North West - Greater Manchester East.

Why have I been asked to take part?
You have been asked to take part because you are supported by a learning disability service. The aim is to recruit 70 people with Intellectual Disabilities and their carers.

Do I have to take part in the study?
No, taking part is voluntary. If you agree to take part, you can leave the study at any time without giving any reasons. This will not impact on you, or the service you are receiving.

What does the study involve?
I will meet with you to explain the study. You will then be asked to think about whether you want to give permission, for

Version 3, 18th October 2012
carers to provide some information about you. This permission is also known as 'consent'.

If you decide to give consent your carer will then be asked to fill out some questionnaires.

The questionnaires ask about some of the things you are good at and some of the things you may find difficult. The questionnaires also ask about what you might do when you are upset and how you cope with different feelings.

**How long will the study last?**
Each person will be asked to give consent for carers to answer questions about them. If consent is given 2 things will happen:

1. I will meet with carers to give them questionnaires.
2. I will return 2 weeks later to collect the questionnaires that staff have completed.

**Risks of participating in the study**
It is unlikely that taking part in the study will cause you any harm.

However, if, at any stage you become upset about carers providing information about you, this can be stopped. You can withdraw your consent at any time. The researcher will come to speak to you and ask you what would help you feel better. She will also offer to talk and listen to you.

The researcher may also speak to their supervisor for advice about how to help you when you are upset. She may also talk to your carers so that they can help you. The researcher will always ask your permission before she speaks to anyone else about you. The researcher may also ask you if you want to see a psychologist so that you can talk about any worries you have.

*Version 3, 18th October 2012*
Will my personal details be confidential?
All records will be kept confidential. This means that your name will not be recorded on any of the questionnaires, so that your identity will be private. If you decide to give consent, you will be asked to complete a consent form, which will have your name on it. This will be separated from the questionnaires, so that answers on the questionnaires can not be identified. Only I and my research supervisors will see the completed questionnaires.
Confidentiality would only be breached if information was gained either from you or from staff that made the researcher concerned for your safety. If this was to happen the researcher would have to speak to the service manager about the information. The service manager may then have to speak to other professionals about the information. The researcher would speak to you about this at the time to keep you informed about what is happening.

What happens to the information collected when the study finishes?
All staff and service user participants will be invited to a feedback session. During this what is already known about attachment will be presented, as well as a summary of the key findings from this study. The results of the study will form part of a report that the University of Manchester will examine as part of my training course. Once the report has been examined the findings will be published in scientific journals.

What if I have a problem about the study?
Complaints
Please speak to me about any concerns you may have about this
study. I will do my best to answer your questions. If I am unable to help, or you wish to make a complaint about the study, please contact a member of the University research team on 0161 2757583 or 0161 2758093 or by email to research.governance@manchester.ac.uk. If you would like to speak to someone who is not connected to the research, you can contact MENCAP on 0808 808 1111.

Harm
In the event that you are harmed during the study you may have grounds for a legal action for compensation against The University of Manchester. You may have to pay your legal costs. The normal National Health Service complaints method will still be available to you.

The University of Manchester has cover for no fault compensation for bodily injury, mental injury or death where the injury resulted from a procedure as part of the study. This would be subject to policy terms and conditions.

Any payment would be without legal commitment. (Please ask if you wish more information on this).

The University would not be bound to pay this compensation where the harm resulted from a procedure when the study protocol was not followed.

How do I get involved with the study?
I will visit you to explain the study.

You will have a minimum of 7 days to consider whether you wish to give consent.

When you have decided if you would like to give consent or not, you will be asked a number of questions to check you

Version 3, 18th October 2012
understand what the study involves. You will then be asked to sign a consent form.

**Who can I contact for further information?**

Lynsey Fulton  
Trainee Clinical Psychologist  
University of Manchester  
Division of Clinical Psychology  
Second Floor, Zachonis Building  
Brunswick Street  
Manchester  
M13 9PL  
Tel: 0161 306 0400  
Email: lynsey.fulton@postgrad.manchester.ac.uk

Please do not hesitate to contact me if you have any questions.

Thank you for taking the time to read this information sheet.
Appendix I – Staff participant consent form

Consent form – For staff participants (Version 3)

Full title of study: Attachment in Intellectual Disabilities: Investigating the contribution of attachment security to challenging behaviour

Short title of study: Attachment and challenging behaviour in adults with Intellectual Disabilities

Researchers: Lynsey Fulton, Dr Dougal Julian Here, Dr Andrea Flood, Dr Sam Walker.

(NB: To accompany participant information sheets 1. To be read aloud if the person has any literacy difficulties that might impact upon their understanding)

Please read this sheet carefully and tick each box

Participant Identification Number:

1. The researcher has been through the information sheet with me. I understood the information sheet dated ............ (version ........). I have had time to think about the study and have had the time to ask the researcher any questions about the study.

2. I understand that my participation in the study is voluntary and that I am free to leave the study at any time, without giving any reason, and my legal rights will not be affected

3. I understand that information collected during the study may be looked at by staff that want to check the research and that people doing the research are doing their job correctly. For example staff at the University of Manchester, or NHS Trusts. I give permission for these staff to see this information.

4. I understand that the results of the study will form part of a report for the University of Manchester. The report will also be published. I agree that my answers from the assessments/questionnaires can be in the report.

5. I agree to take part in the above study

Name of participant __________________________ Signature __________________________

Date of signature __________________________________________

Name of researcher __________________________ Signature __________________________

Date of signature __________________________________________

When completed 1 copy for participant and 1 copy for researcher.
Appendix J – Service user participant consent form

Consent form – For service user participants (Version 1)

Full title of study: Attachment in Intellectual Disabilities: Investigating the contribution of attachment security to challenging behaviour

18/10/12

Short title of study: Attachment and challenging behaviour in adults with Intellectual Disabilities

Researchers: Lynsey Fulton, Dr Dougal Julian Hare, Dr Andrea Flood, Dr Sam Walker.

(NR: To accompany participant information sheet 2. To be read aloud if the person has any literacy difficulties that might impact upon their understanding).

Please read this sheet carefully and initial each box

Participant Identification Number:

1. The researcher has been through the information sheet with me. I understand the information sheet dated ............. (version ........). I have had time to think about the study and have had the time to ask the researcher any questions about the study.

2. I understand that giving consent is voluntary and that I am free to withdraw at any time, without giving any reason, my medical care and my legal rights will not be affected.

3. I understand that information collected during the study may be looked at by staff who want to check the research and that people doing the research are doing their job correctly. For example staff at the University of Manchester, or NHS Trusts. I give permission for those staff to see this information.

4. I understand that the results of the study will form part of a report for the University of Manchester. The report will also be published. I agree that my carers’ answers from the questionnaires can be in the report.

5. I agree to give consent for staff to fill in questionnaires that will ask information about me.

Name of participant __________________________ Signature __________________________

Date of signature __________________________

Name of researcher __________________________ Signature __________________________

Date of signature __________________________

When completed 1 copy for participant and 1 copy for researcher.

The University of Manchester, Oxford Road, Manchester M13 9PL
Appendix K – Questionnaire pack

Service user demographic Information (Version 1) Manchester M13 9PL

Full title of study: Attachment in Intellectual Disabilities: Investigating the contribution of attachment security to challenging behaviour
09/04/12

Short title of study: Attachment and challenging behaviour in adults with Intellectual Disabilities

Researchers: Lynsey Fulton, Dr Dougal Julian Here, Dr Andrea Flood, Dr Sam Walker.

Please complete the following with regards to the service user.

1. Gender (please circle) M F

2. Age ___________

3. Has this person ever had a formal assessment of their learning disability? Y N
   If yes, what was the outcome of this? _______________________________________
   __________________________________________________________
   __________________________________________________________

4. Does this person have a known genetic syndrome or developmental disorder? Y N
   If so, please give details _____________________________________________
   ______________________________________________________________
   ______________________________________________________________

5. Does this person have any mental health difficulties e.g. anxiety, depression, personality issues etc.? Y N
If so, please give details

6. Does this person have any diagnosed medical Conditions (including NEAD or Pseudo seizures) Y N

7. Has this person been cared for within the Looked After Children system (e.g. foster care, adoption etc?) Y N

In your opinion, does this person have any secure attachments? ______

________________________________________
Due to copyright legislation, electronic versions of other included questionnaires have not been presented. For a copy of these questionnaires, please see the attached pocket.
Appendix L – Capacity assessment template

ASSESSMENT OF CAPACITY TO PARTICIPATE IN RESEARCH

This mental capacity assessment tool is designed specifically to support and record the assessment of an individual’s decision making capacity with regards to participating in the research project 'Attachment in Intellectual Disabilities: Investigating the contribution of attachment security to challenging behaviour'.

This research project is being completed by Lynsey Fulton, Trainee Clinical Psychologist. Individuals who are assessed as not having capacity will be appointed a personal consultant, or if not available, a nominated consultant, in line with the Department of Health guidance on nominating a consultant for research, accessible on http://webarchive.nationalarchives.gov.uk/20130107105334/http://www.dh.gov.uk/en/PublicationsPolicyAndGuidance/DH_083131

Name of participant:
Date of birth:

Person/s assessing:
Job Title/s:
Date/s of assessment
Location of assessment

What is the decision that has to be made (the 'Decision in Question')?

(Please note: The MCA Code of Practice makes it clear that this should be a particular and time specific decision. If a range of decisions need to be taken then the capacity of the individual should be assessed in relation to each of the individual decisions and documented separately.)

Whether <name> has the capacity to decide whether to participate in the research project entitled 'Attachment in Intellectual Disabilities: Investigating the contribution of attachment security to challenging behaviour'.
## STEP 1: The Decision Making Process

In order for an accurate assessment to be undertaken it is important that the individual is presented with adequate information about the decision, in a way that is understandable, and in an environment that maximises understanding and communication. The issue of fluctuating capacity should also be considered and whether the decision can be delayed to allow the individual’s decision making ability to improve. The following information therefore informs the process of completing an accurate assessment of capacity to be completed in Step 2.

<table>
<thead>
<tr>
<th>Step</th>
<th>Description</th>
</tr>
</thead>
</table>
| 1.   | Has the person been given all the relevant information needed to make the decision in question?  
      | Is there a choice?  
      | Has information been given on the alternatives?  
      | Please provide details |
| 2.   | Has the information been explained or presented in a way that is easy for the person to understand?  
      | (videos, diaries, role-play)  
      | Does the person have any sensory difficulties e.g. hearing and/or sight loss that needs to be taken into account? Please check if person uses a hearing aid or wears glasses to aid vision.  
      | Please provide details |
| 3.   | Are there particular times of the day when the person’s understanding is better?  
      | Are there particular locations where the person may feel more at ease?  
      | Please provide details |
| 4.   | Can anyone else help or support the person to make the choice, or express the view e.g. relative, advocate, someone to assist communication. (use of sign language, interpreter, picture bank, talking for the person at their request/under their direction)  
      | Please provide details |
| 5.   | Can the decision be delayed until the circumstances are right for the person (this could include people with fluctuating capacity)?  
      | Please provide details |
**STEP 2: Assessment of Capacity**

Having ensured that the relevant information has been presented to the individual in such a way that maximises understanding and communication, including taking into account any sensory difficulties, the following two stage test of capacity should be undertaken. Information documented in STEP1 can be used to help inform your assessment of capacity.

**TEST A**

<table>
<thead>
<tr>
<th>1. Does the person have an impairment of, or a disturbance in the functioning of the mind or brain?</th>
<th>Please provide details</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>❌</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2. Is the impairment temporary/Fluctuating or permanent?</th>
</tr>
</thead>
<tbody>
<tr>
<td>If the impairment is temporary or fluctuating can the decision be delayed until the individual’s decision making ability has improved?</td>
</tr>
<tr>
<td>Please provide details</td>
</tr>
</tbody>
</table>

**Point 1:** If you have answered NO to Point 1 then you should assume that the person has capacity to make the decision. Please proceed to STEP 4 (Conclusion) to record this outcome. If you have answered YES to Point 1 then you may proceed to Test B overleaf, with consideration of the outcome of Point 2 below.

**Point 2:** If the individual has temporary/Fluctuating capacity and delaying the decision is felt to be appropriate then please proceed directly to STEP 4 (Conclusion) to record this outcome.

If the person has temporary/Fluctuating capacity but it is felt that the decision cannot be delayed due to necessity (eg: to avoid deterioration or maintain good care) or urgency (eg: serious medical treatment) please proceed to Test B overleaf.

**TEST B**

For a person to lack capacity to make a decision, the MCA says their impairment or disturbance must affect their ability to make the specific decision when they need to. As indicated in STEP 1 (the decision making process) people must be given all practical and appropriate support to help them make the decision for themselves. Information recorded in STEP 1 may help you determine the individual’s capacity. The following test is therefore designed to establish whether the impairment or disturbance is sufficient enough that the individual lacks capacity to make that particular decision at the time it needs to be made.
<table>
<thead>
<tr>
<th></th>
<th>Question</th>
<th>Please provide details</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Does the person have an understanding of the decision and why they are being asked to make it?</td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>No</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Don’t Know</td>
</tr>
<tr>
<td>2.</td>
<td>Does the person have a general understanding of the effects/ consequences of deciding one way or another or making no decision at all?</td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>No</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Don’t Know</td>
</tr>
<tr>
<td>3.</td>
<td>Is the person able to hold the information in their mind long enough to use it to make an effective decision?</td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>No</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Don’t Know</td>
</tr>
<tr>
<td>4.</td>
<td>Is the person able to weigh up the information and use it to arrive at a decision?</td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>No</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Don’t Know</td>
</tr>
<tr>
<td>5.</td>
<td>Can the person communicate their decision (e.g. talking, signed language, other form of communication)?</td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>No</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Don’t Know</td>
</tr>
</tbody>
</table>

**STEP 3: Additional Information**

1. External influences on the decision making process

When assessing capacity, it is important to take into consideration the views and opinions of other people. It may be the case that the opinions of others are an important consideration in why an individual has made a particular decision. This is entirely reasonable. Consideration should however be made in cases where it appears that a person has been subject to coercion from another (including professionals) to such an extent that they lack the capacity to make a decision.
extent (for example the making of threats) that their ability to make a free and balanced decision may have been impaired. Comments if any:


2. Other information referred to as part of the assessment of capacity
If any other information such as support protocols, or reports such as risk assessments and management plans, or professionals (e.g. Psychology, Speech and Language Therapy, Medical) have been used / consulted please outline below and to what extent they have contributed to help determine capacity. Please include name of individuals and date consulted or report completed.

STEP 4: Conclusion

I consider that the person DOES have capacity to make this decision
☐
This decision should be reached if you have answered 'No' to Test A. or if proceeding to Test B you have answered 'Yes' to all five parts. The influence of external influences as outlined in 'Additional information' Step 3 (1) above should also be considered.

I consider that the person does NOT have capacity to make this decision
☐
This decision should be reached if you have answered 'Yes' to Test A. and if you have answered 'No' to one or more sections in Test B.

I consider that this person has temporary/fluctuating capacity and that the decision can be reasonably and safely DELAYED until such time that capacity can be re-assessed.

Signature of person/s assessing

Post titles of person/s assessing

Date of assessment

Should the named individual be found to NOT have the capacity to make this decision, please complete the following information regarding the appointed consultee:

1. Please select the type of consultee appointed:
   Personal ☐
   Nominated ☐

(N.B. A 'Personal Consultant' will be someone who knows the person who lacks capacity well but is not acting in a professional or paid capacity, for example, a family member, carer or friend or an attorney acting under a Lasting Power of Attorney.
A 'Nominated Consultant' will be a third party unconnected with the research who is willing to act as a nominated consultee, for example, care staff or G.P.)

2. If a Personal Consultant has not been appointed please state why:
   • No family member or friend is willing and able to act as committee ☐
   • The family or friends live a long distance away and/or are not in frequent contact with the person who lacks capacity ☐
• The regular carers of the person who lacks capacity are □
doing so for payment or in a professional capacity (e.g. care home
staff or nurses)

• Other (Please state) □

3. Name of committee  ____________________________

4. Relationship to participant  ____________________________
Appendix M – Consultee information sheet

Full title: Attachment in Intellectual Disabilities: Investigating the contribution of attachment security

Information sheet 3. Information for Consultees (Version 2)

Researchers: Lynsey Fulton, Dr Dougal Julian Hare, Dr Andrea Flood, Dr Sam Walker.

17/04/13

Short title of study: Attachment and challenging behaviour in adults with Intellectual Disabilities

I am a Trainee Clinical Psychologist, based at the University of Manchester. As part of my training I am conducting a research study. I would like to invite you to take part in the study. Before you decide I would like you to understand why the research is being done and what it would involve for you. I will go through the information sheet with you and answer any questions you have. This should take about 10 minutes. Please feel free to talk to others about the study if you wish and ask me if there is anything that is not clear. There is also a research protocol that you can look at that provides more detailed information.

Aim of the research study

The study aims to use a new measure of secure attachment, called the Manchester Attachment Scale-Third party observational measure (MAST). The MAST is for staff to use with individuals with Intellectual Disabilities. The study also hopes to discover how much of an impact attachment has on a persons engagement in challenging behaviour when other contributing factors are controlled for.

Reason for the study

Infants develop an affectional bond with their main caregiver during the first year of life called 'attachment'. This attachment relationship helps us develop ways to cope with our emotions. We know a lot about attachment in children and adults, but our knowledge of attachment in adults with Intellectual Disabilities is limited.

There is increasingly more research examining Intellectual Disabilities and attachment. For example, one study suggests that challenging behaviour presented by people with Intellectual Disabilities may be associated with attachment difficulties. Developing a greater understanding of attachment is crucial, as this will help plan future interventions and improve outcomes for individuals with Intellectual Disabilities.

Due to the lack of research in this area, there are considerable potential research benefits to others gained from the results of the study. A greater understanding of Intellectual Disabilities, attachment and challenging behaviour will help plan services to meet the needs of individuals with Intellectual Disabilities.

Who is organising and funding the study?

The University of Manchester.

Why have I been approached?

You have been approached because concerns have been raised that the person with Intellectual Disabilities may not have the capacity to consent to information being provided about them for the purpose of the study. Therefore it is hoped that you may be able to decide if it would be in the best interests of the client for this information to
be provided by staff. The aim is to recruit approximately 70 staff participants who can complete measures in relation to service users.

**What happens if I decide it is in the person’s best interests?** Staff will be asked to complete a number of questionnaires:
- The MAST
- The Adaptive Behaviour Assessment Schedule
- The Problem Behaviour Inventory
- The Aberrant Behaviour Checklist
- The Glasgow Depression Scale – Learning Disability
- A Trauma Inventory
- A Service User Demographic information sheet

Staff will be asked to complete the above questionnaires based upon the knowledge they have of an individual they are supporting with an Intellectual Disability. The individual does not have to be present when staff fill out the questionnaires. It will take approximately 90 minutes to complete all the questionnaires.

**How long will the study last?**
Staff will be given a minimum of 2 weeks to complete questionnaires which can be completed at their convenience.

**Risks of participating in the study**
Risks - There is low risk of negative consequences resulting from participating in the study. Following completion of questionnaires, staff will be offered the opportunity to have a debriefing session with the researcher. In the unlikely event that staff become distressed during participation, they will be withdrawn from the study and the researcher will provide them with support.

**Will personal details be confidential?**
All records will be kept confidential. Names will not be recorded on any of the questionnaires that are completed, so the identity of staff and service users will be anonymous and private throughout the study. Only I and my research supervisors will see the completed questionnaires.

**What happens to the information collected and when the study finishes?**
All staff and service user participants will be invited to a feedback session, which you will also be able to attend. During this session the existing research regarding attachment theory will be presented, as well as a summary of the key findings from this study. The results of the study will form part of a report that will be submitted to the University of Manchester and examined as part of my training course. Once the report has been examined the findings will be published in a peer reviewed journal. In light of the questionnaires being confidential, I will be unable to give individual feedback about specific service users.

**What if I have a problem about the study?**
Complaints
Please speak to me about any concerns you may have about the study. I will do my best to answer your questions. If I am unable to help, or you wish to make a complaint about the study, please contact a member of the University research team on 0161 2757563
or 0161 2758093 or by email to research@mganecareatmanchester.ac.uk.

Harm
In the event that something does go wrong and staff or service users are harmed during
the research there may be grounds for a legal action for compensation against the
University of Manchester but you may have to pay legal costs. The normal National
Health Service complaints method will still be available to you.

The University of Manchester has cover for no fault compensation for bodily injury,
mental injury or death where the injury resulted from a procedure as part of the study.
This would be subject to policy terms and conditions.

Any payment would be without legal commitment. (Please ask if you wish more
information on this).

The University would not be bound to pay this compensation where the harm resulted
from a procedure when the study protocol was not followed.

How do I get involved with the study?
I will speak with you to tell you more about the study and answer any questions. You
will then have a minimum of 24 hours to consider whether you feel it is in the person’s
best interests to allow staff to provide information. I will provide you with a consent
form which asks a number of questions to check you are fully aware of what the study
involves. If you so wish, you can then sign this form to provide consent.

Who can I contact for further information?
Lynsey Fulton
Trainee Clinical Psychologist
University of Manchester
Division of Clinical Psychology
Second Floor, Zochonis Building
Brunswick Street
Manchester
M13 9PL
Tel: 0161 306 0400
Email: lynsey.fulton@postgrad.manchester.ac.uk

Please do not hesitate to contact me if you have any questions.

Thank you for taking the time to read this information sheet.
Appendix M-Consultee declaration form

Consultee Declaration Form (Version 2)

21/03/13

Short title of study: Attachment and challenging behaviour in adults with Intellectual Disabilities

Researchers: Lynsey Fulton, Dr Dougal Julian Hare, Dr Andrea Flood, Dr Sam Walker.

(NR: To accompany participant information sheets 1. To be read aloud if the person has any literacy difficulties that might impact upon their understanding).

Please read this sheet carefully and tick each box.

Participant Identification Number:

1. The researcher has been through the information sheet with me. I understand the information sheet dated ………….. (version …………). I have had time to think about the study and have had the time to ask the researcher any questions about the study.

2. I understand that staff participation in the study is voluntary and that they are free to leave the study at any time, without giving any reason, and their legal rights will not be affected.

3. I understand that information collected during the study may be looked at by staff that want to check the research and that people doing the research are doing their job correctly. For example staff at the University of Manchester, or NHS Trusts. I give permission for these staff to see this information.

4. I understand that the results of the study will form part of a report for the University of Manchester. The report will also be published.

5. In my opinion he/she would have no objection to staff participating in the study.

Name of consultee __________________________ Signature __________________________

Date of signature __________________________

Name of researcher __________________________ Signature __________________________

Date of signature __________________________

The University of Manchester, Oxford Road, Manchester M13 9PL
Appendix O – Graph showing frequency of experience and/or witness of potentially traumatic events