Attachment and Trauma in People with Intellectual Disabilities

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

2014

Melanie Powney

School of Psychological Sciences
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Attachment and trauma in people with intellectual disabilities

Melanie Powney

Doctorate in Clinical Psychology

University of Manchester, 2014

Abstract

This thesis explored attachment in individuals with intellectual disability (ID). It investigated the role that attachment may have in presenting difficulties, including trauma symptoms, which has a growing body of literature, particularly in people without ID.

Paper 1 describes a systematic review of the available literature relating to the psychological well-being of young people with ID in the UK who are 'looked after children' (LAC) or who live away from their birth families. Evidence suggests that both LAC and people with ID, may be vulnerable to developing mental health difficulties. However, there is a paucity of research investigating the psychological well-being of young people with ID who are LAC or who live away from birth families. 17 studies were reviewed, which ranged between 21% and 71% in quality as measured by the QATSDD (Sirriyeh, Lawton, Gardner, & Armitage, 2012). Only one study was found that directly focused on the psychological well-being of LAC with an ID. The available studies offered some insights into the prevalence, characteristics of young people with ID who are LAC or who live away from their birth families and some of the psychological difficulties they encounter. However, given the methodological limitations of the included studies, no firm conclusions could be drawn.

Paper 2 describes an empirical study that investigated the relationship between attachment security and trauma symptoms in adults with ID. 27 staff and service users participated in the research. Service user participants completed a self-report questionnaire regarding trauma symptoms with the researcher and staff participants provided demographic information and completed questionnaires that measured attachment security, trauma symptoms, depressive mood and traumatic events in relation to the service user. No relationship was found between attachment security and trauma symptoms. However, it provided tentative evidence with respect to the type of traumatic events experienced by people with ID and of the prevalence of mental health difficulties in people with ID. There were however several methodological limitations, including a small sample size. Implications for future research and clinical practice are outlined.

Paper 3 provides a critical and personally reflective account of undertaking the systematic review and empirical study as outlined above. Strengths and limitations of the research are interwoven throughout. Recommendations for future research and implications for practice are also considered.
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Acknowledgements

I would like to thank all of the services who were involved in this research; to service managers for supporting the project, to staff who helped facilitate recruitment and to all of the service users and staff who participated for their time and effort.

There have been 'twists and turns' throughout this project, and so I would like to thank my research supervisor, Dr. Dougal Hare for being a constant source of support and guidance. I would also like to thank Dr. Andrea Flood, Dr. Sam Walker, Dr. Ali Davies, Dr. Barry Ingham and Dr. Anja Wittkowski for their valuable contributions to this thesis.

Finally, thank you to all of my family, friends and my Gracie, who have helped me through this process with their boundless encouragement, understanding and love.
The psychological well-being of young people with intellectual disabilities in the UK who are 'looked after children' or who live away from their birth families: A systematic review

Prepared with a view to submit to Adoption & Fostering

2014

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Word count: 6197
Abstract

Children and young people with intellectual disabilities (ID) who are 'looked after children' (LAC) or who live away from their birth families may be vulnerable to developing emotional and behavioural difficulties. However, the National Institute for Clinical Excellence (NICE) guidance for working with looked after children (NICE, 2010) does not include recommendations for working with LAC with ID due to insufficient evidence. In this systematic review, 17 published articles are examined that can offer some insight into the psychological well-being of children and young people who are LAC or who live away from their birth families. The majority of the studies used quantitative methodology, with two using mixed methods. In the main, these studies provide evidence regarding the prevalence, characteristics and placement types for these young people in the UK, however only one study directly focuses on the psychological well-being of LAC with ID. Recommendations for future research and implications for practice are proposed.

Keywords

Intellectual disability, learning disability, looked after children, mental health, United Kingdom

1.1 Introduction

There are a number of ways that children and young people with ID may come to live away from their birth parents. Where children have multiple disabilities it may be too difficult for some parents to care for their children at home, leading to children being placed in specialised day and residential programmes, which have been criticised for being exclusive environments (Brown, et al., 2011).
Another way that children may come to live away from their birth parents is that they may become 'looked after' by the local authority, either voluntarily or as the result of a care order made by the court (Jones, et al., 2011). Children and young people enter into care for a number of reasons, including neglect, abuse and other factors that may make it difficult for children to receive adequate parenting such as disability in the child or parent (Glenndenning, 2013). LAC are placed in a range of settings, including remaining with family members through kinship care, with foster carers, in children's homes, residential schools, hospitals and secure units.

It is difficult to quantify the number of LAC in the UK due to differences across the countries in how data is collected and published and how LAC is defined. However, the NSPCC estimate that there were over 92 000 LAC in the UK in 2013 (NSPCC, 2014). Knowing how many LAC have an ID is more problematic because whilst data is available on how many children are looked after because of a disability, it is unclear whether this means physical or intellectual disability and further, it is not known how many children with ID become looked after due to other factors, such as neglect or abuse (NSPCC, 2013). It seems that to date, Scotland is the only country to collect data on how many of their LAC have an ID, which in 2012 stood at 261 (Scottish Government, 2013).

Research suggests that LAC are more at risk of adverse outcomes including educational, behavioural and physical health problems (Meltzer, et al., 2003) and mental health difficulties (Blower, et al., 2004; Mount, Lister and Bennum, 2004), which may in part be explained by disrupted attachment relationships and early
maltreatment (Rutter, 2000). LAC with ID may be particularly vulnerable given the finding that children with an ID are more at risk than their non-disabled peers of experiencing neglect or physical, emotional or sexual abuse (Sullivan and Knutson, 2000), developing mental health problems (Emerson, 2003) and developing an insecure attachment style (Ganiban, Barnett and Cicchetti, 2000), which is a risk factor for developing psychological difficulties (Abela, et al., 2005).

1.1.1 Review Aim

This systematic review sought to identify any research undertaken in the U.K. that could offer insight into a) the psychological well-being of children and young people with an ID who are LAC or who live away from their birth families, b) the prevalence and characteristics of this client group and c) service provision and interventions being used for this client group.

1.2 Method

1.2.1 Inclusion Criteria

Papers published in peer reviewed journals that presented original data and directly provided evidence regarding the psychological well-being of children with ID who were LAC or who lived away from birth families were selected for inclusion. Studies using quantitative, qualitative and mixed method approaches were included.

Papers were excluded if results of the studies were not presented separately for ID and non-ID or LAC and non-LAC. Further, papers were excluded if they were not written in English, as was ‘grey literature’, including case studies, book chapters, dissertations, literature reviews, commentaries, conference abstracts, letters and
editorials. Studies were also excluded if any participant was aged over 21 years of age.

Whilst it was acknowledged that research undertaken outside of the UK may be applicable to the psychological well-being of children with ID in the UK and UK practice, the decision was taken to exclude research outside of the UK as one method of keeping the number of included studies at a manageable level.

The decision was taken to exclude orphanage studies as it could not be clear as to whether these children had experienced privation rather than deprivation in their attachment relationships (Rutter, 1998).

1.2.2 Search Strategy

The databases Applied Social Sciences Index and Abstracts (ASSIA), CINAHL Plus, EMBASE, MEDLINE, PsycINFO and Science Direct were searched in August 2013. Limits were applied to restrict results to English language, peer reviewed and published between 1989-2013. 1989 was chosen as a cut off as this coincides with the UK Children’s Act 1989, which was assumed to have marked a significant and still relevant change in practice in the UK as whole.

The following search terms were used; (mental health OR psycholog* OR emotional well-being OR psychiatr*) AND (looked after OR LAC OR foster* OR residential OR adopt* OR children in care OR local authority) AND (child* OR adolescen* OR teenage* OR infant* OR young people OR young person) AND
(intellectual disabilit* or learning disabilit* OR disabled person OR developmental disabilit* OR retard* OR neurodevelopment* OR mental handicap OR subnormal).

The electronic search was undertaken on the 7th August 2013 and a total of 1608 articles were identified, which reduced to 1274 when search results from the separate databases were imported EndNote X6, combined in one file and duplicates removed. To prevent relevant articles being discarded, it is recommended that two researchers review the search results (Edwards, et al., 2002). However, due to restraints on resources, this was not possible. Therefore, a single researcher, M.P. reviewed all 1274 titles and abstracts. 39 studies were identified and full text copies were obtained for closer inspection. Discussion regarding eligibility took place between M.P. and her supervisor, D.H. In total, 9 studies from the electronic search met inclusion criteria. Given the limitations of electronic searches (Hopewell, et al., 2007), the following journals were hand searched; Adoption & Fostering, British Journal of Clinical Psychology and the Journal of Intellectual Disability Research. A further six papers were identified. The reference lists of included studies were also scrutinised and a further two studies were found through this method. Figure 1 outlines the details of the selection process.
Figure 1: Flowchart of study selection process

Total records from databases = 1608
(ASSIA = 232, CINAHL = 391, EMBASE = 300, MEDLINE = 342, PsycINFO = 297, Science Direct = 46)

Duplicates removed = 334

Total records screened on basis of title and abstract = 1274

Total records excluded on basis of title and abstract = 1235

Full text articles obtained and screened for eligibility = 39

Total full text papers obtained from hand search = 8

Total records excluded on basis of eligibility criteria = 30

Reasons
Does not answer research question = 11
Orphanage study = 5
LAC/non-LAC not separate in analysis = 3
ID & non-ID not separate in analysis = 2
ID & LAC presented separately = 1
Case study = 4
Focus on ASD = 1
Outside age range = 1
Outside UK = 1
Study not completed = 1

Total studies included in the review = 17
1.2.3 Quality Assessment

As two of the included studies used mixed methods, the seventeen studies were assessed using the QATSDD. The QATSDD is a 16-item quality assessment tool, which has shown good inter-rater reliability \((k = 71.5\%)\) and validity for the assessment of studies with diverse designs (Sirriyeh, et al., 2012). For accuracy, the QATSDD was designed to produce an overall quality rating expressed as a percentage (Sirriyeh, et al., 2012). Whilst all identified studies that met the inclusion criteria were presented in Table 1, for the purposes of the current review, only studies that were rated above 33.3\% were discussed in further detail in the body of the text (Petticrew and Roberts, 2006).

1.3 Results

1.3.1 Overview of Studies

A summary of the studies found can be found in Table 1.
### Table 1: Summary of Studies

<table>
<thead>
<tr>
<th>Authors, Year, Country</th>
<th>Study Purpose</th>
<th>N</th>
<th>Sample characteristics</th>
<th>Method</th>
<th>Assessment tools</th>
<th>Analysis</th>
<th>Relevant results</th>
<th>Score/rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beail (1989), England</td>
<td>Evaluation of a staffed house for children with severe learning difficulties</td>
<td>6</td>
<td>Aged 12-17 5 males, 1 female</td>
<td>Quantitative: Observation &amp; questionnaire</td>
<td>RCCMS-R</td>
<td>Not reported</td>
<td>Children received higher standard of care than in hospital</td>
<td>23%</td>
</tr>
<tr>
<td>Brown et al. (2011), Scotland</td>
<td>Evaluation of residential &amp; day care for children with cognitive &amp; behavioural challenges</td>
<td>23</td>
<td>Aged 6-19 Majority at full time residential care, 17 had ID diagnosis</td>
<td>Mixed methods: Interviews &amp; focus groups</td>
<td>None</td>
<td>Interviews coded and quantified</td>
<td>11 children demonstrated overall change</td>
<td>36%</td>
</tr>
<tr>
<td>Chadwick et al. (2008), England</td>
<td>Risk factors associated with behaviour problems in adolescents with ID</td>
<td>82</td>
<td>Aged 13-17 46 males, 36 females, 50% BME, varied placements</td>
<td>Quantitative: Follow up longitudinal study using interview &amp; questionnaires</td>
<td>DAS, SCQ, VS, ASQ, TS I-V</td>
<td>Univariate, multi-variate &amp; logistic regression, odds ratio</td>
<td>Lack of continuity of maternal care was associated with behaviour problems</td>
<td>62%</td>
</tr>
<tr>
<td>Ford et al. (2007), England, Scotland, Wales</td>
<td>Prevalence of psychiatric disorder in LAC</td>
<td>1543</td>
<td>Aged 5-15, 57.4% male, 42.6% female, living in various placements</td>
<td>Quantitative: Survey - postal questionnaires and structured interview</td>
<td>DAWBA, SDQ</td>
<td>Chi-square, ANOVA, logistic regression</td>
<td>LAC had higher rates of educational &amp; neurodevelopmental difficulties</td>
<td>62%</td>
</tr>
<tr>
<td>Study</td>
<td>Study Title</td>
<td>Setting/Population</td>
<td>Participants</td>
<td>Methods</td>
<td>Findings</td>
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<tr>
<td>Gralton et al. (1998), England</td>
<td>Use of antipsychotic medication in children with ID</td>
<td>Aged below 19 years</td>
<td>235</td>
<td>Survey &amp; review of medical notes WQ, ICD-9, RMAC</td>
<td>Institutional care was not associated with increased challenging behaviour</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Hillen et al. (2012), England</td>
<td>Mental health needs of pre-school LAC</td>
<td>Aged 0-6 years, 29 males, 14 females, various placements</td>
<td>43</td>
<td>Chi-square, t-test, Cohen's k ASQ: SE, PAPA, ICD-10, RCPL, PIR-GAS, MSEL, PSRS,</td>
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<td>11 preschoolers had a developmental disability, 7 had a mental health disorder</td>
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<tr>
<td>Kiernan &amp; Kiernan (1994), England &amp; Wales</td>
<td>Challenging behaviour in schools for pupils with severe learning difficulties</td>
<td>Aged 1-20 years</td>
<td>1029</td>
<td>Structured interview pilot, postal survey Not reported</td>
<td>Only 6 non-independently mobile children with difficult behaviour lived with their parents full time</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>McConkey et al. (2004), Northern Ireland</td>
<td>Characteristics of LAC with disabilities</td>
<td>Aged 1-19 years, 64 males, 44 females, all were LAC for more than 90 days in a year</td>
<td>108</td>
<td>Chi-square Structured interview using own pro-forma t-tests, regression analysis</td>
<td>Marked differences across four NHS Trusts with regard to need and service provision</td>
<td></td>
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<tr>
<td>Minnis et al. (2006), Scotland</td>
<td>Mental health needs of LAC</td>
<td>Mean age 11 years</td>
<td>182</td>
<td>SDQ, RAQ, CFCQ t-tests, regression analysis</td>
<td>High rates of mental health need in LAC, 28% described as having a learning disability</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Study</td>
<td>Population Description</td>
<td>Sample Size</td>
<td>Age Range</td>
<td>Methodology</td>
<td>Analysis</td>
<td>Findings</td>
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<tr>
<td>Minns et al. (1989), Scotland</td>
<td>Neurodevelopmental study of children with profound ID in hospital care</td>
<td>21</td>
<td>Aged 23 months to 17.75 years</td>
<td>Quantitative: Cohort study</td>
<td>None</td>
<td>Children with profound ID require intensive support</td>
<td></td>
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</tr>
<tr>
<td>Pilling et al. (2007), England &amp; Wales</td>
<td>Characteristics &amp; experiences of children at 52 week residential schools</td>
<td>156</td>
<td>Aged 8-19 years, 77% male, 23% female</td>
<td>Quantitative: postal survey</td>
<td>Not reported</td>
<td>Residential school provides educational and social support but may increase vulnerability</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pollock &amp; Farmer (2005), England</td>
<td>Needs of LAC who have been sexually abused or abuse others</td>
<td>Not clear</td>
<td>51% aged below 10 years</td>
<td>Quantitative: case note review</td>
<td>Case note material was coded</td>
<td>In those that had been sexually abused, 14 had learning difficulties, 3 had severe learning difficulties</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rao et al. (2010), England</td>
<td>Specialist CAMHS involvement with LAC</td>
<td>82</td>
<td>Aged 5-17 years</td>
<td>Quantitative: case note review</td>
<td>Case note material was coded</td>
<td>1 child with mental health problems was not offered intervention. They had LD so referred to LD services</td>
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<tr>
<td>Rees &amp; Selwyn (2009), England</td>
<td>Non-infant adoption</td>
<td>130</td>
<td>Aged 6 to 11 years</td>
<td>Mixed methods: Cohort study, questionnaires &amp; interview</td>
<td>SDQ, PCCS</td>
<td>65% of children had developmental delay. Adopters reported LD affected closeness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study (Year, Location)</td>
<td>Population</td>
<td>Sample Size</td>
<td>Methodology</td>
<td>Findings</td>
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<tr>
<td>Rees (2013), Wales</td>
<td>Mental health, emotional literacy, cognitive ability &amp; resilience of LAC</td>
<td>193</td>
<td>Aged 7-15 years (101 males, 92 females, range of placement types)</td>
<td>Quantitative: Questionnaire and case note audit</td>
<td>SDQ, ELAII, BAS II, BAS II-AS</td>
<td>Independent t tests, chi-square, regression discrepancy analysis</td>
<td>High incidence of LD with 17% obtaining GCA score below 70 in contrast with 2% of norm population</td>
<td></td>
</tr>
<tr>
<td>Taggart et al. (2007), Northern Ireland</td>
<td>Emotional, behavioural &amp; mental health needs of LAC</td>
<td>165</td>
<td>Aged 10-15 years, ID group (n=37), non-ID group (n=128)</td>
<td>Quantitative: Cohort study, social work report review, questionnaires</td>
<td>SDQ</td>
<td>Chi-square</td>
<td>LAC with ID more likely to have emotional &amp; behavioural problems</td>
<td></td>
</tr>
<tr>
<td>Vostanis et al. (2008), England</td>
<td>Service use of LAC - includes learning difficulty</td>
<td>1039</td>
<td>Aged 5-17 years</td>
<td>Quantitative: Survey</td>
<td>DAWBA</td>
<td>Kappa</td>
<td>80.9% of LAC with conduct disorder had learning difficulties</td>
<td></td>
</tr>
</tbody>
</table>

Abbreviations: CAMHS - child & adolescent mental health services; ID - intellectual disability; LD -learning disability; LAC - looked after children

Assessments: ASQ: SE - Ages and Stages Questionnaire: Social Emotional (Squires, Bricker & Twombly, 2003); ASQ - Autism Screening Questionnaire (Berument et al., 1999); BAS II - British Ability Scales II (Elliot, 1997); BAS II-AS - British Ability Scales II- Achievement Scale (Elliot, 1997); CFCQ - Cost of Foster Care Questionnaire (not published); DAS - Disability Assessment Schedule (Holmes et al., 1982; Wing 1989); DAWBA - Development and Well-Being Assessment (Goodman et al., 2000); ELAII - Emotional Literacy: Assessment and Intervention Inventory (Faupel, 2003); ICD-9 - International Classification of Diseases (World Health Organization, 1978); ICD-10 - International Classification of Diseases (World Health Organization, 1992); MSEL - Mullen Scales of Early Learning (Mullen, 1995); PAPA - Preschool Age Psychiatric Assessment (Egger & Angold, 2006); PCCS - Parent-Child Communication Scale (Skinner et al. 1983); PIR-GAS - The Parent Infant Global Assessment Scale (ZERO TO THREE, 2005); PSRS - The Placement Stability Rating Scale (not published); RAD - Reactive Attachment Disorder Questionnaire (Minnis et al., 2002); RCCMS-R - Revised Child Care Management Scale-Revised (King et al., 1971); RCPL - Relationship Problem Checklist (ZERO TO THREE, 2005); RMAC - Rutter's Multi-axial Classification (Rutter et al. 1975); TS I-V - Tanner Stages I-V (Morris & Udry, 1980); SCQ - Social Communication Questionnaire (Rutter et al., 2003); SDQ - Strengths and Difficulties Questionnaire (Goodman, 1997; Goodman et al., 2001); VS - Vineland Screener (Sparrow et al., 1984); WQ - Wessex Questionnaire (Kushlick et al., 1973).
1.3.2 Study Characteristics

The identified studies were diverse both in terms of focus and methodological approaches, which created difficulty in presenting and synthesising the findings in a meaningful way. The studies fell under four broad categories; 1) Studies that directly examined the psychological well-being of children and young people living away from home (Taggart, Cousins and Milner, 2007); 2) Studies that commented on the characteristics and/or service provision for children and young people with ID who live away from home in various settings (Beail, 1989; Brown, et al., 2011; McConkey, et al., 2004; Minns, et al., 1989; Pilling, McGill and Cooper, 2007); 3) Studies that used a wholly ID sample, some of whom lived away from birth families (Chadwick, Kusel and Cuddy, 2008; Gralton, James and Lindsey, 1998; Kiernan and Kiernan, 1994) and 4) Studies that used a LAC sample, some of whom had learning difficulties, developmental delay or an ID (Ford, et al., 2007; Hillen, et al., 2002; Minnis, et al., 2006; Pollock and Farmer, 2005; Rao, Ali and Vostanis, 2010; Rees and Selwyn, 2009; Rees, 2013; Vostanis, et al., 2008).

Eleven studies included data from England, four from Wales, four from Scotland and two from Northern Ireland. Two studies (Brown, et al. 2011; Rees and Selwyn, 2009) used a mixed method design, whereas the remaining fifteen studies used quantitative methods, mainly cross sectional surveys and cohort studies.

1.3.3 Studies that directly examined the psychological well-being of LAC with ID

Only one study, Taggart et al. (2007) sought to directly examine the emotional, behavioural and mental health status of LAC with an ID and this was rated as 48% in quality. Taggart et al. (2007) collected data from social work reports and the
Strengths and Difficulties Questionnaire (SDQ, Goodman, 1997) for 165 young people who were aged ten to fifteen years old, living in state care in Northern Ireland and compared the data of LAC with ID (22.4%) with LAC without ID. Of the thirty-seven young people with ID, 59.5% were male, 40.5% were female and their mean age was 12.24 years. All were reported to have a diagnosed mild or moderate ID. More than half of the LAC with ID sample lived in residential care with the others living with foster carers or kinship foster carers.

For more than half of the LAC with ID, this was not their first admission into care, with the number of previous admissions ranging from six to twenty-four. The majority of LAC were in "long term" placements. All but one of the young people were reported to have a sibling, with twenty-one of them having siblings in state care. However, only seven resided with their siblings with no reported future plans to place them together. When compared with the non-ID LAC sample, there were no significant differences between the two cohorts with respect to gender, age, length of stay, legal status or type of accommodation.

There were various reasons reported as to why the young people had come into care. The most common reason cited was because parents had little (if any) control over the young person's disruptive and confrontational behaviour, followed by parental alcohol abuse and parental inability to provide care. The children in the LAC with ID group had a range of health related problems, with speech impairment, dietary concerns, dental issues, attention deficit hyperactivity disorder and mental health problems being the most frequently reported. Comparison between the ID and non-ID cohort of social worker reports of emotional and
behavioural problems suggested that LAC with ID were significantly more likely to exhibit attention seeking behaviour, challenging behaviour, sexualised behaviour, problems with self care, hyperactivity, self-harm, obsessive compulsive disorder and enuresis. Other problematic behaviours reported that did not reach statistical significance were absconding behaviour, physical aggression, smoking, stealing and fire setting.

When comparing the SDQ scores for LAC with ID and LAC without ID, children in the ID cohort scored significantly higher for hyperactivity and total difficulties but not for emotional symptoms, conduct problems, peer problems and pro-social behaviour, for which there were no statistically significant differences. According to the SDQ data, three-quarters of LAC with ID were rated by their social workers as potentially having a mental health difficulty.

When comparing the five subscales and Total Difficulties Score of the SDQ for the ID and non-ID LAC with normative data from a British 11-15 year old sample, the ID cohort had higher mean scores compared with the non-ID and normative sample on all five of the sub-scales and Total Difficulties Score on the SDQ.

1.3.4 Studies that comment on characteristics and/or service provision

There were five studies in total that offered insight into the characteristics and/or service provision for children and young people with ID who were LAC or who lived away from birth families across a variety of settings, including residential care, hospital and foster care. Pilling et al. (2007) was quality assessed as 38%, Brown et al. (2011) as 36%, Beail (1989) as 33%, McConkey et al. (2004) as 33%
and Minns et al. (1989) as 29%. Therefore, only Pilling et al. (2007) and Brown et al. (2011) will be described in further detail.

Brown, et al. (2011) conducted qualitative interviews and focus groups with twenty-three families that were coded to provide quantitative data to examine the impact of residential and day care support for children with major behavioural and cognitive challenges. The study provides some insight into prevalence data in that over half of the eighty-three students were "full residential term time students", however, it does not report on psychological well-being.

Likewise, Pilling et al. (2006) focused on the characteristics and experiences of children with severe ID and challenging behaviour who attended 52 week residential schools. However, they used a different method, sending postal questionnaires to staff. Data was obtained for 156 children and young people, aged eight to nineteen years old. Around three-quarters of the sample were male, predominately White British, and length of stay at the schools ranged from one month to eleven years. There was diversity within the young people with regard to their verbal and non-verbal communication skills. 12% of the young people required the use of a wheelchair or walking aids, 92% were described as having normal vision and 97% had normal hearing. There was great disparity with respect to the frequency of contact with a range of health professionals but for education, 99% had a designated key worker and had individual tuition or support in addition or instead of class activities.
Challenging behaviour was recorded for all but two of the pupils, with non-compliance, social disruption, aggression and temper tantrums being reported in over 90% of the sample. Other problematic behaviours cited for the majority of young people were self-injury, sleeping problems, inappropriate sexual behaviour and hyperactivity. Around a quarter of the young people were prescribed medication for behaviour management, with Risperidone, an atypical antipsychotic, being cited as the most frequently used. 63% of children had a formal written plan for the use of restraint and 10.9% required protective devices on a daily basis.

1.3.5 Studies that used an ID sample, some of whom lived away from birth parents

There were three studies that used a wholly ID sample, where some of the children lived away from birth families. Chadwick et al. (2008) was quality assessed as 62%, Gralton et al. (1998) as 43% and Kiernan and Kiernan (1994) as 33%, therefore the latter study will not be described in further detail.

Chadwick et al. (2008) conducted a follow up longitudinal study to investigate risk factors associated with behaviour problems in adolescents with severe learning difficulties. They found that children who experienced a lack of continuity in maternal care demonstrated significantly more destructive and overactive behaviour. Lack of continuity of paternal care was associated with overactivity and objectionable behaviour. Out of the eighty-two young people with an ID, six were in full-time institutional care (children’s homes or 52 week residential school) and another six attended residential school as weekly or term-time boarders. Therefore,
it is not clear whether these behaviour problems relate to children who live with or away from their birth parents.

Gralton et al. (1998) undertook a survey and case note review study to explore the use of antipsychotics and psychiatric diagnosis in young people with an ID. They found that institutional care was not associated with an increased prevalence of psychiatric disorder or challenging behaviour, and whilst there was increased use of antipsychotics within institutions, this did not meet statistical significance. Children with ID who had epilepsy, cerebral palsy and visual handicap were more likely to receive institutional care.

1.3.6. LAC studies that offer some insight into the needs of LAC with ID

Eight LAC studies were found that included data on LAC with ID. Hillen et al. (2012) was quality assessed as 71%, Vostanis et al. (2008) as 62%, Ford et al. (2007) as 62%, Minnis et al. (2006) as 55%, Rees (2013) as 48%, Rao et al. (2010) as 34%, Rees and Selwyn (2010) as 29% and finally Pollock and Farmer (2005) as 21%. Therefore, the latter two will not be described in further detail.

In the largest of these studies, Ford et al. (2007) combined the data from three surveys to compare the socio-demographic characteristics and psychopathology of British LAC with children living in deprived and non-deprived private households. They found that LAC were significantly more likely to have a neurodevelopmental disorder, autistic spectrum disorder and have a mental age less than 60% less than their chronological age than both disadvantaged and non-disadvantaged children living in private households. They also found that carer reports of learning
difficulties, literacy and numeracy problems and statement of educational needs were greater in both LAC and children from disadvantaged private households when compared with non-disadvantaged children living in private households. Their analysis suggests that that looked after status interacted with learning difficulties in "an additive way", whereby learning difficulties resulted in a similar percentage increase in the prevalence of psychiatric disorder in LAC and those living in private households.

Again, using survey data, Hillen et al. (2012) found that 25.6% of their sample of preschool LAC fulfilled criteria for at least one developmental disorder and Vostanis et al. (2008) found that 80.9% of LAC with a conduct disorder also had learning difficulties. Rees (2013) examined the mental health, emotional literacy, cognitive ability, literacy attainment and 'resilience' in 193 LAC and found, according to scores derived from the British Ability Scales II (BAS II, Elliot, 1997), that 17% had a learning disability. However, data was not presented in a way to establish the mental health needs of LAC with an ID.

Two studies focused on service use of LAC (Minnis, et al.2006; Rao, et al. 2010). Minnis et al. (2006) studied service use and cost in 182 foster children, 28% of whom were described as having a learning disability. Learning disability, whether or not the child had previously experienced residential care and the Total Difficulties Score on the SDQ (Goodman, 1997) were all found to be a significant predictor of cost. Two families were identified who required a high frequency of social work contact, both of whom cared for a child with a learning disability. Both of these children had high symptom scores for reactive attachment disorder and the
highest possible score for hyperactivity on the SDQ. Rao et al. (2010) examined characteristics and referrals to a specialist CAMHS team and found that the only person with a mental health difficulty not to be offered an intervention was a young person with a learning disability who was subsequently referred to a specialist learning disability team.

1.4 Discussion

Taken together, the LAC studies that were assessed as over 33.3% in quality, offer insight into the prevalence, characteristics, physical and mental health needs of LAC with ID, as well as service provision. The prevalence of LAC that were described as having a developmental disorder or ID ranged from 12.8% to 28% (Chadwick, et al. 2008., Ford, et al. 2007; Hillen, et al., 2003; Minnis, et al., 2006; Rees, 2013; Taggart, et al., 2007), with one study demonstrating that ID was a significant predictor of service cost (Minnis, et al., 2006).

With regard to characteristics, the studies would suggest that there is a higher prevalence of males than females in young people with ID who are LAC or who live away from birth parents (Pilling, et al., 2006; Taggart, et al., 2007), with various reasons for entry into care, largely parental difficulty in managing their child's difficult behaviour (Taggart, et al., 2007).

The available studies suggested that LAC with ID and young people with ID attending 52 week residential schools had a number of physical health problems, including epilepsy, cerebral palsy (Gralton, et al., 1998) and visual handicap (Gralton, et al. 1998; Pilling, et al. 2006), and were diverse with respect to their
verbal and non-verbal communication skills (Pilling, et al., 2006; Taggart, et al., 2007).

Whilst Taggart et al. (2007) was the only study to directly investigate the mental health needs of LAC, another seven studies offered some findings that were relevant to the psychological well-being of young people with ID who are LAC or who live away from their birth families (Chadwick, et al., 2008; Ford, et al., 2007; Gralton, et al., 1998; Minnis, et al., 2006; Pilling, et al., 2006; Rao, et al., 2010; Vostanis, et al., 2008). High levels of challenging behaviour were reported in children and young people who attended residential schools (Pilling, et al., 2006) and in LAC with ID (Taggart, et al., 2007). Although Vostanis et al. (2008) found that a high proportion of LAC with a conduct disorder also had learning difficulties, it is not clear whether these children would meet the criteria for ID. Other difficulties that were cited for children and young people with ID who are LAC or who live away from birth families were; self-injury, sleeping problems, inappropriate sexual behaviour (Pilling, et al., 2006; Taggart, et al., 2007), hyperactivity (Pilling, et al., 2006; Minnis, et al., 2006; Taggart, et al., 2007) and reactive attachment disorder (Minnis, et al, 2006). Chadwick et al. (2008) found some evidence to suggest that disruption to continuity of maternal and paternal care was associated with over active behaviour, however it was not clear whether their finding related to children who lived away from their birth parents.

Taggart et al. (2007) goes further to suggest that not only do LAC with ID experience more emotional and behavioural difficulties than the general population, but that they are more likely to exhibit more hyperactivity, total difficulties,
enuresis, attention seeking behaviour and obsessive compulsive disorder than looked after children without an ID, with three-quarters of LAC with ID being rated as having a probable mental health need. An explanation for this increased incidence of need may be provided by Ford et al's. (2007) finding that learning difficulties led to a similar degree of increased prevalence of psychiatric disorder in both LAC and those living in private household. However, it is not clear whether the level of learning difficulty would meet the threshold for ID.

What was clear from the available studies is that there is a wide range of ways that children and young people with ID may become LAC or live away from birth families, with a variety of placement types, including foster care and residential schools (Brown, et al., 2011), which themselves vary in attendance type (e.g. weekly boarder or term time boarders) and length of stay (Pilling, et al. 2006), with Gralton et al. (1998) suggesting that LAC with ID were more likely to receive institutional care, where they had additional disabilities such as epilepsy and cerebral palsy.

There was very little available information found about interventions offered, with Rao et al (2010) highlighting that the only LAC with a mental health difficulty not to be offered an intervention was a child with ID who was subsequently referred to a specialist learning disability team. Pilling et al. (2006) indicated that there was great disparity among young people with ID at a 52 week residential school with regard to contact with health professionals, that over half had a formal written plan for the use of restraint and that a quarter were prescribed medication, mainly antipsychotic medication, for behaviour management. The increased use of
antipsychotics within institutions was also highlighted in the Gralton et al. (1998) study, although this did not meet statistical significance.

1.4.1 Methodological challenges and limitations

The lack of two independent researchers to screen the electronic search results and to quality assess the studies included in this review, present a threat to the reliability of this systematic review. Further, it is noteworthy that around half of the included studies in this review were discovered by hand searching and the reference screen of the included papers. Whilst this provides further evidence to support the use of hand searching, it may indicate that the electronic search strategy was not robust. Therefore, it is possible that other studies exist that comment on the psychological well-being of children and young people with ID who are LAC or who live away from birth parents, which are not included in this systematic review.

A threat to the validity of this review is the inclusion of studies where the sample are described as having neuro-developmental disorders, learning disabilities and learning difficulties, not just solely intellectual disabilities, reflecting the changing definitions. Where a sample has been described as having learning difficulties (e.g. Beail, 1989; Kiernan and Kiernan, 1994; Vostanis, et al., 2008), this has been made clear for the reader in the summary table (Table 1).

A further complicating factor was the wide range of placement type for children with ID who are LAC or who live away from home. Therefore, in the 52 week residential school studies, whilst some pupils will attend as a result of parental choice, some may be there having come through the LAC system and may therefore
have experienced more early adversity. Conversely, in the LAC studies, it is possible that depending on the type of care order, some LAC children continued to live with birth parents (e.g. McConkey, et al., 2004), which presented difficulty in trying to infer anything from the results regarding the effects of separation from care-givers.

1.5 Future research

Of the seventeen studies included in this review, the highest quality rating given was 71%. Given the complex needs of children and young people with ID who are LAC or who live away from home, it is pressing that high quality studies employing robust methodology are undertaken, not only to identify the characteristics and psychological well-being of LAC with ID but also to ascertain what kinds of intervention are being used with this client group and evaluation of their efficacy.

Given that people with ID are not a homogenous group, it is likely that the needs of LAC with ID will be heterogeneous. Therefore, future research may want to include samples that are homogenous in some way (e.g. examining interventions that address attachment difficulties in LAC with Down's syndrome). However, this would require a multi-site study, otherwise potentially there would be a small sample size.

1.6 Clinical implications

The findings of the studies included in this review would suggest that children and young people with an ID who are LAC or who live away from their birth families have complex needs, including mental health difficulties and physical disabilities,
which has implications for the way in which services are commissioned to target this client group and adequately meet their needs. Some evidence of difficulties in current service design is provided by the Rao et al. (2010) study, whereby the only LAC with a mental health difficulty not to be offered an intervention by specialist LAC CAMHS, was a LAC with ID who was subsequently referred to a specialist learning disability service. Within this team, there were separate operational procedures for the LAC and learning disability teams. However, given the prevalence of LAC with ID, this would suggest that either people working in CAMHS LAC services should receive training in working with young people with an ID or that there should be more joined up working so that LAC with ID get the benefit of the specialist skills of clinicians from both pathways.

It is noteworthy that the main reason for LAC with ID coming into care was parental difficulty in managing their child's difficult behaviour (Taggart, et al., 2007). This would imply that services should invest resources in parenting interventions, aimed at both improving the child's behaviour and promoting an attuned attachment relationship, to reduce the likelihood that children with ID and behaviour that challenges will become LAC.

In order for the needs of young people with ID who are LAC or who live away from their birth families to be more readily identifiable, it is recommended that services review their procedures with regards to what information is collected about service users. Further, recording data regarding the nature of a young person's disability, for example, whether this relates to a physical or intellectual disability, would be valuable to enable service development.
1.7 Conclusion

This review sought to bring together the available evidence relating to the psychological well-being of children and young people with an ID in the UK who are LAC or who live away from birth families. Despite the evidence that LAC and people with ID may be at increased risk of developing mental health difficulties, there is a paucity of research in this area, with one study being identified that directly examined the psychological well-being of LAC with ID. Behaviour that challenges, hyperactivity, self-injury, sleeping problems, inappropriate sexual behaviour and reactive attachment disorder were some of the difficulties cited. However, due to the methodological limitations of the included studies, no firm conclusions could be drawn. There is a need for further research, employing more robust methodology, so that the psychological needs of this client group can be more readily identified and the efficacy of interventions be evaluated.
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Attachment in adults with intellectual disabilities: Investigating the relationship between attachment security and trauma symptoms

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Abstract

Objective. This study explored the degree to which attachment security accounts for variation in reported traumatisation in adults with mild to moderate intellectual disabilities. It was also investigated whether differences in attachment security and trauma symptoms existed between adults who were 'looked after children' (LAC) compared with those who remained in the family home prior to adulthood. Additional data regarding the Manchester Attachment Scale Third Party was also collected as part of this study.

Methods. Twenty-seven pairs of staff and service user participants were recruited from NHS and independent learning disability services. Service user participants completed a self-report trauma measure and staff completed measures about service users' attachment, trauma symptoms, traumatic experiences and mood. The relationship between key variables were analysed.

Results. No statistically significant relationships were found between secure attachment behaviours and traumatic symptoms or number of traumatic events experienced. Statistically significant differences were not found in attachment security or self-reported trauma symptoms between adults who were once 'looked after children' compared with those who remained in the family home.

Conclusion. This study does not provide evidence to suggests that there is a relationship between attachment security and the development of trauma symptoms in response to traumatic events in adults with ID, nor differences in attachment security and trauma symptoms between adults, who prior to adulthood were LAC or
remained in the family home. Further research is required in this area, which utilises more robust methodology.

**Practitioner points**

**Positive clinical implication**

- No relationship was found between attachment security and trauma symptomatology.
- Over 90% of the sample had experienced or witnessed a potentially traumatic event.

**Limitations**

- The small sample size meant the study was underpowered to detect differences between groups.
- Purposive sampling is likely to have introduced bias.

**2.1 Introduction**

**2.1.1 Intellectual disability**

Intellectual disability (ID) is a disability that originates before the age of 18 and is characterised by significant limitations in adaptive behaviour (everyday social and practical skills) and intellectual functioning (reasoning, learning, problem solving), the latter being usually taken as an IQ score <70 (Schalock *et al.*, 2010).

**2.1.2 Trauma and intellectual disability**

To date, studies suggest that people with ID are more likely than the general population to experience traumatic and adverse events such as sexual abuse (Sequeira & Hollins, 2003), physical abuse (Focht-New, Clements, Barol, Faulkner,
& Pekala, 2008), bereavement and moving house (Hatton & Emerson, 2004), with one prospective study demonstrating a causal and cumulative relationship between psychopathological symptoms and previous exposure to negative life events in adults with ID (Esbensen & Benson, 2006).

Whilst exposure to traumatic events does not necessarily result in mental health problems (Bonnano, 2004) some people go on to develop post-traumatic stress disorder (PTSD). Pynoos, Steinberg, & Piacentini (1999) proposed that coping with traumatic events requires the capacity to appraise, process, and encode the trauma memory as well as an ability to regulate emotions. A number of individual factors influencing the development of PTSD have been identified, including intelligence (Bowman, 1999) good communication skills (Phillips, Prince, & Schiebelhut, 2004), cognitive functioning (Kremen et al., 2007), motivational abilities such as self-efficacy and locus of control (Simmen-Janevska, Brandstätter, & Maercker, 2012), cognitive appraisals and coping strategies such as problem solving and expression of emotion (Duraković-Belko, Kulenović, & Dapić, 2003). Many of these factors may be affected by ID, which may therefore constitute a vulnerability factor for developing PTSD (Finzi-Dottan, Dekel, Lavi, & Su’ali, 2006).

PTSD has been included in the ‘Diagnostic Manual - Intellectual Disability’ (Fletcher, Loschen, Stavrakaki, & First, 2007). However, there is no established conceptualisation of trauma in people with ID and little empirical evidence to support the symptom criteria (Wigham, Hatton, & Taylor, 2011). Until recently with the development of the Lancaster and Northgate Trauma Scales (LANTS; Wigham et al., 2011) and the Impact of Event Scale-Intellectual Disabilities (IES-IDs; Hall, Jobson, & Langdon, 2014) there was no psychometrically valid self-
report measure for trauma in people with intellectual disability, which has contributed to the paucity of research in this area.

2.1.3 Attachment

Attachment is conceptualised as the affectional tie that a person forms with a specific individual (Salter Ainsworth, 1969). Bowlby (1969) argued that the first attachment relationship that infants are likely to form is with their primary caregiver and that 'attachment behaviours' such as crying, clinging and smiling are designed to create close proximity between the child and caregiver, are innate and essential for survival. When infants are frightened or distressed, their attachment system and behaviours are activated in order to achieve satisfaction, safety and security (Carr, 2006). When caregivers are attuned to the needs of the child, physiological arousal and emotional distress is reduced and the attachment system 'switches off' (Howe, 2006). Ainsworth, Blehar, Waters, & Wall (1978) proposed that when an attuned response is consistent and sufficiently sensitive, children will develop a secure attachment to their caregivers who provide a secure base from which the child can explore the world. However, when the caregiver's response is inconsistent for whatever reason, or the caregiver is consistently physically or emotionally unavailable, or abusive, the child may develop insecure (Ainsworth et al., 1978) or 'disorganised' (Main & Soloman, 1990) attachment relationship, whereby children re-organise their attachment behaviour to maintain their caregiver's interest in them (Crittenden, 2006). Infant attachment quality has been shown to be related to cortisol stress reactivity (Luijk et al., 2010) and insecurely attached children may be at increased risk of developing psychological problems (Carr, 2006). Research suggests that 'looked after children' may be more at risk of having an insecure
attachment style because they are likely to have experienced neglect, maltreatment or institutionalisation (van den Dries, Juffer, van IJzendoorn, & Bakermans-Kranenburg, 2009).

Bowlby (1969) noted that through the caregiver’s response, infants construct an internal working model that guides both the child's behaviour and strategies for managing stress in times of distress, loss or danger (Rutgers, Bakersman-Kranenburg, van Ijzendoorn, & van Berckelaer, 2004). These internal working models allow humans to predict how the self and significant others will behave in relationships, thus providing a template for future intimate relationships (Carr, 2006). Attachment is a two-way process and other factors, such as the infant’s temperament also influence attachment security (Ganiban, Barnett, & Cicchetti, 2000).

2.1.4 Attachment and intellectual disability

The propensity to seek proximity and comfort with a preferred attachment figure when distressed is demonstrated in studies with children with Down syndrome (Thompson, Cicchetti, Lamb, & Malkin, 1985) and autism (Dissanayake & Crossley, 1996). As per typically developing children, after controlling for level of ID, secure attachment in children with ID has been linked to positive developmental outcomes (John, Morris, & Halliburton, 2012), including better social interaction skills (Willemsen-Swinkels, Bakermans-Kranenburg, Buitelaar, van IJzendoorn, & van Engeland, 2000). However, research indicates that children with ID are more likely than typically developing children to exhibit insecure attachment behaviour (Ganiban, Barnett, & Cicchetti, 2000; Naber, et al., 2007; Rutgers, et al., 2004, Vaughn et al., 1994), particularly in children with both ID and autism spectrum
disorder (van IJzendoorn, *et al.*, 2007). However, insecure and disorganised attachment styles do not neatly correlate with the increased level of ID and again there is an interplay between child and parent factors in developing attachment security (Howe, 2006). Proposed reasons for impaired attachment in ID include caregiver's unresolved grief regarding their child’s ID diagnosis (Marvin & Pianta, 1996), atypical attachment signals from the child which may be more difficult for caregivers to interpret (Janssen, Schuengel & Stolk, 2002), parental stress (Baxter, Cummins, & Yiolitis, 2000) and increased stressful experiences and appraisals in people with ID (Schuengel & Janssen, 2006). Janssen *et al.* (2002) purport that pre-school children with ID may lack the planning skills and cognitive flexibility required to develop a goal-directed relationship whereby the child and caregiver accommodate each other’s needs.

However, other studies have not found significant differences between people with ID and comparison samples with regards to secure attachment behaviours. Rutgers *et al.* (2007) found that whilst children with autism were more at risk of insecure attachment than non-clinical samples, children with an ID were not. In contrast, Willemsen-Swinkels *et al.* (2000) found no significant differences in secure attachment between children with a pervasive developmental disorder and non-clinical samples, however children were more likely to be classified as 'disorganised' if they had co-morbid pervasive developmental disorder and an ID.

One barrier to research in this area with people with ID has been a lack of empirically tested measures. However, the Manchester Attachment Scale - Third party observational measure (MAST; Penketh, Hare, Flood, & Walker, 2013) has recently been developed, which has been shown to have good reliability and validity.
2.1.5 Trauma, attachment and intellectual disability

In studies of people without ID, securely attached individuals have been shown to be less likely to develop PTSD after exposure to traumatic events than those with insecure attachment styles (Dieperink, Leskela, Thuras & Engdahl, 2001; Zakin, Solomon, & Neria, 2003), possibly due to utilising less emotion-focused coping strategies (Benoit, Bouthillier, Moss, Rousseau, & Brunet, 2010). However, it would seem that this relationship is not that 'clear cut' as other studies have found that in addition to secure attachment relationships, insecure attachment of the dismissive type was also protective (Declercq & Willemsen, 2006; Muller, Sicoli, & Lemieux, 2000). Conversely, in Cohen, Dekel, & Soloman's (2002) study of child Holocaust survivors, securely attached and preoccupied individuals were less at risk of developing PTSD than those with a highly avoidant style. However, in former political prisoners, it was securely attached individuals who were more vulnerable to PTSD than insecure-preoccupied individuals (Kanninen, Punamaki, & Qouta, 2003).

Some of this ambiguity may depend on the varying types of trauma involved, as whilst Sandberg, Suess, & Heaton (2010) found a positive correlation between attachment security and PTSD, only a few types of traumatic event were related to attachment security. They found that attachment anxiety mediated the development of PTSD for traumatic events that involved interpersonal violence, childhood sexual abuse and adolescent or adult sexual victimisation, however attachment avoidance was unrelated to any event apart from the sudden or unexpected death of a loved one.

Tomasulo & Razza (2007) suggest that hospital admissions and early separation from parents due to institutionalisation may make people with ID more
vulnerable to developing PTSD. However, few studies have examined the relationship between attachment security and the development of PTSD in people with ID. Finzi-Dottan et al. (2006) compared PTSD reactions among children with ID with typically-developing children, all of whom had been exposed to terror attacks. A significantly higher prevalence of PTSD in children with ID was observed. Further, avoidant and anxious attachment styles and the interaction between anxious attachment and threatening past life events contributed significantly to the explained variance in PTSD.

2.1.6 Rationale for study

This study aimed to investigate the relationship between attachment security and the development of trauma symptoms in response to traumatic events in adults with an intellectual disability, when other factors (e.g. mood) were controlled. The research also examined whether there was a difference in trauma symptoms and attachment security between adults who were "looked after children" compared with those who remained in the family home as children.

2.1.7 Hypotheses

1: Greater levels of secure attachment behaviours as measured by the MAST would be significantly related to lower levels of trauma symptoms as measured by the LANTS.

2. There would be a significant difference in attachment behaviour between adults who were looked after children compared with those who remained in the family home.
3. There would be a significant difference in trauma symptoms between adults who were looked after children compared with those who remained in the family home.

2.2 Methods

2.2.1 Ethics

The study received ethical approval from the University of Manchester Psychological Sciences Ethics Sub-Committee (see Appendix A) and National Research Ethics North West - Greater Manchester East, (see Appendix B). The relevant Research and Development approval for each trust was also obtained (see Appendix C).

2.2.2 Participants

Participants were twenty-seven adult service users with mild to moderate intellectual disabilities and staff members, usually key workers, who had worked with the service user participant for at least three months. To be eligible to take part, participants had to be able to communicate using the English language and be aged over 18 years. In line with the Mental Capacity Act (2005), service user participants were assumed to have capacity to consent to take part in the study. However, if staff raised concern about their capacity to consent, they were not eligible to participate as there was not the resources to undertake individual capacity assessments.

2.2.3 Power

Power calculations were performed using nQuery Advisor 7.0. For the proposed primary analysis of multiple linear regression, a sample of sixty participants would
have 80% power to detect correlation coefficients of at least 0.357. Further, the study would have sufficient power to differences for a maximum of six independent predictors. For the Pearson's correlation, with the current sample of 27 participants, this empirical study had 80% power to detect a correlation coefficient of at least 0.52.

2.2.4 Design

This study used a within-and between-group design. The independent variables were security of attachment, demographics (e.g. whether they were LAC), previous traumatic experiences and mood with the dependent variable being the severity of trauma symptoms.

2.2.5 Measures

Attachment security

The Manchester Attachment Scale - Third party observational measure (MAST; Penketh, et al., 2013) was used to determine attachment security. The MAST contains 16 items relating to attachment security, for example, "the individual actively solicits comforting when distressed" (Penketh, et al., 2013, p. 4). It requires the informant, in this case staff member, to make inferences about the internalised states, needs and feelings of service user participant with ID and to rate how much they agree with 16 items based on their observations using a 4-point likert scale. The maximum score on the MAST is 64, with higher numbers being suggestive of more adaptive attachment behaviours. The MAST has been designed as a continuous measure of secure attachment to support the assessment of the adaptive functioning of an individual's attachment style. Therefore, there is no 'cut off' score
to determine secure attachment. The MAST has adequate internal consistency ($\alpha = 0.75$) with no evidence of multi-collinearity. It has been shown to have convergent validity with total frequency scores with the Self Report Assessment of Attachment Security (SRAAS; Smith & McCarthy, 1996; $r_s = .504$; $p = 0.03$), an already existing measure of attachment. Further, the MAST total scores have been shown to be reliable over time.

_Trauma symptoms_

The Lancashire and Northgate Trauma Scales (LANTS, version 2, Oct 2009; Wigham, et al., 2011) consist of both a self-report and informant version, and were used to measure trauma symptoms. It is noteworthy that Hall et al. (2014) assert that the LANTS provides a more general measure of trauma psychopathology rather than a measure of symptoms associated with PTSD. There is both a self-report and informant version of the LANTS. The self-report version consists of 29 items that each have a 4-point visual rating scale and the informant version has 43 items and has three subscales; 'Behavioural Changes', 'Frequency' and 'Severity'. Each item is rated on a 6-point likert scale for frequency and 3-point scale for severity. The informant version was empirically tested with informants who had known service users for at least a year. Good internal consistency has been demonstrated for both the self-report ($\alpha = 0.84$) and informant versions ($\alpha = 0.89$) as well as test-retest reliability. However, with respect to convergence, only the behavioural changes subscale of the informant LANTS was significantly related to the self-report LANTS, the strength of which was low ($r_s = .20$, $p < .005$).
Frequency of traumatic events

In order to measure the frequency of potentially traumatic events that had been experienced or witnessed by service users, a version of the Life Events Checklist (LEC) adapted and used by Fulton (2013) was utilised. The LEC, which is contained within the Clinician Administered PTSD Scale (Blake, et al., 1995), has been shown to have adequate temporal stability and convergence with other established measures of trauma (Gray, Litz, Hsu, & Lombardo, 2004).

Mood

The Glasgow Depression Scale - Learning Disability, Carer Supplement (GDS-LD; Cuthill, Espie, & Cooper, 2003) was used to assess depressive symptoms. The GDS-LD carer supplement consists of 16 items and measures depressive symptoms over a one week period. It has been shown to have good reliability ($r = 0.98; \alpha = 0.88$) and convergence with the self-report version of the GDS-LD ($r = 0.98$).

2.2.6 Procedure

Service managers from services for adults with ID in the north of England were contacted and provided with information about the study. A total of six organisations agreed to participate. Staff teams within the participating services were provided with the protocol, staff and service user participant information sheets and summary information sheet (see Appendix D, E, F and G, respectively).

Staff were asked to disseminate summary sheets to service users, give a brief explanation of the study and ask service users whether they would be happy to meet with the researcher to learn more about the study. The researcher met with potential service user participants on an individual basis to give a verbal explanation
of the study and provided them with a service user participant information sheet. Potential staff participants were informed of the research by either the researcher, their line manager or service users who had expressed interest in taking part and were given a staff participant information sheet.

Both service user and staff participants were given at least a week to decide whether they wanted to take part. Consent from service users was obtained in writing or verbally with a witness signature (see Appendix H). Staff who consented to take part, signed a consent sheet (see Appendix I). The researcher arranged a convenient time to meet with the service user to complete the self-report LANTS and provided staff participants with the questionnaires, which they had at least two weeks to complete. All participants were provided with the researcher's contact details should they have any further questions.

2.2.7 Data analysis

The data was analysed using SPSS Statistics 20. The distribution of the data was checked by producing histograms prior to any further analysis. It was planned to undertake initial correlation analysis followed by multiple regression using LANTS scores (DV) and MAST, gender, number of traumatic events and LAC status (IV) to investigate the contribution of attachment security to the development of trauma symptoms in response to traumatic events. Independent t-tests were used to examine differences in MAST score and LANTS scores across LAC/non-LAC groups.

2.3 Results

2.3.1 Demographic information

Service user demographic data can be found in Table 1.
### Table 1: Demographic Data

<table>
<thead>
<tr>
<th>Service user gender</th>
<th>Frequency</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>18</td>
<td>66.7</td>
</tr>
<tr>
<td>Female</td>
<td>9</td>
<td>33.3</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Age</th>
<th>Frequency</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Range</td>
<td>19 – 73</td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>38.32</td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>2</td>
<td></td>
</tr>
</tbody>
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<table>
<thead>
<tr>
<th>Developmental diagnoses</th>
<th>Frequency</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No developmental diagnosis</td>
<td>18</td>
<td>66.7</td>
</tr>
<tr>
<td>Asperger Syndrome</td>
<td>1</td>
<td>3.7</td>
</tr>
<tr>
<td>Apert Syndrome</td>
<td>1</td>
<td>3.7</td>
</tr>
<tr>
<td>Down’s Syndrome</td>
<td>1</td>
<td>3.7</td>
</tr>
<tr>
<td>Klinefelter’s Syndrome</td>
<td>1</td>
<td>3.7</td>
</tr>
<tr>
<td>Turner Syndrome</td>
<td>1</td>
<td>3.7</td>
</tr>
<tr>
<td>Do not know</td>
<td>3</td>
<td>11.1</td>
</tr>
<tr>
<td>Missing</td>
<td>1</td>
<td>3.7</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Health conditions</th>
<th>Frequency</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>7</td>
<td>25.9</td>
</tr>
<tr>
<td>No</td>
<td>17</td>
<td>63.0</td>
</tr>
<tr>
<td>Missing</td>
<td>3</td>
<td>11.1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Mental health</th>
<th>Frequency</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety</td>
<td>7</td>
<td>25.9</td>
</tr>
<tr>
<td>Attachment difficulties</td>
<td>1</td>
<td>3.7</td>
</tr>
<tr>
<td>Mood difficulties</td>
<td>11</td>
<td>40.7</td>
</tr>
<tr>
<td>Psychosis</td>
<td>2</td>
<td>7.4</td>
</tr>
<tr>
<td>Personality difficulties</td>
<td>8</td>
<td>29.6</td>
</tr>
<tr>
<td>No mental health difficulty</td>
<td>3</td>
<td>11.1</td>
</tr>
<tr>
<td>One or more mental health difficulties</td>
<td>22</td>
<td>81.5</td>
</tr>
<tr>
<td>Missing</td>
<td>2</td>
<td>7.4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>‘Looked after child’ in the past</th>
<th>Frequency</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>6</td>
<td>22.2</td>
</tr>
<tr>
<td>No</td>
<td>18</td>
<td>66.7</td>
</tr>
<tr>
<td>Missing</td>
<td>3</td>
<td>11.1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Described as having secure attachments</th>
<th>Frequency</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>13</td>
<td>48.1</td>
</tr>
<tr>
<td>No</td>
<td>5</td>
<td>18.5</td>
</tr>
<tr>
<td>Do not know</td>
<td>1</td>
<td>3.7</td>
</tr>
<tr>
<td>Missing</td>
<td>8</td>
<td>29.6</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Setting</th>
<th>Frequency</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community</td>
<td>12</td>
<td>44.4</td>
</tr>
<tr>
<td>Inpatient</td>
<td>5</td>
<td>18.5</td>
</tr>
<tr>
<td>Secure inpatient</td>
<td>10</td>
<td>37.0</td>
</tr>
</tbody>
</table>
Service user participants were aged 19 to 73 years old \((M = 38.32\) years). Two-thirds of the service users were male (66.7%) and were reported to have no specific developmental diagnosis (66.7%). Five service users were reported to have a specific diagnosis. These were; Klinefelter’s syndrome, Asperger syndrome, Turner syndrome, Apert syndrome and Down’s syndrome. Seven service users (25.9%) were reported to have medical conditions.

There was a range of mental health difficulties noted with 81.5% of the sample described as having one or more mental health difficulties. Mood difficulties, to include depression, bipolar disorder and seasonal affective disorder, were the most frequently cited (40.7%); followed by personality difficulties (29.6%), anxiety (25.9%), psychosis (7.4%) and attachment difficulties (3.7%).

Staff documented that around a fifth (22.2%) of service users were LAC in the past. 48.1% of service users were described as having at least one secure attachment relationship. However, this item was not completed for 29.6% of the sample.

44.4% of service users resided in the community, 18.5% in an inpatient hospital and 37% in a secure hospital. Within the community sample, some service users lived independently with minimum support while others required 24 hour staff support in shared houses. Whilst all staff members had worked with service users for at least three months, information was not collected on the precise nature of the professional relationship (e.g. support worker, named nurse).
2.3.2 Frequency of traumatic events

For the twenty-five service users for which the traumatic events checklist was completed, all but two (92%) had either experienced and or witnessed a potentially traumatic event (Table 2).

Table 2. Frequency of each potentially traumatic event experienced and or witnessed

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

Of the traumatic events that staff were aware service users had experienced, the most frequently reported experiences were ‘physical assault’ (16), hospitalised due to injury or illness (16), hospitalised due to illness or injury and family discord (16), followed by the sudden or unexpected death of someone close (12).
2.3.3 Assessment data

Assessment data from the standardised self-report and staff completed measures can be found in Table 3.

Table 3. Summary of scores on standardised measures

<table>
<thead>
<tr>
<th>Measure</th>
<th>N*</th>
<th>Minimum-Maximum (range)</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>MAST</td>
<td>27</td>
<td>26-48 (22)</td>
<td>33.93</td>
<td>5.74</td>
</tr>
<tr>
<td>LANTS Self-report</td>
<td>27</td>
<td>29-93 (64)</td>
<td>57.07</td>
<td>15.08</td>
</tr>
<tr>
<td>LANTS Informant</td>
<td>13</td>
<td>46-102 (56)</td>
<td>72.00</td>
<td>18.51</td>
</tr>
<tr>
<td>Frequency (Freq)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>LANTS Informant</td>
<td>14</td>
<td>1-52 (51)</td>
<td>25.31</td>
<td>14.52</td>
</tr>
<tr>
<td>Severity (Sev)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>LANTS Informant</td>
<td>13</td>
<td>48-142 (94)</td>
<td>94.69</td>
<td>33.12</td>
</tr>
<tr>
<td>Total = Freq + Sev</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>GDS</td>
<td>26</td>
<td>1-20 (19)</td>
<td>10.04</td>
<td>4.84</td>
</tr>
</tbody>
</table>

* Participants with >10% missing data on a measure were excluded from analysis, where missing data <10%, scores were pro-rated

Scores on the MAST yielded a median score of 33 out of a possible score of 64. The scores on the standardised measures suggest a wide range of trauma symptomology as measured by both the self-report and informant LANTS. The LANTS informant data is presented here, as a matter of being transparent with the data. More than half of the participants had >10% missing data on this measure, therefore they were not included in the analysis. A median score of 9 out of a possible 32 was obtained on the GDS-LD, with high scores indicative of more difficulties with mood.
2.3.4 Statistical Analyses

*Hypothesis 1*

A Pearson’s product-moment correlation coefficient was undertaken to examine the relationship between MAST scores and total score from the self-report LANTS, however no significant relationship was found ($r = -.066$, $p = .743$). The relationship between these variable is shown in Figure 1.

*Figure 1. Graph showing the relationship between MAST and LANTS self-report scores*

![Graph showing the relationship between MAST and LANTS self-report scores](image)

Given the small number of participants for whom there was usable data for the informant LANTS, a Pearson's correlation was undertaken to look at whether there was a relationship between the MAST scores and informant LANTS scores, purely as an exploratory exercise. However, a statistically significant relationship was not found ($r = -.26$, $p = .38$). As no statistically significant relationship was found between attachment security and trauma symptoms, conducting a further multiple regression analysis as planned was not appropriate.
For the thirteen participants for whom there was usable informant LANTS data, a Pearson's correlation was undertaken to examine the relationship between the total score for the informant and self-report LANTS. Whilst a medium effect size (> .3, Field, 2005) was found, the relationship did not reach significance at the 0.05 level ($r = .499, p = .083$).

A series of Pearson's correlations were completed to investigate the relationship between variables. Negative correlations were found between the number of traumatic events experienced and secure attachment behaviour ($r = -.243, p = .253$) and between self-reported trauma symptoms and number of traumatic events experienced ($r = -0.07, p = .746$), however, both were far from statistically significant. Similarly, no statistically significant relationships were found between scores for depression and secure attachment behaviours ($r = .128, p = .533$) or between scores for depression and self-reported trauma symptoms ($r = 0.092, p = .653$).

**Hypothesis 2**

An independent-samples t-test was conducted to examine whether there was a significant difference in attachment behaviour between adults who were looked after children compared with those who remained in the family home. However, no significant difference were found ($t = .158, p = .876$).

**Hypothesis 3**

An independent-samples t-test was used to investigate whether there was a significant difference in self-reported trauma symptoms between adults who were
looked after children compared with those who remained in the family home. However, no significant differences were found ($t = -.517, p = .611$).

### 2.4 Discussion

The demographic data suggests a complex picture and heterogeneity regarding the characteristics of adults who come into contact with learning disability services. Around a fifth were reported to have been LAC in the past and the majority of the sample were reported to have mental health difficulties, although this may not be surprising given that the majority were recruited from NHS trusts. No relationship was found between depression scores and scores for trauma symptoms and secure attachment behaviour. With around a third of respondents not answering whether they believed that the service user had at least one secure attachment relationship, the researcher wondered whether respondents had understood the question.

All but one of the sample were reported to have experienced potentially traumatic events, supporting the findings from earlier studies that found a high occurrence of traumatic events in people with ID (Focht-New, Clements, Barol, Faulkner, & Pekala, 2008; Hatton & Emerson, 2004; Sequeira & Hollins, 2003). No relationship was found between the number of potentially traumatic events experienced and self-reported trauma symptoms, and therefore does not lend support to Esbensen & Benson's (2006) study, who suggested a cumulative relationship between traumatic events and psychopathological symptoms. However, there were limitations in the current study with regard to how the service users' trauma history was generated. The current study relied on staff report, which meant that frequencies of the different types of potentially traumatic events experienced were likely to be underestimated. Further, staff often gave "I don't know" responses
and therefore could not be counted. Future researchers may want to consider using the Trauma Information Form (Hall, et al. 2014), which has been designed as a self-report measure of traumatic events for adults with ID.

With respect to the first hypotheses, no significant relationship was found between secure attachment behaviours and both self-reported and informant ratings for trauma symptoms. One explanation could be that there is no relationship, however, another explanation could be that the relationship between trauma and attachment is complex and non-linear, meaning that the measures used were not sufficient enough to identify a relationship if there was one. There are a number of limitations in using the MAST because it measures secure behaviours that have been observed by staff (third-party). Therefore, staff report could be biased by factors such as the amount of time that the staff member has observed the service user (e.g. clients in the community had less contact with staff than in inpatient settings) and also the quality of the relationship between the service user and that particular staff member as well as the staff member's relational style. Further, the MAST does not allow categorisation of different attachment patterns (e.g. ambivalent or avoidant). However, in studies with adolescents with ID (Finzi-Dottan, et al., 2006) and in people without ID (Cohen, et al., 2002; Declercq & Willemsen, 2006; Kanninen, et al., 2003; Muller, et al., 2000; Sandberg, et al., 2010), different attachment styles have been shown to be related to the development of PTSD, with Sandberg et al. (2010) proposing that certain insecure attachment styles may be 'protective' depending on the type of trauma. Further, there may be an issue with the LANTS in that it measures overall trauma symptoms rather than PTSD (Hall, et al., 2014).
In consideration of the second and third hypotheses, no statistically significant differences were found in secure attachment behaviours or trauma symptoms between adults with ID who were LAC compared with those who remained in the family home. It is of note that with only six participants in the LAC group and eighteen in the non-LAC group, the t-test lacked statistical power. Further, an assumption has been made that remaining in the family home is suggestive of a more stable upbringing, however, this may not be the case for some people.

2.5 Limitations

A strength of this study is that it aimed to contribute to a relatively under-researched area and offers insight into the characteristics and needs of adults with ID but there are a number of limitations. Firstly, the low sample size meant that whilst the study had enough power to detect relationships between groups, it was underpowered to detect differences between group and therefore caution is needed when considering the findings. Whilst data was not formally collected on ethnic background, the sample was not ethnically diverse. However, it was diverse with respect to age, developmental diagnosis, mental health difficulties and setting, which may have led to the sample being too heterogeneous when considering the small sample size. Further, the amount of staff support that service users received ranged from half hour a week visits to 24 hour care, which led to variance in the amount of information that staff knew about service users. Over half the sample were either recruited from inpatient or secure NHS hospitals, which may have biased results with regard to co-morbid mental health difficulties.
Due to time constraints, purposive rather than random sampling was used. Further, to prevent acquiescence, the researcher was not able to approach service users directly to participate but rather, the researcher was reliant on staff to identify and introduce her to service users who they thought would be interested in participating. Therefore, the recruitment procedure is likely to have led to bias.

Further limitations arose from the measures used. Limitations with the MAST are outlined in the discussion section, however, there were also issues with the Trauma Events Checklist and LANTS. Whilst the Trauma Events Checklist allowed for the frequency of traumatic events to be identified, and only then if staff members were aware that the service user had experienced the event, it could not provide further information regarding how long ago the event occurred. There were a number of difficulties using the informant LANTS. Following personal communication with the author (Wigham, et al., 2011), it was agreed to only analyse two subscales of the informant LANTS (frequency and severity). However, only thirteen participants had either complete data or <10% missing data, and then the researcher could not be sure that staff had understood how to complete the measure, which affected both validity and power.

2.6 Implications for future research and practice

Whilst the current study did not find evidence that there was a relationship between attachment security and trauma symptoms, this study did indicate that a high proportion of service users had either experienced or witnessed a potentially traumatic life event. Therefore clinicians working with ID should be mindful of this in their assessment.
Although a potentially biased sample, a high proportion of the service users with ID included in the study had co-morbid mental health difficulties. This has implications for the ways in which services are designed to ensure that clinicians have the necessary skills to meet service user needs.

Further research in this area is necessary, employing more robust methodology; ideally a multi-site project, using a large sample size, random sampling and including a comparison group. However, this type of study is likely to be costly and therefore financial investment in this area is required. Given the heterogeneity of the needs of the people within ID services and paucity of research in this area, it may be preferable to repeat a similar study using a sample that is homogenous in some way (e.g. people with the same genetic syndrome).

2.7 Conclusion
This study did not provide evidence to suggest that there is a relationship between attachment security and the development of trauma symptoms in response to traumatic life events in adults with ID. However, although tentative, it does provide evidence to suggest high-levels of co-morbidity between ID and mental health difficulties, and of the type of traumatic events that adults with ID are exposed to (e.g. physical assault). This study has a number of methodological limitations that need to be considered, including a small sample size. Further research is required in this area, which utilises more rigorous methods.
Acknowledgments

Many thanks to Sigrid Whiteside for her assistance with the statistical analysis and to Caitriona Collins for helping with data collection; I am sincerely grateful for your time and effort.
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Greenberg, D. Cicchetti & E. M. Cummings (Eds.), *Attachment in the preschool years* (pp. 121-160). Chicago: University of Chicago Press.


3.1 Introduction
This paper aims to provide a critical and personally reflective account of undertaking a systematic review and empirical study in the area of attachment and trauma in people with intellectual disabilities (ID). Strengths and limitations of the research are interwoven throughout. Recommendations for future research and implications for practice are also considered.

3.2 Systematic literature review
3.2.1 Focus of the review
A number of topic areas relating to trauma and attachment in people with ID were considered. The researcher was aware that a systematic review of the literature relating to PTSD in people with ID (Mevissen & de Jongh, 2010) had already been completed and through discussion with her supervisor, agreed that focusing on the psychological well-being of looked after children (LAC) would be an appropriate related topic area, given the evidence that LAC are likely to have experienced disrupted attachment early adverse events (Rutter, 1998). Initially, the review was going to focus on all LAC, not just those with an ID and not limited to the UK. However, when screening the results of the search, the researcher found a relatively recent review with a similar focus conducted by a team at the University of Sheffield (Jones, Everson-Hock, Papaioannou, et al., 2011). Further, the original search terms yielded over 30 000 articles and it was not considered feasible within the time frame. It was agreed to narrow the focus of the systematic review by concentrating on the literature related to the psychological well-being of LAC with ID in the UK. The researcher acknowledges that deciding on the focus of the review after looking at the available evidence is likely to have introduced bias (Higgins &
Green, 2011). However, the researcher was mindful of the amount of time that would need to be invested into producing a systematic review and therefore wanted it to be valuable and applicable to services in the UK.

3.2.2 Study identification and selection

Identifying relevant studies proved challenging due to the different terminology that is used to describe people with ID and the complex picture that arose with respect to the different types of placement where LAC reside. A number of papers were identified that focused on residential schools and also orphanage studies. After lengthy discussion, it was agreed to exclude the orphanage studies because they focused on privation rather than deprivation of attachment relationships (Rutter, 1998) and agreed to include residential school studies as it was hypothesised that separation from the family may disrupt attachment relationships (Schaverien, 2011).

3.2.3 Quality assessment

Initially the researcher adapted a quality assessment tool developed by Fulton (2013) to assess the quality of the studies. However, when rating the studies, the researcher could not be confident that she was not introducing bias by being too critical. This feeling was particularly strong when rating the Minns (1989) paper due to the way in which characteristics and traits of young people with profound ID were described. The researcher therefore searched for an assessment tool that had been empirically tested regarding reliability and validity and found the QATSDD, which can be used for diverse designs (Sirriyeh, Lawton, Gardner, & Armitage, 2012) and repeated the quality assessment of all 17 papers.
Ideally, the papers should have been independently reviewed to reduce bias (Higgins & Green, 2011) and whilst the researcher identified a clinician who agreed to do this, due to a combination of the shift in focus of the review and the length of time it took to decide on the inclusion criteria, there was not enough time for the studies to be independently rated. This additional work will be completed prior to submission for publication.

3.2.4 Results
The researcher is aware that the findings of the included studies are merely described rather than being synthesised in a meta-analysis or narrative synthesis. However, meaningful synthesis was difficult due to the diverse focus and methodologies employed in the included studies. Initially, the researcher had thought about reporting under the headings of placement type (e.g. residential school, foster care), however many studies (e.g. Taggart, et al., 2007) did not present their data in a way to allow for this. This led to the results in the current study being presented by study focus/sample, which was not ideal.

3.2.5 Implications for practice
The researcher was struck but not surprised by Rao et al's. (2010) finding, that the only person referred to CAMHS with an identified mental health difficulty not be offered intervention, was a child with ID who was instead referred to learning disability services. The researcher had worked previously as a mental health nurse in CAMHS for a number of years, in which she observed grossly unequal waiting list times for children with ID. She hypothesised that the waitlist reflected that there were only a limited number of clinicians who felt skilled enough to work with a
child with an ID who also had a mental health problem (Sin, Francis, & Cook, 2010). She reflected on how nurse training programmes may perpetuate this by being divided into general nursing (physical health), mental health and learning disability, when in reality, people can have a complex mixture of needs that span the 'specialities'. The introduction of the Equality Act (2010) has made it a legal requirement for services to make reasonable adjustments to meet the needs of people, including those with ID, which will therefore have implications for training needs of employees working within services such as CAMHS. Further implications for practice are outlined in Paper 1.

3.3 Empirical paper

3.3.1 Topic area

The researcher had developed an interest in trauma in people with ID through her previous experience of being a mental health nurse and findings from her Master's degree. As part of her Master's degree, the researcher had undertaken a literature review regarding the efficacy of cognitive behaviour therapy (CBT) for children and adolescents who experienced post-traumatic stress disorder in response to child sexual abuse and identified that children and adolescents with ID were excluded from all of the randomised controlled trials, which provide the evidence base for the NICE guidelines. This led to questions firstly as to why they had been excluded and secondly, what this meant for efficacy of CBT for use with children and adolescents with ID. From speaking with other researchers and looking at the available literature, it seemed that there were a number of barriers to research with people with ID, including issues around informed consent and a lack of validated measures (Lennox, et al., 2005). However, by not attempting to undertake research with
people with ID only serves to maintain a lack of evidenced based interventions for service users with ID.

The researcher identified a supervisor (D.H.) who had an interest in research with people with ID and wondered whether it was possible to design a research project in the area of trauma in people with ID. The researcher was made aware of the growing body of research in the area of attachment in people with ID (Fulton, 2013; Penketh, Hare, Flood, & Walker, 2013) affiliated with the University of Manchester and in considering a research focus, the first idea proposed was to develop a first person trauma measure for adults with ID. However, during a preliminary search of the background literature, it transpired that the Lancaster and Northgate Trauma Scales (LANTS; Wigham, Hatton, & Taylor, 2011), which included a first person measure of trauma symptoms in adults with mild to moderate ID had already been developed. Other research ideas were considered and the design of the present study was proposed by A.F, who later agreed to be a field supervisor.

3.3.3 Recruitment

The main challenge for the research project was recruitment. The initial plan was for the researcher to contribute to recruitment for another study (Fulton, 2013) with a view to sharing participants as both studies used four of the same measures. However, due to the time lapse between ethical approval for Fulton's (2013) study, it was not feasible or appropriate. Knowing that Fulton (2013) had experienced challenges to recruitment, the researcher for the current study explored other avenues for recruitment and identified other Trusts who agreed to support the research. Trying to recruit from several sites presented obstacles in terms of
geographical distance, varying research and development procedures and also service design, which affected access to participants.

When presenting the research proposal to service managers, they were often concerned regarding what questions service users would be asked in relation to traumatic events because they were worried about service users becoming distressed. When presented with the LANTS measure, service managers were satisfied that service users would not be asked about their experience of traumatic event. However, this attempt to protect service users from becoming upset is likely to maintain barriers to research with service users with ID, particularly for qualitative research, meaning that the voices of people with ID continue being unheard.

To reduce the risk of acquiescence, it was outlined in the procedure that the researcher could only access service user participants via staff. Whilst letters of access were granted in August 2013 for three sites, it took until November 2013 to recruit the first participant. During this time, several meetings took place with ward managers and despite apparent interest in the study at team meetings, this did not translate to staff and service user participants wanting to take part in the study. The researcher arranged to meet with potential staff participants on a number of occasions, only to arrive on site to be told that staff could not be released from inpatient wards and to rearrange. This was costly in terms of time, had financial implications and was incredibly frustrating. The researcher hypothesised that participating in research was not a priority for staff.

In November 2013, it was agreed that if no participants had been recruited by January 2014, that the current study be terminated and another project be implemented. The researcher liaised with the Research and Development team to
inform them of this plan who offered their assistance in thinking about barriers to recruitment. A different approach was used to recruit from one ward, whereby, the ward manager and occupational therapist asked service users if they consented to the researcher attending a community meeting to speak with them regarding the current study, which they did. Having presented the study to service users at the meeting, eight out of ten service users present agreed to meet with the researcher on an individual basis to go through the participant information sheet and to think about whether they would like to take part. Key workers and named nurses were identified and informed that service users were considering taking part in the research and asked whether they would also want to take part to complete staff measures. All eight service users and key workers consented to take part leading to a sense of relief for the researcher.

Interestingly, the researcher received a telephone message from a service user at a different site, who was interested in taking part in the study, having been given a summary sheet by a staff member when attending a meeting. However, when the researcher approached the service user's key worker, her key worker was annoyed that she (the key worker) was being asked to take part because she did not feel that she had capacity with her work demands. The researcher explained that taking part was voluntary and another staff member could be approached to complete the measures. However, on hearing more about the project (e.g. how long the questionnaires would take to complete), she agreed to take part. This change highlighted the willingness of service users to take part and seemed to fit with her hypothesis that research was not a priority for staff with competing demands, particularly in the context of staff shortages.
The researcher attended a special interest group regarding attachment in ID and made contact with a consultant clinical psychologist from Northumbria, but from a different service where recruitment had been planned. The consultant expressed interest in supporting the project and put the researcher in contact with an assistant psychologist within his service who agreed to assist with data collection. The researcher liaised with the relevant R&D department to ensure that this was appropriate. Four staff and service user participants were recruited this way.

3.3.4 Sample
The barriers to recruitment described in the previous section vastly limited the sample size. Whilst the study had enough power to detect a relationship between variables via correlation, it was under powered to detect differences between groups (e.g. LAC and non-LAC), even if they existed. A lack of statistical power is therefore a limitation of the current study and could lead to non-representative findings (Maxwell, Kelley, & Rausch, 2006). The researcher met with a statistician to consider what statistical analysis would be appropriate, given the sample size.

3.3.5 Measures
There were a number of challenges using the informant LANTS, to the extent that the researcher could not be sure of the validity of the findings. At one stage, it was decided to omit the informant LANTS from the analysis. However, the researcher did not want to be accused of 'hiding' data and so it was agreed to present the findings but be explicit about the limitations and caution needed in interpreting the results.
On two occasions, the researcher was present when the staff participants tried to complete the informant LANTS. Despite detailed instructions on how to complete the measure being available, staff were not clear whether they were rating new behaviours (within the last three months) or all behaviours that were present. The researcher was concerned that if these two staff members were having difficulty, then it is likely that other participants also experienced confusion when completing the measure. There were further issues with the design of the measure. The scoring on the final item was missing leading to many staff not providing a response (some realised and wrote the scoring in), and half way through the measure, the "don't know" and "same as usual" options swapped over, which again made it more difficult to complete.

The researcher had obtained the LANTS directly from the author and therefore assumed it was the correct version. However, when asking for the scoring instructions, the scoring instructions did not 'map on to' the measure. The scoring options that were provided for the first subscale were; 0 if the symptom had not been observed, 1 if the symptom has been observed but is something they usually present with and 2 if the symptom is seen as something new for the person and only observed this month. However, this did not match the instructions or options available for the version of the LANTS that was used in the current study (e.g. don't know/same as usual). This apparent change seemed in line with the confusion staff participants experienced when trying to complete the measure.

Via personal communication with the author of the LANTS, the author explained that the scoring had been "tweaked", that they were considering removing the first subscale (behaviour changes) and advised that the frequency and severity scales were just reported. This strategy was therefore employed. However, just
including two subscales led to a lot of missing data as often where staff rated the behaviour as "same as usual", they had not gone on to report frequency and severity. One hypothesis is that staff thought that they should only rate new behaviours. These concerns were shared with the author who reported that the instructions would also be amended to make them more user friendly.

Another study that had used the informant LANTS was identified (Hall, Jobson, & Langdon, 2014). In the write up of the Hall et al. (2014) study, there was no indication that they experienced the same difficulties with the measure, leading to feelings of self-blame for the difficulties encountered in the current study. On further inspection, it was found that the informant LANTS used by Hall et al. (2014) had forty seven items whereas the informant LANTS used in the current study only had forty three items. Via personal communication with the author it was confirmed that Hall et al. (2014) had used an earlier version.

3.3.6 Response bias

When administering the self-report LANTS with service users, particularly those within inpatient settings, three items; "I want to smash things up", "I want to hurt people" and "I feel like hurting myself really badly", often led to "no" responses. The researcher considered that this might be evidence of response bias (Furnham, 1986) as service users might think that by answering anything but "no" to these items may lead to more restrictive care.

3.3.7 Missing data

There was a high proportion of missing data, particularly for the informant LANTS. The decision was made to exclude participant data from the analysis where there
was >10% missing data. Where there was less than <10%, scores were pro-rated and included, which is not ideal.

Accurate demographic data was not always provided. For example, information regarding level of ID was given rather than information relating to known genetic disorders. This problem was also identified by Fulton (2013). Therefore in future research, forced choice answers may be preferable.

3.4 Findings and future research

3.4.1 Key variables

The findings of this study did not support the hypothesis of there being a relationship between trauma and attachment in adults with ID. This was initially surprising, given that research with non-ID samples have found a relationship between these variables (Dieperink, Leskela, Thuras, & Engdahl, 2001; Zakin, Solomon, & Neria, 2003). However, when re-examining the findings of original studies, the researcher came to realise that she had massively underestimated the complexity of the relationship, in that the relationship may not be linear. The MAST, which was used to measure attachment security, is a continuous measure and does not seek to categorise different attachment styles, as this has been thought to be unhelpful (Crittenden, 2006). However, the available research would suggest that different attachment styles can be a protective factor for some traumatic events, but a risk factor for others events (Sandberg, Suess, & Heaton, 2010). Future research would need to consider this when thinking about appropriate measures. Further, it may be preferable to focus on investigating the relationship in response to a specific potentially traumatic event, such as physical assault, rather than overall. Future research may also want to incorporate a measure of intelligence,
given that this has also been shown to influence the development of PTSD (Bowman, 1999).

Given that over the passage of time, many people recover following traumatic events without developing mental health difficulties, future research should take into consideration how long ago a traumatic event occurred, and may also want to investigate resiliency factors.

3.4.2 Measures

Given the willingness of service users to take part in the research, in retrospect, more of an emphasis on self-report measures rather than informant measures may have led to an increased sample size and more accurate reporting, particularly regarding the Life Events Checklist (Blake, et al., 1995). However, given service managers' concerns about what questions service users would be asked, there may be resistance to using this measure with service users.

With respect to a self-report measure of attachment, the Self-Report Assessment of Attachment Security (SRAAS; Smith & McCarthy, 1996) has been empirically tested for use with adults with ID and may therefore be an option to use. The SRAAS demonstrates reasonable divergent and convergent reliability as well as good test-retest reliability, however it is limited in that it requires good comprehension and expressive language skills (Penketh, et al., 2013).

For mood, the self-report version of the Glasgow Depression Scale could be employed (Cuthill, Espie, & Cooper, 2003). With regard to measuring overall symptomotology, the self-report version of the LANTS could be used. However, to measure symptoms that are more associated with PTSD, the Impact of Event Scale-Intellectual Disabilities (IES-ID; Hall et al., 2014) may be preferable.
3.4.3 Participant sample

Future research in the area of trauma and attachment in people with ID would benefit from having a larger sample size and controls for bias, for example, using random sampling. The researcher feels that the purposive sampling employed in the current study did not only lead to bias, but also meant that not all service users had an equal opportunity to take part, just those that staff thought would be interested and for those where no concerns were raised about capacity to consent. Further, this study only included service users with mild to moderate ID, therefore future research may want to focus on the relationship between trauma and attachment in people with severe and profound ID. However, research aimed at developing an established conceptualisation of trauma in people with ID (Wigham, et al., 2011) should take priority, in order for efficacy of interventions to be determined.

3.5 Clinical implications

Whilst this study did not provide evidence that there was a relationship between trauma and attachment in adults with ID, it did provide evidence, albeit tentative, regarding the kinds of traumatic experiences that people with ID experience and of high levels of co-morbidity of mental health difficulties in people with ID. Further, a wide range of trauma symptomatology was reported in people with ID. This has implications with regard to service design and provision, as people working with this client group should have skills in identifying and treating mental health difficulties in people with ID.

The observation that a number of staff completed the demographic sheet incorrectly (e.g. reporting personality disorder as a genetic syndrome or
developmental disorder), may indicate that that further training is needed for staff working with this client group.

Recruitment was one of the main challenges to this study. The researcher hypothesised that one of the barriers, particularly to staff participation, was that research was not a priority in the context of competing work demands. Therefore, where services have agreed to support research projects, this has implications for staffing in order for staff to have the time to participate. Whilst it is tempting in 'times of austerity' not to prioritise research, this could be a 'short sighted' approach. Because without continued research in this area, the efficacy of interventions cannot be determined, and having evidence based interventions would save the NHS money in the long-term.

3.6 Dissemination to services
Service users, staff and service managers from the services who took part in the study will be offered the opportunity to hear the findings, via a number of presentations. Whilst there are no statistically significant results to feed back, hopefully the clinical implications and recommendations for future research will be beneficial for attendees.

3.7 Submission for publication
The systematic literature review (Paper 1) will be submitted to Adoption & Fostering and the empirical study (Paper 2) will be submitted to the British Journal of Clinical Psychology.
References


Appendix A: University of Manchester Psychological Sciences
subcommittee ethical approval letter

Dear Melanie,

Re: Feedback from Research Sub-committee - 19th November 2012

Thank you for your revised research proposal. The proposal has been revised in line with the recommendations of the Research Subcommittee meeting of 19th November 2012. It has been reviewed by Dr John Fox and is now satisfactory.

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

[Signature]

Dr Dougal Hare
Senior Lecturer in Clinical Psychology
Panel A Chair, Research Sub-Committee
Cc Anja Witkowski, Andrea Flood
21 June 2013

Ms Melanie Powney, Trainee Clinical Psychologist
University of Manchester
2nd Floor, Zochnis Building, Brunswick Street
Manchester
M13 9PL

Dear Ms Powney

Study title: Attachment in adults with intellectual disabilities:
 Investigating the relationship between attachment
security and trauma symptoms.

REC reference: 13/NW/0401
Protocol number: N/A
IRAS project ID: 125017

The Research Ethics Committee reviewed the above application at the meeting held on 18 June 2013. Thank you for attending to discuss the application.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Elaine Hutchings, nrescommittee.northwest-gmsouth@nhs.net.

Discussion

Your study was found to be well-written and presented no major ethical issues of concern. It was pleasing to see that input on the development of the study had been obtained from the Community Liaison Group at the University.

On the inclusion of staff as participants, you explained that you will be comparing the information obtained from staff with that obtained from service user participants, and therefore consider it appropriate to treat them as participants.
With regard to capacity, you confirmed that all participants are required to have capacity to consent and if there are any concerns about capacity, the participant will not be recruited or will be withdrawn from the study. Staff will make an approach about the study only to those service users who have capacity and will monitor capacity on an on-going basis. This was welcomed in light of the fact that capacity can fluctuate.

You clarified that 'appropriate means' of consenting allows for the participation of service users who are unable to write by the taking of verbal consent which will be formally documented.

You were complimented on the lay-out of the self-report version of the scale for intellectual difficulties and on the summary information sheet which was found to be particularly appropriate for the study population as it is easily understood. You were asked whether the summary sheet will be provided to participants at the same time as the main information sheet and said that it will be given separately. It was pointed out that the summary sheet ask people to contact you without giving contact details, and you undertook to rectify this.

Ms Powell was thanked for attending and left the meeting.

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.rdforum.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**

1. The summary information sheet needs to provide contact details so that participants can get in touch with you as requested in the sheet.

2. In the staff information sheet, the reference to the review of the study should appear under a heading 'Who has reviewed the study?' and not under the heading referring to organising and funding the study. The correct name of the NRES Committee should be given.

3. In the staff information sheet, a section needs to be included to say what would happen if a staff participant revealed that a service user was at risk, along the lines of the information provided in the answer to question A23 of the study.

4. The reference to 'staff' in point 5 of the consent form for service users and point 3 of the consent form for staff could be confusing. The standard research governance paragraph is given below and this should be adapted to your study; for example, the reference to 'medical notes' can be removed from the staff consent form.

   "I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from [COMPANY NAME], from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records."

**Suggestion**

It is suggested that under the heading 'Why have I been asked to take part?', a sentence is included along the lines of 'The service user you work with has given consent for you to complete questionnaires about them.'

Please 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 and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

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).

**Approved documents**

The documents reviewed and approved at the meeting were:
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<tr>
<th>Document</th>
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<td>Referees or other scientific critique report</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 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

13/NW/0401 Please quote this number on all correspondence

We are pleased to welcome researchers and R & D staff at our NRES committee members’ training days – see details at http://wwwhra.nhs.uk/hra-training/

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

Yours sincerely

[Signature]

Mr Francis Chan
Chair

Email: nrescommittee.northwest-gmsouth@nhs.net

Enclosures: List of names and professions of members present at the meeting

"After ethical review – guidance for researchers"

Copy to: Ms Lynne MacRae, University of Manchester

Miss Paula Johnson, Calderstones Partnership NHS Foundation Trust
30 July 2013

Ms MJ Powney
Trainee Clinical Psychologist
Manchester Mental Health and Social Care Trust
University of Manchester, Division of Clinical Psychology
2nd Floor, Zochonis Building, Brunswick Street
Manchester
M13 9PL

Dear Ms Powney

Study title: Attachment in adults with intellectual disabilities: Investigating the relationship between attachment security and trauma symptoms.

REC reference: 13/NW/0401
IRAS project ID: 126017

Thank you for your email of 26 July 2013. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 21 June 2013.

Documents received
The documents received were as follows:

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<td>Protocol</td>
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Approved documents
The final list of approved documentation for the study is therefore as follows:

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<tr>
<td>Evidence of insurance or indemnity</td>
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<td>01 May 2013</td>
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<tr>
<td>Investigator CV</td>
<td>Ms M Powney</td>
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<tr>
<td>Letter from Sponsor</td>
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<td>01 May 2013</td>
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<tr>
<td>Letter from Statistician</td>
<td></td>
<td>23 October 2012</td>
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</table>

A Research Ethics Committee established by the Health Research Authority
| Other: Insurance assessment form | 05 April 2013 |
| Other: Supervisor CV - Dr D Hare |
| Other: Supervisor CV - Dr A Wittkowski |
| Participant Consent Form: Staff | 26 April 2013 |
| Participant Consent Form: Service User Participants | 17 July 2013 |
| Participant Information Sheet: Summary information sheet | 22 March 2013 |
| Participant Information Sheet: Information Sheet 1 - Information for staff participants / services | 17 July 2013 |
| Participant Information Sheet: Service User PIS | 17 July 2013 |
| Protocol | 17 July 2013 |
| Questionnaire: MAST |
| Questionnaire: LANTS |
| Questionnaire: Glasgow Depression Scale |
| Questionnaire: Trauma events checklist | 10 May 2013 |
| Questionnaire: Service User demographic information | 10 May 2013 |
| REC application | 17 January 2013 |
| Referees or other scientific critique report |

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

13/NW/0401 Please quote this number on all correspondence

Yours sincerely

Signed on behalf of
Elaine Hutchings
Committee Co-ordinator

E-mail: nrescommittee.northwest-gmeast@nhs.net

Copy to: Ms L MacRae – University of Manchester
Miss P Johnson - Calderstones Partnership NHS Foundation Trust

A Research Ethics Committee established by the Health Research Authority
Appendix C: Research and development approval letters

South West Yorkshire Partnership NHS

5th August 2013

Ms Melanie Powney
Trainee Clinical Psychologist
Manchester Mental Health & Social care Trust
University of Manchester
Division of Clinical Psychology
2nd floor, Zochonis Building
Brunswick Street
Manchester
M13 9PL

Dear Ms Powney,

Re: Attachment in adults with intellectual disabilities: investigating the relationship between attachment and trauma symptoms

REC ref: 13/NW/0401

Reda ID: 135

Following the recent review of the above project I am pleased to inform you that the above project complies with Research Governance standards, and NHS Permission has been granted on behalf of Trust management. We now have all the relevant documentation relating to the above project. As such your project may now begin within South West Yorkshire NHS Foundation Trust.

The final list of documents reviewed and approved is as follows:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
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<tbody>
<tr>
<td>Protocol</td>
<td>7</td>
<td>17th July 2013</td>
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<tr>
<td>Participant Consent Form: Service Users</td>
<td>5</td>
<td>17th July 2013</td>
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<tr>
<td>Participant Information Sheet: Service Users</td>
<td>5</td>
<td>17th July 2013</td>
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<tr>
<td>Participant Information Sheet: Information Sheet</td>
<td>4</td>
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<td>Evidence of Insurance</td>
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<td>CVs or researcher and supervisors</td>
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<td>Participant Consent Form: Staff</td>
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<td>26th April 2013</td>
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<tr>
<td>Participant Information Sheet: Summary Information Sheet</td>
<td>3</td>
<td>17th July 2013</td>
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<tr>
<td>Questionnaire: MAST</td>
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<td>Questionnaire: LANTS</td>
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<tr>
<td>Questionnaire: Glasgow Depression Scale</td>
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<tr>
<td>Questionnaire: Trauma Events Checklist</td>
<td>1</td>
<td>10 May 2013</td>
</tr>
<tr>
<td>Questionnaire: Service User Demographic Information</td>
<td>2</td>
<td>27th July 2013</td>
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This approval is granted subject to the following conditions:

- You must comply with the terms of your approval. Failure to do this will lead to permission to carry out this project being withdrawn. If you make any substantive changes to your protocol you must inform us immediately.

Chair: Ian Black   Chief Executive: Steven Michael
• You must comply with the procedures on project monitoring and audit.
• You must comply with the guidelines laid out in the Research Governance Framework for Health and Social Care (RGF). Failure to do this could lead to permission to carry out this research being withdrawn.
• You must comply with any other relevant guidelines including the Data Protection Act, The Health and Safety Act and local Trust Policies and Guidelines
• If you encounter any problems during your research you must inform your Sponsor and us immediately to seek appropriate advice or assistance.
• Research projects will be added to any formal Department of Health research register.

Please note that suspected misconduct or fraud should be reported, in the first instance, to local Counter Fraud Specialists for this Trust. R&D staff are also mandated to do this in line with requirements of the RGF.

Adverse incidents relating to the research procedures and/or SUSARs (suspected unexpected serious adverse reactions) should be reported, in line with the protocol requirements, using Trust incident reporting procedures in the first instance and to the chief investigator.

They should also be reported to:
• The R&D Department
• the Research Ethics Committee that gave approval for the study (if applicable)
• other related regulatory bodies as appropriate.

You are required to ensure that all information regarding patients or staff remains secure and strictly confidential at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

Changes to the agreed documents MUST be approved by in line with guidance from the Integrated Research Applications System (IRAS), before any changes in documents can be implemented. Details of changes and copies of revised documents, with appropriate version control, must be provided to the R&D Office. Advice on how to undertake this process can be obtained from R&D.

Projects sponsored by organisations other than the Trusts are reminded of those organisations obligations as defined in the Research Governance Framework, and the requirements to inform all organisations of any non-compliance with that framework or other relevant regulations discovered during the course of the research project.

The research sponsor or the Chief Investigator, or the local Principal Investigator, may take appropriate urgent safety measures in order to protect research participants against any immediate hazard to their health or safety.

The R&D office should be notified that such measures have been taken. The notification should also include the reasons why the measures were taken and the plan for further action.

__________

2 Details from:
2 SUSARS – this must be within 24 hours of the discovery of the SUSAR incident

Chair: Ian Black  Chief Executive: Steven Michael
Note that NHS indemnities only apply within the limitations of the protocol, and the duties undertaken therewith, by research staff with substantive or honorary research contracts with this Trust.

Once you have finished your research you will be required to complete a Project Outcome form. This will be sent to you nearer the end date of your project (Please inform us if the expected end date of your project changes for any reason).

We will require a copy of your final report/peer reviewed papers or any other publications relating to this research. Finally we may also request that you provide us with written information relating to your work for dissemination to a variety of audiences including service users and carers, members of staff and members of the general public. You must provide this information on request.

If you have any queries during your research please contact us at any time.

May I take this opportunity to wish you well with the project.

Yours sincerely

Dr Nisreen Booya
Medical Director
15th August 2013

Ms Melanie J Powney
University of Manchester
Division of Clinical Psychology
2nd Floor, Zochonis Building
Brunswick Street
Manchester
M13 9PL

Dear Melanie,

Re: NHS Trust Permission to Proceed

Project 2013-05: Attachment in adults with intellectual disabilities: Investigating the relationship between attachment security and trauma symptoms

REC reference: 13/NW/0401

IRAS project ID: 126017

Following the approval by NRES Committee North West – Greater Manchester East on 21.6.13 and Calderstones Partnership NHS Foundation Trust Research & Development 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.doh.gov.uk) and fully adhere to the submitted project 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 Calderstones Partnership NHS Foundation 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.
Recruitment:

I note that, according to the SSI form (section 11), recruitment to this study will involve you meeting service managers initially and then staff teams who may show an interest in taking part in the project. I am aware that your local collaborator (Dr Sam Walker) will assist you in this process. Please do contact me should you wish to make any amendment to this recruitment plan.

Please note that, in line with national standards, it is good practice for you to recruit your first participant to Calderstones within 30 days of being granted Trust permission. Please do let me know the date of first recruitment to enable me to record the date of first recruitment as per national guidelines.

Monitoring & Reports

A representative from the Research Department will contact you to monitor the progress of your research within Calderstones. 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, we request that you forward a copy of your final summary report so that your findings are made available to local NHS staff and to allow feedback to Calderstones R&D committee meeting.

On behalf of Calderstones Trust I wish you every success for your research and I look forward to finding out more about the progress and outcomes. Please do not hesitate to contact me if I can be of further assistance with this study.

Yours sincerely,

[Signature]

Paula Johnson
Research & Development Manager
Calderstones Partnership
NHS Foundation Trust
Internal Extn: 3916
External direct line: 01254 821916
paula.johnson@calderstones.nhs.uk
16th August 2013

Ref: PL/NW

F. A. O. Melanie Powney
Trainee Clinical Psychologist
University of Manchester
Department of Clinical Psychology
2nd Floor, Zochonis Building
Brunswick Street
Manchester,
M13 9PL

Dear Melanie,

Firstly I would like to apologise for the delay in responding to your correspondence.

I would to confirm that I give approval for you to undertake the study requested within the parameters of the research protocol.

Please could I ask you to contact my secretary Nicky Walsh at nicky.walsh@futuredirectionscic.co.uk who will arrange the initial meeting with Senior Managers to discuss the research.

I would however like to mention that a community sample size may be small as we have a limited number of service users who will be able to give consent.

Yours sincerely

Paul Lord
Director of Operations
Future Directions CIC.

Future Directions CIC
Marle House, Oldham Broadway Business Park, Chadderton, Oldham OL9 9XA - Tel 01254 821720
Northumberland, Tyne and Wear NHS Foundation Trust

Research & Clinical Effectiveness Department
St Nicholas Hospital
Jubilee Road
Gosforth
Newcastle upon Tyne NE3 3XT
Tel: (External) 0191 223 2338
(Internal) 35318
Fax: 0191 223 2341

01/11/13

RES-13-029

Melanie Powney
Trainee Clinical Psychologist
Manchester Mental Health & Social Care Trust
Manchester
M21 9UN

Dear Melanie

Re: Attachment and trauma in adults with LD

I write to confirm that Northumberland, Tyne and Wear NHS Foundation Trust are happy to support and approve the above study. Please accept this letter as verification of Trust approval.

Approval is granted with the condition that the R&D Department are notified of:

- Commencement and completion of the study
- Any significant changes to the study design
- Suspension or abandonment of the study
- Copy of annual REC report and end of project REC report
- All publications and/or conference presentation of the study findings

The Department of Health’s minimum standards for research governance state that at least 10% of projects should be routinely audited. It is a condition of our approval that the researchers accept the Trust’s right to include this project in the auditing and monitoring process.
Best wishes

Yours sincerely

Simon Douglas
Senior Manager for Research, Innovation and Clinical Effectiveness
Appendix D: Study protocol

Research protocol (Version 7)

17/07/13

Short title of study: Attachment and trauma in adults with ID

Chief Investigator: Melanie Powney
Trainee Clinical Psychologist, The University of Manchester

Academic Supervisors: Dr Dougal Hare, The University of Manchester
Dr Anja Wiltkowski, The University of Manchester

Field Supervisor/Local Collaborators
Dr Andrea Flood, Engage Clinical
Dr Sam Walker, Calderstones Partnership NHS Foundation Trust
Dr Barry Ingham, Northumberland, Tyne and Wear NHS Foundation Trust
Dr Ali Davies, South West Yorkshire Partnership NHS Foundation Trust

Other Researchers: Ms Lynsey Fulton, The University of Manchester

Background

Intellectual disability (ID) originates before the age of 18 and is characterised by significant limitations both in adaptive behaviour (everyday social and practical skills) and intellectual functioning (reasoning, learning, problem solving) (Schalock et al, 2010).

People with ID are more likely than the general population to experience traumatic events such as sexual abuse (Sequeira & Hollins, 2003), physical abuse (Focht-New, Clément, Barol, Faulkner, & Pekala, 2008), and negative life events including bereavement and moving house (Hatton & Emerson, 2004). In a prospective study, Esbensen and Benson (2006) demonstrated a causal and cumulative relationship between psychopathological symptoms and previous exposure to negative life events. There is evidence that developmental level can influence the development of post-traumatic stress disorder (PTSD) (Bowman, 1999). Further, Tomasulo & Razza (2007) suggest that hospital admissions and early separation from parents due to institutionalisation may make people with ID more vulnerable to developing PTSD.

Attachment is conceptualised as the affectional bond that infants form between themselves and their care giver (Ainsworth, Blehar, Waters and Wall, 1978; Bowlby 1969). The attachment between child and caregiver is the outcome of the child’s experiences of interaction with the caregiver over the first year of life (Ainsworth, 1979). From such experiences, the child constructs an internal working model of the attachment relationship which guides their behaviour in times of distress. The child’s attachment behaviours are a reflection of their anticipations about caregiver reactions and these guide the child’s strategies for managing stress (Rutgers, Bakersmans-Kranenburg, van IJzendoorn and van Berkelaker, 2004).

Caregivers of children with ID are at increased risk of stress, relating to problems with communication, interpretation and understanding of the child’s needs (Johnston et al, 2003)
which can lead to less attuned relationships. Therefore people with ID are at increased risk of developing insecure attachments with caregivers (Ganiban, Barnett and Cicchetti, 2000) which means that they are less likely to have developed effective coping strategies and self-soothing skills which may lead to increased psychological distress in response to traumatic events.

The current research will contribute to a growing body of research in the area of attachment in ID (Penketh, 2011, Walker 2009, Fulton 2014 - in progress). This study aims to investigate the relation of attachment security and traumatic life events and is it the first study to use a first person measure of trauma in this area.

**Aims and objectives**

1. To investigate to what degree attachment security accounts for variation in traumatisation in adults with mild to moderate ID.
2. To investigate whether differences in attachment security can be observed in adults who were ‘looked after children’ (LAC) compared with those who remained in the family home.
3. To investigate whether there are differences in trauma symptoms in adults who were LAC compared with those who remained in the family home.

In addition, additional data about the psychometric properties of the MAST (Penketh, Hare, Walker & Flood, 2011) will be collected as part of the present study.

**Design**
The study will be a within-and between-group design with the following variables:

**Independent Variables:**
- Security of Attachment – MAST score (Penketh et al, 2011)
- Demographics (gender, age, types of I/DD, other diagnoses, whether they were LAC.
- Previous traumatic experience – Trauma Index (Fulton, 2014 in progress)

**Dependent Variables:**

**Statistical Analysis**
- Aim 1: initial correlation analysis followed by multiple regression using LANTS scores (DV) and MAST, gender, number of traumatic events and LAC status (IV)
- Aim 2: t-test (2-tailed) would be used to examine between differences in MAST scores across LAC/non-LAC groups
- Aim 3: t-test (2-tailed) would be used to examine between differences in LANTS scores across LAC/non-LAC groups

A secondary analysis using odds-ratios would be conducted to determine whether adults who were LAC are more likely to have low MAST scores

**Participants and eligibility**
The project aims to recruit 60 service user participants who are adults with mild to moderate ID and staff appointment as their main care staff. Staff participants will be asked to complete the
MAST, demographic sheet, LANTS informant measure, Trauma Index and Glasgow Depression Scale.

Service user participants will be asked to complete the LANTS self-report measure with the researcher, although they can have a member of their care staff with them if they wish.

Recruitment will be primarily from residential and inpatient services. A number of Trusts have been contacted and have confirmed support to facilitate recruitment from their respective services. These include Calderstones Partnership NHS Foundation Trust, Northumberland, Tyne and Wear NHS Foundation Trust, South Yorkshire NHS Foundation Trust and Future Directions – Community Interest Company.

**Inclusion Criteria**

- Staff participants must have been working with/supporting individuals with an Intellectual Disability (ID), for a minimum of three months prior to participating in the study.
- All staff participants must be able to communicate using English due to the nature of the measures used.
- Service user participants should be over the age of 18 and therefore considered an adult.
- Service user participants will have an intellectual disability; as defined by MENCAP (2012) this is a ‘reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life’. According to the DSM-IV someone with an intellectual disability is someone who has an IQ score of <70 and has difficulty with activities of daily living.
- Service user participants should have capacity to provide consent, which will be assumed in line with the Mental Capacity Act (2005) unless otherwise indicated.

**Exclusion Criteria**

- Staff participants will not be eligible to participate if they have not worked with the service user for at least three months.
- Staff participants will not be eligible to participate if they are unable to communicate using the English language
- Service user participants will not be eligible if concerns are raised by either staff members of the researcher regarding their capacity to consent.

**Justification for the number of participants – power calculations**

The power/sample size calculations were performed using nQuery Advisor 7.0.

Pearson’s Correlation – with 60 participants the study will have 80% power to detect correlation coefficients of at least 0.357.

Multiple Regression Analysis/ANCOVA - With 60 participants there will be reasonable power to detect differences for a maximum of 6 independent predictors in the model, which include confounders and predictors of interest.

Independent Group t-test - With 26 participants in each group (52 total participants) the study will have 80% power to detect large effect sizes of 0.8 or greater between both groups.
Procedure
Meetings will take place with service managers within the Calderstones Partnership NHS Foundation Trust, Northumberland, Tyne and Wear NHS Foundation Trust, South West Yorkshire NHS Foundation Trust and Future Directions (Community Interest Company). Staff from community ID services and ID in-patient services will be approached regarding their willingness to facilitate the research, before approaching service users who might want to participate.

Staff participant consent
The researcher will arrange an appropriate time to meet with potential staff participants. The researcher will present information on the rationale and aims of the research and what participating will entail. Information will also be provided in written form. Participant information sheets have been developed and contain all information essential in obtaining informed consent to take part in research i.e. what the research it about, the procedure of the research, what participants will be required to do, risk and benefits of participating in the study, alternatives available to the participant and the consequences of choosing those alternatives. The information sheets are written in simple language. Information sheet 1 for staff participants has a Flesch Readability Ease score of 47.7 and a Flesch-Kincaid Grade Level 11 (Flesch 1948).

Staff will be given a minimum of one week to decide whether they want to participate in the study or not. One week later the researcher will again meet with staff who have expressed an interest in participating. Each individual will again receive a verbal explanation of the participant information sheet, and another copy of the information sheet if required. If individuals would still like to participate they will then be asked to give written consent (see consent form 1).

Consent forms will be completed and will have each participants name on them. Participants will be given a unique identification number that correlates with their name. The identification numbers and names will be stored separately so that the identification numbers on the questionnaires cannot be identified. This will allow the questionnaires to be matched together anonymously. Only the researcher will have access to the consent forms.

Service user consent
Staff will be asked to approach individuals they are working with/supporting with ID to give them a brief explanation of the study, an A4 summary sheet and ask individuals whether they would be happy to meet with the researcher to learn more about the study. The service user will be reassured that by meeting with the researcher they will be under no obligation to take part in the study. The researcher will see them individually in order for the study to be explained and for the consent process to begin.

The consent procedure will be as follows and follows good practice guidance in ID research (Dye, 2001):
-Each individual with ID will be given a written participant information sheet (Information sheet 2) which has a Flesch Readability Ease score of 78.5 and a Flesch-Kincaid Grade Level 6 (Flesch 1948).
-Each individual will receive a verbal explanation of the participant information sheet.
-The information will be presented using simple words and sentences and will be paced to allow individuals time to formulate their thoughts and communicative responses.
-The researcher will ask questions about the study to check their understanding of the essential information of the research i.e. what the research it about, the procedure of the research, what
participants will be required to do, risk and benefits of participating in the study, alternatives available to the participant and the consequences of choosing those alternatives.

Individuals will then be asked to indicate whether they are interested. However, they will be assured they have a minimum of one week to consider taking part in the study. Individuals will be encouraged to talk to staff, friends, relatives, if they wish to, before signing consent form. The researcher will then return after at least one week, at which point the service user will have the option to provide consent for staff to complete measures in relation to them and meet with the researcher to complete the trauma measure, or decline. Should the service user wish to consent, the service user can then sign the Service user consent form (Consent form 2) or provide consent via an appropriate alternative means.

During this process, if it identified that these staff and service users took part in Lynsey Fulton’s current study (Reference: 12/NW/I0701) they will be asked whether they consent to the data collected from the MAST, demographics and trauma index to be used in the proposed study to reduce repetition and demand on participants and services. For the participants who took part in study 12/NW/I0701, this would mean that just the Glasgow Depression Scale and self-report/informant LANTS would need to be completed.

Following gaining written consent from staff participants and service users, staff will be provided with a number of measures to complete. It will take approximately 60 minutes for staff to complete the measures. The researcher will then return following a minimum of three weeks to collect completed measures. The researcher will arrange a convenient time to meet with the service user participants to complete the trauma measure (this may or may not be at the time of giving consent, depending on whether this is convenient for service users).

Following completion of questionnaires, both staff and service user participants will be offered the opportunity to have a debriefing session. The primary aim of the debrief will be to answer any questions or concerns that may have arisen following participation. In the unlikely event that a participant becomes distressed during the debrief, it is anticipated that that the researcher will be able to provide appropriate support and/or refer to relevant services.

Once data has been collected it will be subject to appropriate statistical analysis.

All participants will be invited to a feedback session. During this session the existing theory/research regarding attachment theory will be presented, as well as a summary of the key findings/results from this study.

**Data analysis and storage**

Participants will be assured that all information they provide will be treated with the utmost confidentiality and that their anonymity will be respected at all times. Participants will be informed that when the research is published all information they provide will not be identifiable. However, the limitations of confidentiality (e.g. where there may be a threat to self or others in which the researcher is obliged under law to break confidentiality) will be explained to participants. All participant personal information and questionnaires collected will be given an identification number. This will allow the questionnaires to be anonymous and enable the questionnaires to be matched according to respondents. Participant’s personal data and
questionnaires will be stored separately so that the identification number on the questionnaires cannot be identified.

All paper based research data (e.g. consent forms/questionnaires) will be kept securely at the University of Manchester in a locked filing cabinet and a locked room.

The data will be analyzed using a statistical package on The University of Manchester computers and by the researcher, under supervision. This data will be stored on the university network drive and will be encrypted and password protected.

The University of Manchester policy on storage of research data is 5 years after the last publication of the study or for 10 years, whichever is the greater. Consent forms will be retained as essential documents, but items such as contact details will be deleted as soon as they are no longer needed.

After the study has been completed, the data will be stored on a CD rom, in a locked filing cabinet and room, and be encrypted and password protected.

**Dissemination**
All staff participants will be invited to a feedback session. During this session the existing theory/research regarding attachment theory will be presented, as well as a summary of the key findings/results from this study.
Appendix E: Staff participant information sheet

Information sheet 1 - Information for staff participants/services (Version 4)

17/07/13

Short title of study: Attachment and trauma in adults with ID

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 investigate whether the quality of relationships is related to the occurrence of trauma symptoms following stressful life events in people with intellectual disabilities, when other factors (e.g. mood) are taken into account.

The research will also look at whether there is a difference in trauma symptoms and quality of relationships between adults who were "looked after children" compared with those who remained in the family home.

A secondary aim is to gain more information about the Manchester Attachment Scale-Third party observational measure (MAST). The MAST is a measure of attachment (quality of relationship) for staff to use with individuals with intellectual disabilities.

Reason for the study:
Research suggests that that people with intellectual disabilities are more likely than people without intellectual disabilities to experience traumatic life events. Further, the more traumatic life events that someone with intellectual disabilities experiences, the more likely they are to experience symptoms associated with mental health problems.

In people without intellectual disabilities, secure early relationships (attachment) between infants and their care givers has been shown to be protective in reducing the likelihood of developing mental health problems in later life in response to stressful life events. Although research exists, which shows that people with intellectual disabilities are less likely to have secure attachments, little research has been done which looks at whether there is a relationship between attachment and the occurrence of trauma symptoms in response to traumatic life events.

It is hoped that a greater understanding of the relationship between trauma and attachment will lead to more effective therapies being developed for people with ID.

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 trauma will help plan future interventions and improve outcomes for individuals with intellectual disabilities.

Who is organising and funding the study?
The University of Manchester is organising and funding the study.
Who has reviewed the study?
This study has been reviewed by the National Research Ethics Service Committee - 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 60 service user participants and 60 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:
- Demographics sheet
- The MAST
- The Lancaster and Northgate Trauma Scale
- The Glasgow Depression Scale – Learning Disability
- Trauma Index

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 60 minutes to complete all the questionnaires.

You will be asked if you have recently taken part in a similar study led by trainee clinical psychologist, Ms Lynsey Fulton, titled: Attachment and challenging behaviour in adults with Intellectual Disabilities. If you have, you will be asked if you consent to the researcher gaining access to and using the information gathered from three questionnaires that were used in that study (the MAST, demographic sheet and Trauma Index). If you gave consent, this would mean that you would only need to complete two measures for the current study (Lancaster and Northgate Trauma Scales and the Glasgow Depression Scale), with the aim of reducing demand on you.

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. 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 60 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 support you to identify appropriate support.

Benefits of participating in the study
Although there are no direct benefits of participating in the study, you might develop your knowledge of attachment theory by attending the feedback session (see below).
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 cannot be identified from their responses on the questionnaires. Only I and my research supervisors will see the completed questionnaires.

Should you share information with the researcher that suggests that you or a service user is at risk, confidentiality must be broken. Senior ward staff or house managers will be informed so that they can take any necessary risk precautions.

What happens to the information collected and when the study finishes?
All staff and service user participants will be invited to a feedback session, where the summary of key findings from this study and the existing research regarding attachment theory will be presented. 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. As the questionnaires are 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 2757563 or 0161 2758093 or by email to research.complaints@manchester.ac.uk.

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

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 7 days 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?
Melanie Powney
Trainee Clinical Psychologist
University of Manchester
Division of Clinical Psychology
Second Floor, Zochonis Building
Brunswick Street
Manchester
M13 9PL
Tel: 0161 306 0400
Email: melanie.powney@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 F: Service user participant information sheet

Full title of study: Attachment in adults with intellectual disabilities: Investigating the relationship between attachment security and trauma symptoms.

Participant Information Sheet

My name is Melanie. I am asking if you would like to take part in a research study. Please take time to read or listen to the following information carefully. We will talk about it afterwards.

Ask if there is anything that is not clear or if you would like more information. Take time to think about whether or not you would like to take part. Thank you for reading this.

What is the study about?

The relationship that babies develop with their parent or main carer in the first year of life is called attachment. Attachment can affect the relationships that people have when they get older.

The study will look at whether attachment helps people with intellectual disability cope with stressful life events.

Why have I been asked?

You have been asked to take part because you are supported by a service for people with intellectual disability.

No. Taking part is up to you.

If you don’t want to take part, that is ok. It will not change anything about the services that you receive.

If you want to take part you will be given this information sheet to keep. I will ask you to sign a form to say you understand it and agree to take part. You will also be given a copy of this signed form to keep.

If you change your mind, you can stop at any time and don’t have to give a reason.
The study has several parts:

- I will meet with you to explain the study.
- You will be given at least 7 days to think about if you want to take part.
- If you do not want to take part you do not have to meet with me again. If you want to take part, you will be asked a number of questions to check that you understand what the study involves.
- You will be asked to sign a form if you agree to take part in the study. Agreeing to take part is also called consent.
- I will meet with you to ask you about how you feel. This will take about 45 minutes.
- I will ask a member of staff to fill out some forms about how you get along with other people, difficult events that might have happened and how they think you feel.
- I will ask you if you took part in Lynsey Fulton’s research. Lynsey’s research looked at the relationship between how people get on with others and how they cope with their emotions. If you took part, I will ask if you consent to me asking Lynsey if I can use some of the answers provided about you by staff in that study. This means that staff would not have to fill out as many forms about you for my study. You do not have to agree to this.
- I will return at least 2 weeks later to collect the forms that staff have done.

Taking part is unlikely to benefit you directly. The study will help us understand if relationships help people cope with stress so we can find better ways to help them.
You may become a bit upset when you talk about how you are feeling. If you become upset I will stop asking you questions. You can withdraw consent at any time. I may speak to my supervisor or your carers so they can help you but only with your permission.

Your name will not be on the forms that staff fill out, so your identity will be private. Your name will only be recorded on the consent form that you sign. This will be kept safe and separately from the staff forms.

All information about you won’t be shared with anyone else and will be kept safe, unless I think that you or someone else is at risk. If this happens, I will speak to the service manager about the information. The service manager may speak to other professionals. I would speak to you so that you know what is happening.

When the study is written up, I won’t use your real name, so no one will know it’s about you.

All staff and service users will be invited to a feedback session where the main findings from the study will be presented, as well as information about attachment.

The results of the study will form part of a report that the University of Manchester will examine as part of my training and will be published in scientific journals.

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 or the National Health Service (NHS) Trust but you may have to pay your legal costs. The normal NHS complaints mechanisms will still be available to you.
If you have any concerns about anything to do with the study, do ask to speak to me. 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 University Research Practice and Governance Co-coordinator on 0161 2757583 or 0161 2758093 or email research.complaints@manchester.ac.uk. You can ask your key worker to help you if you want to complain.

If you want to ask any questions you can contact me:

Melanie Powney, Trainee Clinical Psychologist
Division of Clinical Psychology
2nd Floor, Zochonis Building
University of Manchester Brunswick Street
Manchester M13 9PL
melanie.powney@postgrad.manchester.ac.uk
Tel: 0161 306 0400
Appendix G: Summary information sheet

Full title of study: Attachment in adults with intellectual disabilities: Investigating the relationship between attachment security and trauma symptoms.

**Summary Information Sheet**

This is Melanie. She is doing some research to see if relationships help people cope with stressful life events. She would like to talk to you.

If you agree, Melanie will ask to meet with you to fill out a questionnaire about how you are feeling. This will take about 45 minutes. Melanie will ask a member of staff to complete some questionnaires about you.

Taking part is up to you.

If you do take part, you can stop at any time. You don’t have to tell Melanie why.

Everything you tell Melanie will be kept private, unless Melanie is worried about you or someone else. Melanie won’t use your real name in anything she writes after she had talked to you.

If you want to take part, or if you have any questions or would like to know more:

- Speak to your key worker
- or you can contact Melanie;
  by telephone: 0161 306 0400 (ask for Melanie Powney)
  or e-mail: melanie.powney@postgrad.manchester.ac.uk
Appendix H: Service user consent form

Consent form – For service user participants (version 5)

17/07/13

Short title of study: Attachment and trauma in adults with ID

Chief Investigator: Melanie Powney

Participant Identification Number:

Please read this sheet carefully and initial each box

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 agree to take part in the above study. This includes meeting with the researcher to fill out a questionnaire about how I feel.

3) I agree for staff to fill in questionnaires that will ask information about me.

4) I understand that giving consent is my choice. I do not get paid for taking part. I am free to withdraw at any time, without giving any reason, and my medical care and my legal rights will not be affected.

5) I understand that information collected during the study may be looked at by staff from the University of Manchester, from the NHS Trust and regulatory bodies who want to check the research and that people doing the research are doing their job correctly. I give permission for these staff to see this information.

6) 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.
7) For participants who took part in Lynsey Fulton's project (please cross out as necessary) – I agree/do not agree for the researcher to have access to and use the answers from three questionnaires gathered in Lynsey Fulton's research project: Attachment and challenging behaviour in adults with Intellectual Disabilities.

8) For participants who are not sure if they took part in Lynsey Fulton's project (please cross out as necessary) – I agree/do not agree for the researcher to ask Lynsey Fulton if I took part in her study. If I did take part, I agree/do not agree for the researcher to have access to and use the answers from three questionnaires gathered in Lynsey Fulton's research project: Attachment and challenging behaviour in adults with Intellectual Disabilities.

Name of participant ___________________________  Signature ___________________________

Date of signature ___________________________

Name of researcher ___________________________  Signature ___________________________

Date of signature ___________________________

**Where verbal consent has been given**

Name of witness ___________________________  Signature ___________________________

Designation ___________________________

Date of signature ___________________________

When completed 1 copy for participant and 1 copy for researcher.
Appendix I: Staff consent form

Consent form – For staff participants (Version 3)

28/04/13

Short title of study: Attachment and trauma in adults with ID

Chief Investigator: Melanie Powney

Participant Identification Number:

Please read this sheet carefully and initial each box

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 locked 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.

6) Only to be completed for participants who took part in Lynsey Fulton’s project (please cross out as necessary) – I agree/do not agree for the researcher to have access to and use the answers gathered from three of the questionnaires in Lynsey Fulton’s research project: Attachment and challenging behaviour in adults with Intellectual Disabilities

7) For participants who are not sure if they took part in Lynsey Fulton’s project (please cross out as necessary) – I agree/do not agree for the researcher to ask Lynsey Fulton if I took part in her study. If I did take part, I agree/do not agree for the researcher to have access to and use the answers from three questionnaires gathered in Lynsey Fulton’s research project: Attachment and challenging behaviour in adults with Intellectual Disabilities.

Name of participant

Signature

Date of signature

Staff Consent Sheet (Version 3)
26/04/13
Name of researcher ______________________ Signatory ______________________

Date of signature ______________________
When completed 1 copy for participant and 1 copy for researcher.

The University of Manchester, Oxford Road, Manchester M13 S9L

Staff Consent Sheet (Version 3)  
26/04/13

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