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University of Glasgow | College of Medical,  
Veterinary & Life Sciences

## **Understanding the cognitive and behavioural sequelae of child maltreatment**

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Submitted in partial fulfilment of the requirement for the  
degree of Doctorate in Clinical Psychology

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## **Foreword**

For this thesis, the Major Research Project (Chapter 2) involved an observational study and secondary analysis of data already held within the research team. The observational study involved the collection of data from three samples of children: typically developing, those with Autism Spectrum Disorder (ASD) and those with symptoms of Disinhibited Social Engagement Disorder (DSED). The COVID-19 pandemic caused some disruption to data collection; although enough data from the typically developing and ASD samples had been collected, insufficient data from the DSED sample had been collected. The DSED sample data was therefore supplemented with video data on a sample of children with DSED symptoms already held within the research team. This data depicted a procedure with enough similarity to the procedure used for in-person data collection to facilitate the analysis of the data from both DSED samples as one group, following the analysis procedures initially planned. As the data for the secondary analysis was already held within the research team, no changes to this component of the study were required. No changes to the Systematic Review (Chapter 1) were made as a result of the pandemic.

## **Authors Declaration**

“I hereby declare that I am the sole author of this thesis, except where the assistance of others has been acknowledged. It has not been submitted in any form for another degree or professional qualification.”

Genevieve Young-Southward

July 2020

## Chapter 1: Systematic Review

Investigating the causal relationship between maltreatment and cognition in children: a systematic review

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See Appendix 1 for author guidelines

See Appendix 2 for copy of published paper

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## **Abstract**

*Background:* Cognitive impairment (i.e. lower IQ/cognitive development) in individuals who have experienced childhood maltreatment is well documented in the literature. It is not yet clear whether maltreatment itself causes cognitive impairment, or whether reduced cognitive functioning pre-dates maltreatment exposure and places children at risk of maltreatment.

*Objective:* This systematic review critically evaluated the evidence for a causal association between child maltreatment and impaired cognition in children under 12 years.

*Methods:* Following PRISMA guidelines, databases were searched and articles extracted according to inclusion criteria. Quality rating of articles was conducted independently by two reviewers and the evidence for a causal association was evaluated using guidelines based on the Hill criteria for causation in epidemiological and public health research.

*Results:* 31 articles were included in the review, with results that suggested lower IQ/cognitive development in maltreated children compared to controls, and a dose-response relationship between timing and duration of maltreatment and impaired cognition. Assessment of causality indicated strong evidence for a causal association between maltreatment and reduced overall cognitive performance in institutionalised children. Findings were less robust for non-institutionalised samples. Evidence regarding specific cognitive functions was mixed.

*Conclusions:* Extreme maltreatment may lead to reduced cognitive functioning in children under 12 years. More research is required to determine the impact of the nature and timing of maltreatment, as well as additional heritable and social factors, on specific profiles of cognition in this population.

## Introduction

Child maltreatment, including emotional, physical or sexual abuse, or neglect, can be regarded as a form of “toxic stress” linked to dysregulation of the human stress response (Alink, Cicchetti & Kim, 2012; Young-Southward, Svelnys, Gajwani, Bosquet Enlow & Minnis, 2019) and to alterations in the brain (Pechtel & Pizzagalli, 2011). Several systematic reviews have documented impaired cognitive functioning (lower IQ/cognitive development) in adults (Irigaray et al., 2013) and school-aged children (Maguire et al., 2014) who have experienced childhood maltreatment. One such review reported associations between duration, severity, type and timing of maltreatment and cognition in children and adolescents (Kavanaugh et al., 2017).

Cognitive impairment in maltreated children is hypothesised to result from disruptions to normal brain development as a result of the experience of maltreatment. Chronic exposure to stress in early life may impact upon specific areas of the brain that undergo protracted postnatal development, such as the prefrontal cortex and superior temporal gyrus (Pechtel & Pizzagalli, 2011). These areas are responsible for higher-order functions, such as aspects of executive functioning, and insults to these areas may explain impairment in cognition observed in this population. Evidence from longitudinal studies of institutionalised children support this hypothesis: length of time spent in institutionalised care is positively associated with the extent of cognitive impairment (Castle et al., 1999; O’Connor et al., 2000; Rutter et al., 2001; Beckett et al., 2006; Loman et al., 2009) and once removed from the depriving environment, cognitive catch-up, with group scores increasing, and some entering the normal range has been demonstrated (Rutter et al., 1998; Beckett et al., 2006; Nelson et al., 2007).

An alternative hypothesis is that vulnerabilities in the brain are a consequence of heritable or social factors, such as poverty, that are present prior to maltreatment. In an assessment of causality of childhood victimisation on cognitive impairment among individuals involved in

large longitudinal studies in the UK and New Zealand, Danese and colleagues (2016) demonstrated that cognitive impairment pre-dated experiences of victimisation. Furthermore, children with developmental disorders are at greater risk of maltreatment (Olson & Jacobson, 2009); this could explain the higher prevalence of maltreatment documented in this population.

Difficulties establishing a causal relationship between maltreatment and cognitive outcomes, should one exist, may relate to the heterogeneity in maltreatment experiences (e.g. abuse, neglect, or both) and in cognitive outcomes. Additionally, limitations within the current literature restrict the potential of establishing a possible causal relationship between child maltreatment and cognitive impairment. Many studies assessing IQ in maltreated children do not control for heritable factors (Pechtel & Pizzagalli, 2011) and cross-sectional, rather than longitudinal, study designs are often used to examine brain functioning following maltreatment exposure (Danese et al., 2016). Yingying, D'Arcy, Shuai and Xiangfei (2019) conducted a systematic review of 11 prospective studies evaluating cognition among children exposed to maltreatment. They concluded that childhood maltreatment was associated with cognitive functioning but they were unable to judge whether maltreatment *causes* cognitive impairment or vice versa.

## **Criteria for establishing causal relationships**

The Hill criteria (1965) have long been used to evaluate causal relationships in epidemiology and public health research. Recent reappraisal of the Hill criteria (see Panel 1) suggests a careful focus on separating probabilistic (i.e. likely) associations from causality, scrutiny of potential mechanistic processes, and replicability in more than one study (Howick, Glasziou & Aronson, 2009). Examining existing studies using these guidelines may help to evaluate the evidence for causality in the association between child maltreatment and cognitive functioning.

**Panel 1. Revised Hill criteria for causal relationships**

- Size of effect not attributable to plausible confounding
- Appropriate temporal and/or spatial proximity
- Dose-responsiveness
- Reversibility (if the cause is removed then the effect should also disappear)
- Plausible mechanism of action
- Coherence
- Replicability
- Similarity

To this end, the purpose of this systematic review is to synthesise the evidence examining an association between child maltreatment and cognitive impairment, and to assess whether a causal relationship between child maltreatment and cognitive impairment can be established using the updated Hill criteria proposed by Howick, Glasziou and Aronson (2009). Because interventions to minimise possible long-term consequences of impairments in cognitive functioning rely on prompt identification of children with such difficulties (Maguire et al., 2014), this review focused on children under the age of 12 years. This systematic review aimed to address the following question: what is the evidence for a causal relationship between experiences of maltreatment and cognitive impairment in children under 12 years?

## **Method**

Preferred Reporting Items for Systematic reviews and Meta analyses (PRISMA) guidelines were followed. PsycInfo (1981-2019), Embase (1996-2019) and Medline (1996-2019) were searched using the following terms:

1. Child\* N4 (abus\* OR neglect\* OR maltreat\* OR institutional\* OR postinstitutional\*)
2. (Cognit\* OR intellectual\* OR neurocognit\*) N4 (impair\* OR deficit\* OR dysfunction OR function\* OR performance OR outcome\*)

3. 1 and 2 were combined with AND.

The final search was conducted in July 2019 (Appendix 3). Reference sections of included articles were screened to ensure that no relevant articles were missed. Articles that were available in English were selected based on the following inclusion criteria:

- Children aged 0-12 years.
- Association between child maltreatment (verified by child protection agencies or equivalent) and performance-based cognition (including general intelligence, memory, executive functioning, processing speed, verbal comprehension, perceptual reasoning) assessed. Articles utilising parent/caregiver measures of cognition only were excluded because only weak and limited correlations between parent-rated and performance-based executive functioning have been found previously (e.g. Fay-Stammbach & Hawes, 2018).

Case reports, reviews, conference proceedings and theses were excluded. Besides type of article, there were no other exclusion criteria. A sub-sample of 20% of titles and abstracts were screened by a second reviewer. Any differences in agreement were solved via conference.

Relevant data were extracted from each included study, and the Crowe Critical Appraisal Tool (CCAT, v1.4) (Appendix 4) was used to assess the quality of each study. The tool creates a score out of 5 for each of the following domains: preliminaries, introduction, design, sampling, data collection, ethical matters, results, and discussion, resulting in a total score out of 40. In line with the tool's guidelines, a score of <20 was considered low quality; 20-30 moderate quality, and >30 high quality. Quality assessment of each article was completed independently by two reviewers. Any differences in agreement (25% of papers) were solved via conference.

Causality of the association between child maltreatment and cognition was assessed using the revised Hill (1965) guidelines for causation (Howick, Glasziou & Aronson, 2009) (Panel 1).

## Results

The search yielded a total of 1,250 articles. 347 duplicates were removed, along with 715 articles that were clearly not relevant (Figure 1). 188 abstracts were screened, and 55 articles were read in full. 22 articles met the inclusion criteria. The reference sections of included articles were screened, yielding an additional 9 articles for inclusion. 31 articles were included in the review. All articles were assessed as being of high or moderate quality (CCAT score >20). Tables 1 and 2 describe the characteristics of the included studies. These were heterogeneous in samples, methodologies and outcomes; as such, it was not possible to conduct a meta-analysis. A narrative synthesis of the findings was therefore conducted. Where possible, effect sizes are reported for studies that included a non-maltreated comparison group. The following section will present the findings from community samples of maltreated children, followed by the findings from samples of institutionalised children.

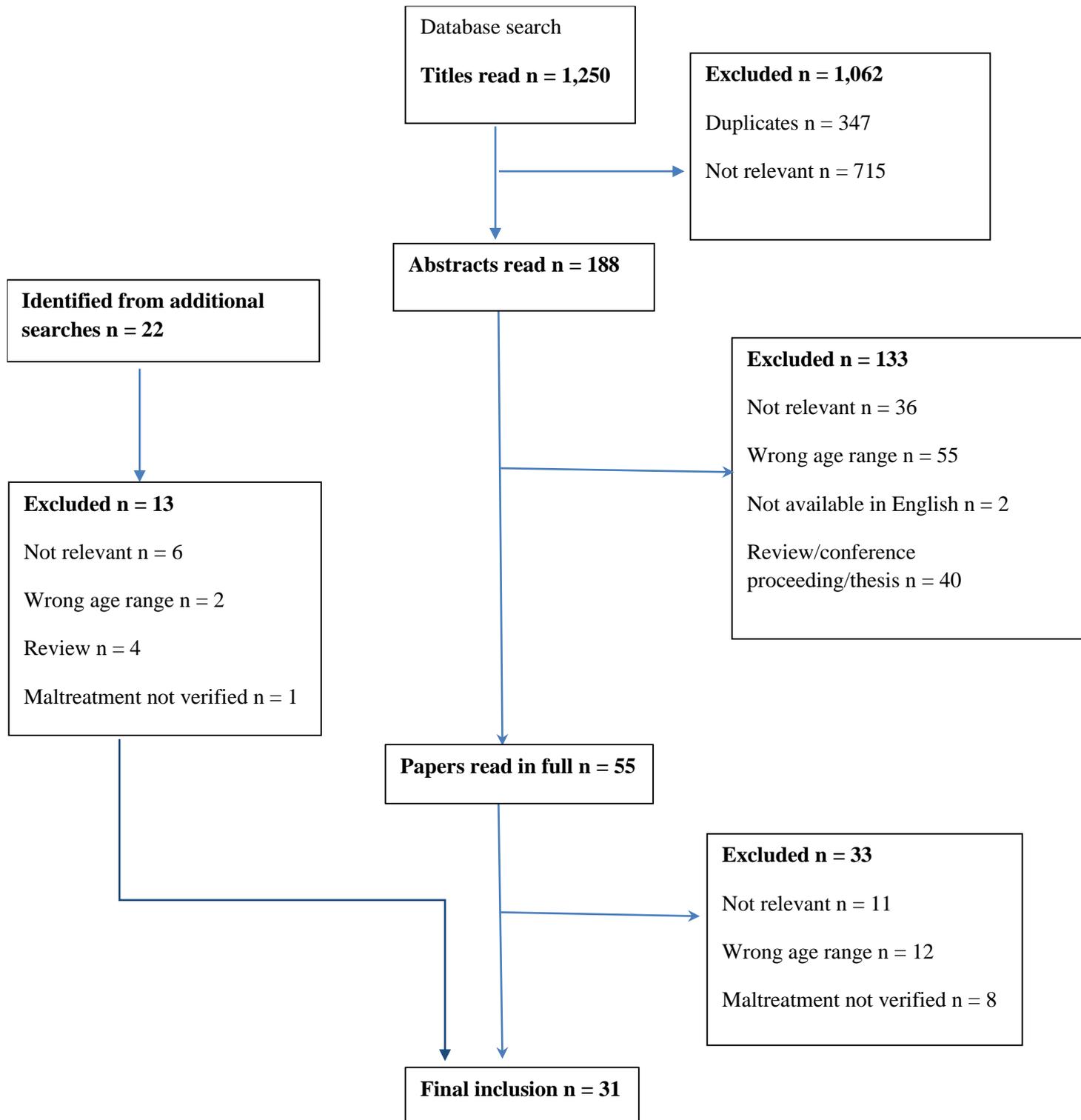


Figure 1: Inclusion and exclusion of articles

Table 1: Included studies of community samples, organised via CCAT score

	Authors/ date	Study design	Outcomes	Participants (n, age, country, recruitment)	Type of maltreatment	Cognitive domains and assessment	Results	Confounders	Limitations	CCAT Score (Max = 40)	Bradford Hill Criteria (Max = 7)
1	Bosquet Enlow et al. (2012)	Longitudinal assessments at 2, 5 and 8 years old.	Influence of timing of maltreatment exposure on the magnitude and persistence of cognitive impairment.	Data from the Minnesota Longitudinal Study of Parents and Children, USA. Children (n = 206) whose mothers were recruited during pregnancy from hospitals.	Physical abuse, emotional abuse or neglect, sexual abuse, witnessing maternal partner violence, identified via observations, interviews, and reviews of medical and child protection records.	General cognitive performance.  Bayley, WPPSI, WISC.	Maltreatment in infancy significantly associated with poor cognitive outcomes (r = -.038).	Race, gender, SES, maternal IQ, birth complications, birth weight, cognitive stimulation in the home.	Small sample size	33	6
2	Strathearn et al. (2001)	Longitudinal follow-up over 4 years.	Relationship between child maltreatment and cognitive development in extremely low birth weight infants.	Infants with low birth weight (n = 352) recruited from a hospital, Australia.	Physical abuse, sexual abuse, emotional abuse or neglect, identified via Families Youth and Community Care Queensland reports.	IQ  GQ, GCI	Neglect was associated with cognitive delay (r <sup>2</sup> = 0.15).	Birth weight, gestation, small for gestational age status, gender, multiple births, requirement for home oxygen, grade 3 to 4 periventricular haemorrhage, moderate to severe ventricular dilation, necrotizing enterocolitis, retinopathy of prematurity, maternal age, race, marital status, maternal education, hospital insurance status.	No non low birth weight control group.	33	6
3	DeBellis et al. (2009)	Cross- sectional	Neurocognitive impact of neglect.	Children age 3-12 years. Neglected children with	Neglect identified through the	IQ, fine motor skills, language, visual-spatial,	Neglect groups had significantly lower IQ	IQ.	Small sample size.	32	4

	Authors/ date	Study design	Outcomes	Participants (n, age, country, recruitment)	Type of maltreatment	Cognitive domains and assessment	Results	Confounders	Limitations	CCAT Score (Max = 40)	Bradford Hill Criteria (Max = 7)
				PTSD (n = 22), neglected children without PTSD (n = 39) recruited through Departments of Social Services, and controls (n = 45) recruited through schools and paediatric clinics, USA.	Department of Social Services.	memory/ learning, attention/ executive functions.  NEPSY, CPT, PPVT-3, WISC-III/WPPSI-R, WJ-III, WASI.	compared to controls ( $\eta^2 = .09$ )				
4	Cowell et al. (2015)	Cross-sectional.	Effect of childhood maltreatment on neurocognitive functioning based on developmental timing of maltreatment (including onset, chronicity and recency).	Maltreated (n = 223) children age 3-9 years recruited from the Department of Human Services. Non-maltreated (n = 136) children aged 3-9 years matched for SES recruited from families receiving Temporary Assistance to Needy Families, USA.	Sexual abuse, physical abuse, emotional maltreatment or neglect, identified through child protection services records.	Inhibitory control, working memory, memory, attention.  Day-night Stroop-like task, tapping task, three pegs task, Corsi-Milner test of temporal order and recognition memory, six boxes task, global-local spatial processing task, line bisection task.	Maltreated children had a significantly lower inhibitory control/working memory score compared to controls ( $\eta^2 = .026$ ).	Age.	Parental characteristics not controlled for.	31	6
5	Bucker et al. (2012)	Cross-sectional.	Comparison of cognitive function in children compared with age- and sex-matched controls.	Children with early trauma (n = 30), age 5-12 years, recruited from a child protection programme and a foster care home in Brazil. Age- and sex-matched children without early trauma (n = 30) recruited from community	Sexual abuse, maltreatment or neglect identified via child protection services.	IQ, working memory, attention, impulsivity and executive function.  Vocabulary, block design and digit-span subtests of the WISC-III, WCST, CPT.	Maltreated children performed worse than controls on tests of attention ( $d = 0.91$ ).	Age, sex.	Small sample size.	31	4

	Authors/ date	Study design	Outcomes	Participants (n, age, country, recruitment)	Type of maltreatment	Cognitive domains and assessment	Results	Confounders	Limitations	CCAT Score (Max = 40)	Bradford Hill Criteria (Max = 7)
				primary health care centres, a school, and a university paediatric clinic.							
6	Nolin & Ethier (2007)	Cross-sectional.	Differentiation of neglected children with or without physical abuse from comparison children using cognitive profiles.	Children age 6-12 years with histories of neglect and physical abuse (n = 56) and neglect without physical abuse (n = 28) recruited from child protection services. Comparison children (n = 53) recruited from schools, Canada.	Neglect with or without physical abuse, identified through child protection services.	Motor performance, attention, learning, visual-motor integration, language, executive function, intelligence.  Purdue Pegboard, NEPSY, CVLT-C, VMI, WISC-III.	Physically abused neglected children and non-physically abused neglected children had lower scores than controls on measures of auditory attention ( $d = 0.31$ ) and visual-motor integration ( $d = 0.12$ ). Physically abused neglected children had lower scores than controls on measures of mental calculation ( $d = 0.05$ ) and concept formation ( $d = 0.07$ ).	SES.	Only examined physical abuse and neglect.	31	4
7	Pears et al. (2008)	Cross-sectional.	Profiles of maltreatment and their association with cognitive functioning, internalising and externalising problems.	Maltreated foster children (n = 117) aged 3-6 years recruited from child welfare system, USA.	Physical abuse, sexual abuse, physical neglect, supervisory neglect, emotional maltreatment, identified through child welfare case records.	Cognitive functioning, neuropsychological functioning and language development.  WPPSI-R, NEPSY, PLS-3.	Lower cognitive functioning demonstrated in children with histories of neglect, physical abuse, or both.		Small sample size. No maltreated comparison group.	31	3
8	Scarborough et al. (2009)	Longitudinal assessments at 18- and 36-months	Relationship among child, caregiver and maltreatment	Data from the National Survey of Child and Adolescent	Physical, sexual or emotional abuse, neglect identified	Global development.	Neglect and sexual abuse associated with low scores on		No non-maltreated comparison group.	30	5

	Authors/ date	Study design	Outcomes	Participants (n, age, country, recruitment)	Type of maltreatment	Cognitive domains and assessment	Results	Confounders	Limitations	CCAT Score (Max = 40)	Bradford Hill Criteria (Max = 7)
		following investigation of maltreatment .	characteristics and low scores on developmental measures.	Wellbeing, USA. Maltreated children age 0-3 years (n = 997).	through child protection services.	BDI, VABS, KBIT, PLS.	measures of development.				
9	Petrenko et al. (2012)	Cross-sectional.	Effects of maltreatment subtypes on cognitive, academic and mental health functioning.	Children age 9-11 years (n = 334) recruited to an RCT for the Fostering Healthy Futures programme.	Physical abuse, sexual abuse, physical neglect, supervisory neglect identified from child welfare records.	IQ  K-BIT.	Supervisory neglect associated with higher verbal IQ scores.		No non-maltreated comparison group	30	1
10	Pears & Fisher (2005)	Cross-sectional.	Types of developmental delays observed in young children in foster care and how placement and maltreatment experiences are associated with these delays	Children age 3-6 years in foster care (n = 99) recruited through the child welfare system. Comparison children (n = 54) recruited via advertisements in supermarkets, day care centres, Head Start classrooms and newspapers/newsletters, USA.	Physical abuse, sexual abuse, emotional abuse, neglect, identified through child protection services.	Language, attention/executive function, visuospatial processing, sensorimotor function, memory, learning, general cognitive function.  NEPSY, block design and vocabulary sub-tests of the WPPSI-R, PLS-3, stroop task, card sort task	Positive correlation between age at first foster care placement and executive functioning (r = 0.30). Negative correlations found between being placed in foster care due to neglect/emotional abuse and visuospatial processing (r = -0.27), language (r = -0.22), memory (r = -0.36) and executive functioning (r = -0.26).	Whether the child was new to foster care.	Parental characteristics not controlled for.	29	4
11	Spratt et al. (2012)	Cross-sectional.	Impact of neglect on children's cognition, language, behaviour and	Children age 3-10 years with history of physical or emotional neglect (n = 17), adopted from international institutions (n =	Physical or medical neglect, physical abuse, sexual abuse or emotional abuse identified through child	Cognitive functioning, language.  DAS, TELD or TOLD.	Children with a history of neglect or institutional rearing demonstrated lower cognitive scores compared	Annual household income.	Small sample size.	28	3

	Authors/ date	Study design	Outcomes	Participants (n, age, country, recruitment)	Type of maltreatment	Cognitive domains and assessment	Results	Confounders	Limitations	CCAT Score (Max = 40)	Bradford Hill Criteria (Max = 7)
			parenting stress.	15), and with no history of neglect or adoption (n = 28) recruited through medical/mental health practitioners or through flyers, USA.	protection services.		to those with no history of neglect or adoption ( $d = 1.1$ )				
12	Barrera et al. (2013)	Cross-sectional.	Neuropsychological functioning in abused children compared to controls.	Children age 8-12 years (n with sexual abuse histories and PTSD symptoms = 13; n with sexual abuse history and no PTSD symptoms = 26) recruited from an organisation supporting children affected by sexual abuse who were involved in legal action against their alleged abusers. Controls (n = 37) recruited from a school, Colombia.	Sexual abuse identified via recruitment organisation.	Neuropsychological functioning.  MINI, TMT, CVLT, Ray-Osterrieth Complex Figure Task, Stroop Test, WCST.	History of sexual abuse was associated with reduced attentional inhibition ( $d = 0.46$ )		Small sample size.	27	3
13	Kocovska et al. (2012)	Cross-sectional.	Neurodevelopmental difficulties in maltreated adopted children.	Children age 5-12 years. Children with history of severe maltreatment and symptoms of indiscriminate friendliness (n = 34) recruited via Adoption UK charity.	Physical abuse, sexual abuse, emotional neglect or physical neglect identified via social work records.	IQ  WASI.	Lower IQ in maltreated children compared to controls ( $d = 1.0$ )		Small sample which may be skewed due to recruitment via adoption charity.	27	3

	Authors/ date	Study design	Outcomes	Participants (n, age, country, recruitment)	Type of maltreatment	Cognitive domains and assessment	Results	Confounders	Limitations	CCAT Score (Max = 40)	Bradford Hill Criteria (Max = 7)
				Comparison children (n = 32) recruited via medical practices, UK.							
14	Kerr et al. (2000)	Cross-sectional.	Relationship between failure to thrive, maltreatment cognitive performance, adaptive functioning at school, classroom behaviour and home behaviour.	6-year-old children (n = 193; n with maltreatment only = 21; n with maltreatment and failure to thrive = 28) recruited from paediatric clinics, USA.	Neglect, physical abuse or sexual abuse, identified through child protection services.	Cognitive performance.  Vocabulary and block design subtests of WPPSI-R.	Children with both failure to thrive and maltreatment has significantly lower cognitive scores than children with neither risk factor ( $d = 0.45$ ).	Age, gender, SES.	No examination of mechanisms underlying associations	26	4
15	Prasad et al. (2005)	Cross-sectional.	Cognitive, motor and language skills of physically abused pre-schoolers.	Physically abused children age 1-6 years (n = 19) recruited from hospitals. Comparison children (n = 19) recruited from hospitals, subsidised clinics, and community notices, USA.	Physical abuse identified through child protection services and child protection committee at hospitals.	General cognitive ability, language, motor skills.  Bayley-II or Stanford-Binet Intelligence Scales-IV, MSCA, SICD or CELF (Preschool or Third Edition).	Lower cognitive ability found in abused children compared to controls ( $d = 0.81$ )		Small sample size.	26	3
16	Hoffman-Plotkin & Twentyman (1984)	Cross-sectional.	Behavioural and cognitive functioning in abused and neglected children compared to controls.	Children age 3-6 years with a history of child abuse or neglect (n = 28) recruited via social services or no history of maltreatment (n = 14) recruited through local day care centres, Canada.	Physical abuse, neglect, identified through social services.	Cognitive functioning.  PPVT, Stanford-Binet Intelligence Scale, Merrill-Palmer Scale of Mental Tests.	Abused or neglected children had lower cognitive functioning than controls.		Small sample size.	26	3

	Authors/ date	Study design	Outcomes	Participants (n, age, country, recruitment)	Type of maltreatment	Cognitive domains and assessment	Results	Confounders	Limitations	CCAT Score (Max = 40)	Bradford Hill Criteria (Max = 7)
17	Augusti & Melinder (2013)	Cross-sectional.	Executive functioning in maltreated children compared to non-maltreated peers.	Children age 8-12 years. Maltreated children (n = 21) recruited through child protection services and domestic violence shelters. Non-maltreated children (n = 22) recruited from schools, Norway.	Physical abuse, witnessing violence, neglect identified via child protection services.	Executive function. WASI, CANTAB, D-KEFS colour-word interference test.	Maltreated children performed significantly worse on spatial working memory task compared to controls ( $\eta^2 = 0.10$ )		Small sample size.	26	4
18	Crozier & Barth (2005)	Cross-sectional.	Cognitive functioning and academic achievement in maltreated children.	Data from the National Survey of Child and Adolescent Wellbeing. Maltreated children aged 6-11 years (n = 814), USA.	Physical abuse, sexual abuse, neglect, 'other' identified through child welfare services.	IQ. K-BIT.	32.6% maltreated children scored one standard deviation below the mean for cognitive functioning compared to national norms.	Age, gender, race, ethnicity, maltreatment type, poverty, prior history of child welfare services involvement, caregiver mental health problems, clinical behaviour problems.	No non-maltreated comparison group.	26	4
19	McNichol & Tash (2001)	Longitudinal : assessments 18 months apart.	Impact of parental substance abuse on cognition and behaviour in children.	Children age 5-7 years (n = 268) recruited via a family foster care agency, USA.	Physical abuse, neglect, prenatal exposure to illegal drugs, parental substance abuse, parental mental illness, sexual abuse, domestic violence, identified via social work.	IQ. WISC, McCarthy scales, KABC.	Children scored in low range of cognitive functioning overall but demonstrated significant improvement in cognitive functioning over time.		No non-maltreated comparison group.	22	6
20	Sandgrund et al. (1974)	Cross-sectional.	Impact of child abuse and neglect on cognitive development.	Children age 5-12 years (abused n = 60; neglected n = 30) recruited from families receiving public assistance. Non-maltreated	Abuse, neglect identified via child protection agencies.	IQ. WPPSI, WISC.	25% of the abused sample, 20% of the neglected sample, and 3% of the control sample exhibited an IQ of below 70.		Small sample size.	21	4

	Authors/ date	Study design	Outcomes	Participants (n, age, country, recruitment)	Type of maltreatment	Cognitive domains and assessment	Results	Confounders	Limitations	CCAT Score (Max = 40)	Bradford Hill Criteria (Max = 7)
				children (n = 30) recruited from a paediatric hospital, USA.							
21	Friedrich et al. (1983)	Cross- sectional.	Cognitive differences among abused and non-abused preschool children.	Children aged 3-5 years. Physically abused children (n= 11) recruited via a day programme for abused children. Controls (n = 10) recruited via a Head Start programme, USA.	Physical abuse identified via child protection services.	Cognition.  MSCA, WRAT.	Physically abused children performed worse on verbal and memory scales of MSCA compared to controls.		Small sample size.	20	3

Abbreviations: Bayley – Bayley scales of infant development; BDI – Battelle screening test; CANTAB – Cambridge neuropsychological test automated battery; CAPI – Child Abuse Potential Inventory; CELF – Clinical evaluation of language fundamentals; CPT – Continuous performance task; CVLT-C – California verbal learning test for children; DAS – Differential abilities scale for children; DCCS – Dimensional change card sort; DDS – Denver Developmental Scales; D-KEFS – Delis-Kaplan executive function system; GCI – McCarthy general cognitive index; GQ – Griffiths general quotient; IQ – intelligence quotient; KABC – Kaufman assessment battery for children; K-BIT – Kaufman brief intelligence test; MCA – Minnesota comprehensive assessment; MSCA – McCarthy scale of children’s abilities; NEPSY – Developmental neuropsychological assessment; PCCTS – Parent Child Conflict Tactics Scale; PLS – Preschool language scale; PPVT – Peabody picture vocabulary test; PTSD – Post traumatic stress disorder; SES – socioeconomic status; SICD – sequenced inventory of communication development; TELD – Test of early language development; TOLD – Test of language development; USA – United States of America; VABS – Vineland adaptive behaviour

scale; VMI – Beery Buktenica developmental test of visual-motor integration; WASI – Wechsler abbreviated scale of intelligence; WCST – Wisconsin card sorting task; WISC-III – Wechsler intelligence scale for children-III; WJ-III – Woodcock-Johnson tests of cognitive abilities-III; WPPSI-R – Wechsler preschool and primary scale of intelligence-revised; WRAT – Wide Range Achievement Test.

Table 2: Included studies of institutionalised samples, organised via CCAT score

	Authors/date	Study design	Outcomes	Participants (n, age, country, recruitment)	Cognitive domains and assessment	Results	Confounders	Limitations	CCAT Score (Max = 40)	Hill Criteria (Max = 7)
22	Nelson et al. (2007)	Longitudinal: assessments took place at 4 time points.	Cognitive development in post-institutionalised children.	Data from the BEIP. Institutionalised children (n = 136), half of whom remained in institutions and half of whom were allocated to foster care. Never institutionalised controls (n = 72) recruited from community paediatric clinics. Cognitive assessments took place at baseline, 30 months, 42 months and 54 months.	Cognitive development.  Bayley-II or WPPSI-R.	Placement in foster care led to improved cognitive outcomes ( $d = 0.62$ at 42 months; $d = 0.47$ at 54 months).	Birth weight, gender.	No data on characteristics of institutionalised children's birth families.	31	N/A
23	O'Connor et al. (2000)	Longitudinal: assessments took place at age 4 and 6 years.	Cognitive development and catch-up in neglected children.	Data from the ERAS. Romanian adoptees (n = 165; placed before 24 months = 117, placed after 24 months n = 48) and UK adoptees (n = 52) age 4-6 years recruited through adoption agencies and social services departments.	Cognitive development.  MSCA.	Duration of deprivation associated with cognitive development at age 6 years ( $r = -0.48$ ).	Gender.	No data on characteristics of institutionalised children's birth families.	31	6
24	Beckett et al. (2006)	Longitudinal assessments at age 6 and 11 years old.	Cognitive outcomes in post-institutionalised children.	Data from the ERAS. Romanian adoptees (n = 131). UK adoptees (n = 50) recruited via adoption agencies.	General cognitive performance.  MSCA, WISC.	Significant correlation between age at entry to UK and IQ at age 6 among children placed later than 6 months ( $r = -0.32$ ) but this disappeared by age 11 ( $r = -0.08$ ).	Year of adoption, parental motivation to adopt, age at placement.	No data on Romanian adoptees' experiences prior to UK entry.	30	6
25	Bauer et al. (2009)	Cross-sectional.	Role of early deprivation in maturation of the cerebellum and aspects of cognitive development.	Children age 9-12. Post-institutionalised children (n = 31) recruited from Wisconsin International Adoption Project registry. Controls (n = 30) recruited from	Memory, executive function, attention.  CANTAB.	Post-institutionalised children had smaller superior-posterior cerebellar lobe volume compared to controls, which	Duration of institutionalisation height/weight at adoption, country of origin, condition of orphanage setting.	Small sample size.	30	4

	Authors/date	Study design	Outcomes	Participants (n, age, country, recruitment)	Cognitive domains and assessment	Results	Confounders	Limitations	CCAT Score (Max = 40)	Hill Criteria (Max = 7)
				community advertisements, USA.		mediated test performance between groups, with larger volumes yielding better results on tests of memory and planning.				
26	Loman et al. (2009)	Cross-sectional.	Developmental outcomes of post-institutionalised children.	Children age 8-11 years (post- institutionalised n = 91; internationally adopted early from foster care n = 109; non-adopted n = 69). Adopted children recruited from the Minnesota International Adoption Registry. Non-adopted children recruited from university registry of community families, USA.	IQ.  Block design and vocabulary subtests of the WISC-III or Leiter International Performance Scale-Revised.	Post-institutionalised children performed more poorly on cognitive measures compared to children adopted from foster care ( $d = 0.57$ ) and non-adopted children ( $d = 1.0$ ). Increased time in an institution was associated with lower IQ ( $r = -0.36$ )		Lack of data on pre-adoption experiences.	29	4
27	Rutter et al. (2001)	Longitudinal: assessments took place at age 4 years and age 6 years.	Behavioural patterns associated with early deprivation.	Data from the ERAS. Romanian adoptees who came to the UK before age 3.5 years (n = 156) and UK adoptees placed before age 6 months (n = 50).	General cognitive ability  MCSA	Significant association between cognitive impairment and age of entry to the UK ( $d = 0.64$ ), with greater impairment among those who were older at entry		No data on characteristics of institutionalised children's birth families.	28	5
28	Pollak et al. (2010)	Cross-sectional.	Impact of early deprivation on cognitive processes.	Children age 8-9 years. Post-institutionalised children (n = 48) and early adopted children (n = 40) recruited through the Minnesota and	Memory, attention, executive control, learning.	Post-institutionalised children showed deficits in visual memory and attention and	Sex.	No data on characteristics of institutionalised children's birth families.	28	4

	Authors/date	Study design	Outcomes	Participants (n, age, country, recruitment)	Cognitive domains and assessment	Results	Confounders	Limitations	CCAT Score (Max = 40)	Hill Criteria (Max = 7)
				the Wisconsin International Adoption Project registries. Non-adopted children (n = 44) recruited from advertisements and the Institute of Child Development Participant Pool, USA.	CANTAB, NEPSY, WISC.	visually mediated learning and inhibitory control but performed at developmentally appropriate levels on tests involving auditory processing and executive processes.				
29	Rutter et al. (1998)	Longitudinal measures taken at entry to UK and age 4 years.	Developmental impairment and catch-up following adoption after early deprivation.	Data from the ERAS. Children age 4 years. Romanian adoptees who came to the UK before age 2 years (n = 111). UK adoptees placed before age 6 months (n = 52).	General cognitive ability.  DDS, MCSA.	Association between age at entry to the UK and cognitive ability at 4 years in Romanian adoptees (r = -0.41).		Measure of developmental level at entry to UK relied on parent's retrospective accounts.	27	5
30	Castle et al. (1999)	Longitudinal: assessments took place at age 4 years and age 6 years.	Impact of variations in quality of depriving environment and duration of institutional care on intellectual functioning.	Data from the ERAS. Romanian adoptees (n = 129), UK adoptees (n = 52).	IQ.  MSCA.	Association between age at entry to the UK and cognitive scores at age 6 years among Romanian adoptees (r = -0.50)	Age at entry to UK, weight at entry to UK, quality of food in institution.	Quality of institutional care identified via parent report.	26	5
31	Hostinar et al. (2012)	Cross-sectional.	Executive functioning in post-institutionalised children.	Children age 2-4 years (n who had experienced institutional care = 60; n who had not experienced institutional care = 30).	Executive functioning.  DCCS, spin the pots task, delay of gratification task.	Post-institutionalised children showed reductions in executive functioning compared to controls ( $\eta_p^2 = 0.24$ ).	IQ.	No data on characteristics of institutionalised children's birth families.	25	5

Abbreviations: Bayley – Bayley scales of infant development; BEIP – Bucharest Early Intervention Project; CANTAB – Cambridge neuropsychological test automated battery; DCCS – Dimensional change card sort; DDS – Denver Developmental Scales; ERAS – English and Romanian Adoptees Study; IQ – intelligence quotient; MSCA – McCarthy scale of children's abilities; NEPSY – Developmental neuropsychological assessment; UK – United Kingdom; USA

– United States of America; WISC-III – Wechsler intelligence scale for children-III; WPPSI-R – Wechsler preschool and primary scale of intelligence-revised.

The following sections will present findings from community samples of maltreated children, followed by those from institutionalised samples of children. Within these sections, findings on specific neuropsychological functions will be presented first, followed by findings on IQ/cognitive development. Within these sections, findings will broadly be presented in the order of assessed quality (beginning with lower quality).

## **Findings from community samples of maltreated children**

Seventeen articles presented cross-sectional findings from samples of children abused and/or neglected in family settings (Table 1: 3, 4, 5, 6, 7, 9, 10, 11, 12, 13, 14, 15, 16, 17, 18, 20, 21). Findings related to general cognition point to worse performance among maltreated children, with effect sizes ranging from small to large (Table 1). Significant findings were not present across all areas of cognition.

## **Findings on specific neuropsychological functions**

Nine studies examined specific neuropsychological functions; seven of which included a non-maltreated control group. In a sample of physically abused preschool children and controls, Friedrich, Einbender and Luecke (1983) found significant differences on the verbal and memory scales of the MCSA, with physically abused children performing worse than controls. Augusti and Melinder (2012) measured executive functioning in 8-12-year-old maltreated children and controls. Maltreated children performed significantly worse on a spatial working memory task compared to controls. Barrera, Calderon and Bell (2013) compared neuropsychological performance in children who had experienced sexual abuse and had a diagnosis of PTSD; children who had experienced sexual abuse and did not have a diagnosis of PTSD; and controls. Regardless of PTSD, reduced attentional inhibition was associated with a history of sexual abuse, but most neuropsychological tests did not show a clear difference between groups.

Nolin and Ethier (2007) attempted to differentiate 6-12-year-old children with neglect and/or physical abuse and comparison children using cognitive profiles. Physically abused neglected children demonstrated significantly lower scores than controls on measures of attention, visual-motor integration, mental calculation, and concept formation. Non-physically abused neglected children demonstrated significantly lower scores than controls on measures of auditory attention and visual-motor integration. Non-physically abused neglected children showed significantly higher scores than physically abused neglected children on measures of planning, control, self-regulation and problem-solving. Bucker and colleagues (2012) compared children aged 5-12 years with histories of maltreatment with controls on measures of IQ, working memory, attention, impulsivity and executive function. Maltreated children demonstrated worse performance than controls on tests of attention, but no other significant differences were found. Further, maltreated children exhibited higher prevalence of subsyndromal symptoms than controls, which was associated with worse cognitive performance.

De Bellis and colleagues (2009) examined the cognitive impact of neglect on 3-12-year-old neglected children with and without PTSD, and controls. Neglected children showed significantly lower IQ, language, visual-spatial, learning/memory and attention/executive functions than controls. After controlling for IQ, all measures except visual-spatial remained significant.

In contrast to other findings, Petrenko and colleagues (2012) demonstrated that supervisory neglect was associated with higher verbal IQ scores in a sample of maltreated 9-11-year-olds, with no comparisons to non-maltreated controls. However, it must be noted that children in this group still scored on average half to a full standard deviation below the mean for normative samples on a measure of IQ.

Two studies provided evidence for dose-response relationships between maltreatment and

cognition (10, 4). Pears and Fisher (2005) examined relationships among developmental delays and maltreatment and placement experiences in 3-6-year-old children in foster care. They found a moderate positive correlation between age at first foster care placement and executive functioning. Further, significant negative correlations were found between being placed into foster care due to neglect or emotional abuse and visuospatial processing, language, memory and executive functioning. Cowell, Cicchetti, Rogosch and Toth (2015) looked at the impact of developmental timing of maltreatment on cognitive functioning in children aged 3-9 years compared to non-maltreated children. Maltreated children had significantly lower inhibitory control scores compared to controls but no significant differences between maltreated children and controls were found on memory or attention scores. Children who were maltreated in infancy had significantly worse performance than children who were maltreated later. Children who experienced maltreatment during a single period of development performed as well as non-maltreated children, while children who experienced maltreatment during three or more developmental periods performed significantly worse than other children.

### **Findings on IQ/cognitive development**

Seven studies compared findings on IQ/cognitive development in maltreated children to controls. Sandgrund, Gaines and Green (1974) collected data on IQ in abused or neglected children and controls aged 5-12 years, finding that 25% of the abused sample, 20% of the neglected sample, and 3% of the control sample exhibited an IQ of below 70. Crozier and Barth (2005) used data from the National Study of Child and Adolescent Wellbeing to show that 32.6% maltreated children aged 6-11 years scored one standard deviation below the mean or lower on a measure of cognitive functioning compared to national norms. Hoffman-Plotkin and Twentyman (1984) found that abused or neglected children aged 3-6 years had lower cognitive functioning than controls. In a sample of physically abused children and controls aged 1-6 years, Prasad, Kramer and Ewing-Cobbs (2005) found lower cognitive ability among those who were abused. Kerr,

Black and Krishnakumar (2000) examined cognitive performance in 6-year-old children with histories of failure to thrive and maltreatment, maltreatment alone, or neither risk factor. Children with both risk factors had lowest cognitive scores; with maltreatment only intermediate scores; and with neither highest scores. Kocovska and colleagues (2012) reported IQ data on 5-12-year-old children with symptoms of indiscriminate friendliness and maltreatment histories and controls. Mean IQ among maltreated children was an average of 15 points lower than the control group. Spratt and colleagues (2012) found that children aged 3-10 years with a history of neglect or institutional rearing demonstrated lower cognitive scores compared to those with no history of neglect or adoption.

One study examined cognitive functioning in association with profiles of maltreatment in a sample of maltreated foster children aged 3-6 years, finding that lower cognitive functioning was associated with profiles of neglect, physical abuse, or both (Pears, Kim & Fisher, 2008).

Four articles reported findings from longitudinal studies carried out in populations of children abused and/or neglected in a family setting (1, 2, 8, 19). Two studies examined factors associated with cognitive impairment in this population. Scarborough, Lloyd and Barth (2012) examined data on global development gathered at 18 and 36 months following an investigation of child maltreatment in 0-3-year-old children who took part in the National Survey of Child and Adolescent Wellbeing to identify factors associated with low scores on developmental measures at one or both time points. While case worker reports of special needs at the time of maltreatment investigation, living in poverty, caregiver cognitive impairment and caregiver lack of high school education were all associated with low scores, neglect and sexual abuse were more highly associated with low scores. Bosquet Enlow and colleagues (2012) used data from the Minnesota Longitudinal Study of Parents and Children to examine the influence of maltreatment timing on cognitive outcomes, assessing children at 2, 5 and 8 years. Maltreatment in infancy, but not in preschool, was significantly associated with poor cognitive outcomes; those who were maltreated

in infancy demonstrated cognitive scores 7.25 points lower on average than those without exposure during this period.

Two prospective longitudinal studies examined the impact of maltreatment on cognition over time. McNichol and Tash (2001) assessed IQ in children aged 5-7 years in family foster care twice over a period of 18 months, finding that they scored in the low range of cognitive functioning overall but demonstrated significant improvement in cognitive functioning over time. Strathearn, Gray, O'Callaghan and Wood (2001) followed children referred for low birth weight over 4 years to show that cognition at 4 years was significantly reduced in infants who were referred for neglect, and that those with substantiated neglect showed progressive decline in cognitive function over time compared with non-neglected children, suggesting an association between neglect and reduced cognitive functioning.

In summary, cross-sectional studies of community samples of maltreated children demonstrate largely consistent findings of reduced cognitive performance generally in maltreated children compared to controls with small to large effect sizes (Table 1). There are some discrepancies in findings related to specific cognitive functions; again, with small to large effect sizes (Table 1). Additionally, data on dose-response relationships between maltreatment and cognition, as well as prospective longitudinal data demonstrating associations between maltreatment and impaired cognition are found in these samples.

### **Findings from samples of institutionalised children**

Several cross-sectional studies have demonstrated associations between institutionalisation and cognitive functioning (Table 2: 25, 26, 28, 31).

## **Findings on specific neuropsychological functions**

Three studies examined specific neuropsychological functions, all of which included a control group. In a sample of 2-4-year-old post-institutionalised children, Hostinar and colleagues (2012) found that these children showed reductions in executive functioning compared to controls; effects which remained significant after controlling for child IQ. Pollak and colleagues (2010) examined the impact of early deprivation on cognition among post-institutionalised, early-adopted, and non-adopted children aged 8-9 years. Post-institutionalised children showed deficits in visual memory and attention and visually mediated learning and inhibitory control, but these same children performed at developmentally appropriate levels on tests involving auditory processing and executive processes. Bauer and colleagues (2009) measured cerebellar volume and performance across memory, attention and executive functioning in post-institutionalised children aged 9-12 years and controls. Post-institutionalised children had smaller superior-posterior cerebellar lobe volume, which mediated test performance between groups, with larger volumes yielding better results on tests of memory and planning.

## **Findings on IQ/cognitive development**

Findings from institutionalised populations demonstrate associations between institutionalisation and lower IQ/cognitive development, with medium to large effect sizes (Table 2). One cross-sectional study presented findings on IQ in this population. Loman and colleagues (2009) considered IQ in post-institutionalised children; children internationally adopted early from foster care, and non-adopted controls aged 8-11 years. Means for estimated IQ were in the average range for all groups. However, post-institutionalised children performed more poorly on cognitive measures compared to children adopted from foster care and non-adopted children. Moreover, increased time in an institution was related to lower performance.

Six high quality prospective longitudinal studies have demonstrated a dose-response relationship

between length of time in the institution and degree of cognitive impairment as well as “cognitive catch-up”, i.e. increase in group cognitive scores, in some cases entering the normal range, for some children. Five studies provided evidence from the ERAS (23, 24, 27, 29, 30) (Romanian adoptees  $n = 165$ ; UK adoptees  $n = 52$ ), demonstrating poor cognition in institutionalised Romanian children, with worse outcomes for those who spent more time in institutions, and some evidence of cognitive catch-up following placement in family homes. Castle and colleagues (1999) assessed IQ in adoptees at age 4 and 6 years, finding evidence for a strong dose-response relationship between age at entry to the UK and cognitive scores at age 6 years among Romanian adoptees that was a function of institutional care rather than time in the adoptive home. Rutter and colleagues (1998) showed that, within this sample, Romanian adoptees who came to the UK before age 2 years showed developmental delay, with over half functioning in the intellectually disabled range. Developmental catch-up by age 4 years among Romanian children placed before age 6 months was comparable with UK adoptees. Age of entry to the UK was the best predictor of cognitive ability at age 4 years. In Romanian adoptees who came to the UK before age 3.5 years, 14% demonstrated cognitive impairment, compared with 2% of UK adoptees placed before age 6 months (Rutter, Kreppner & O’Connor, 2001). Furthermore, there was a significant association between cognitive impairment and age of entry to the UK, with greater impairment among those who were older at entry.

Adding to these findings, with the same sample, Beckett and colleagues (2006) found that Romanian children who entered the UK aged 6 months or above had an IQ that was 15 points on average below that of children who entered the UK before the age of 6 months, or within-UK adoptees. There was strong continuity in IQ overall across the follow up period, but the degree of impairment at age 6 years predicted cognitive catch-up, with only the most severely impaired showing significant catch-up by age 11. Furthermore, O’Connor and colleagues (2000) found evidence for a dose-response association between duration of deprivation during institutionalisation and lower cognitive scores at age 6 in this sample.

One unique randomised controlled trial (RCT) of foster care has shown that institutionalised care causes cognitive impairment, and placement in foster care is an effective intervention to reduce such difficulties (22). Nelson and colleagues (2007) report on data from cognitive assessments administered to children in the BEIP comprising (n = 136) institutionalised children, half of whom were allocated to foster care and half who remained in institutions, and (n = 72) never-institutionalised controls. Assessments took place at baseline, then 2.5 years, 3.5 years, and 4.5 years later. Institutionalised children showed lower intellectual performance than never-institutionalised children who had been raised within their birth families. Children randomly assigned to foster care experienced significant gains in cognitive functioning, with better outcomes for children who were placed at a younger age. Indeed, regression analysis revealed that the cost of remaining in an institution was 0.59 IQ points per month at age 4.5 years.

Table 3: Causality assessment

	Article	Size of effect not attributable to plausible confounding	Appropriate spatial and/or temporal proximity	Dose-responsiveness and reversibility	Plausible mechanism of action	Coherence	Replicability	Similarity
1	Bosquet Enlow et al. (2012)	✓	✓		✓	✓	✓	✓
2	Strathearn et al. (2001)		✓	✓	✓	✓	✓	✓
3	DeBellis et al. (2009)				✓	✓	✓	✓
4	Cowell et al. (2015)	✓		✓	✓	✓	✓	✓
5	Bucker et al. (2012)	✓				✓	✓	✓
6	Nolin & Ethier (2007)	✓		✓	✓		✓	
7	Pears et al. (2008)					✓	✓	✓
8	Scarborough et al. (2009)	✓	✓			✓	✓	✓
9	Petrenko et al. (2012)						✓	
10	Pears & Fisher (2005)				✓	✓	✓	✓
11	Spratt et al. (2012)					✓	✓	✓
12	Barrera et al. (2013)					✓	✓	✓
13	Kocovska et al. (2012)					✓	✓	✓
14	Kerr et al. (2000)	✓				✓	✓	✓
15	Prasad et al. (2005)					✓	✓	✓

	<b>Article</b>	<b>Size of effect not attributable to plausible confounding</b>	<b>Appropriate spatial and/or temporal proximity</b>	<b>Dose-responsiveness and reversibility</b>	<b>Plausible mechanism of action</b>	<b>Coherence</b>	<b>Replicability</b>	<b>Similarity</b>
16	Hoffman-Plotkin & Twentyman (1984)					✓	✓	✓
17	Augusti & Melinder (2013)				✓	✓	✓	✓
18	Crozier & Barth (2005)	✓				✓	✓	✓
19	McNichol & Tash (2001)		✓	✓	✓	✓	✓	✓
20	Sandgrund et al. (1974)				✓	✓	✓	✓
21	Friedrich et al. (1983)					✓	✓	✓
22	Nelson et al. (2007)							
23	O'Connor et al. (2000)		✓	✓	✓	✓	✓	✓
24	Beckett et al. (2006)		✓	✓	✓	✓	✓	✓
25	Bauer et al. (2009)				✓	✓	✓	✓
26	Loman et al. (2009)			✓		✓	✓	✓
27	Rutter et al. (2001)		✓	✓		✓	✓	✓
28	Pollak et al. (2010)				✓	✓	✓	✓
29	Rutter et al. (1998)		✓	✓		✓	✓	✓
30	Castle et al. (1999)		✓	✓		✓	✓	✓

	<b>Article</b>	<b>Size of effect not attributable to plausible confounding</b>	<b>Appropriate spatial and/or temporal proximity</b>	<b>Dose-responsiveness and reversibility</b>	<b>Plausible mechanism of action</b>	<b>Coherence</b>	<b>Replicability</b>	<b>Similarity</b>
31	Hostinar et al. (2012)			✓	✓	✓	✓	✓

## **Causality assessment**

Table 3 details the results of the causality assessment across included articles. Nelson and colleagues (2007) was excluded from the causality assessment as its randomised controlled design eliminates confounding. Articles most commonly met criteria for similarity, replicability and coherence. The least commonly met criteria related to confounding variables; while six articles included measures of birth parent IQ (or a proxy variable, such as household income) (1, 2, 6, 11, 14, 18), the remaining articles did not. Effects could therefore be attributable to differences between groups in heritable factors rather than maltreatment experiences. Ten studies (1, 2, 8, 19, 22, 23, 24, 27, 29, 30) were longitudinal in design, facilitating the measurement of change in cognition following maltreatment over time, and 11 (2, 4, 6, 19, 23, 24, 26, 27, 29, 30, 31) provided evidence for a dose-response relationship between maltreatment and cognition, finding that more neglectful institutional experiences, longer duration of maltreatment experiences and the occurrence of maltreatment within specific developmental periods or multiple periods were associated with poorer cognition. Fourteen studies (1, 2, 3, 4, 6, 10, 17, 19, 20, 23, 24, 25, 30, 31) discussed a plausible mechanism of action for the relationship between maltreatment and cognition, such as the deleterious impact of stress on the developing brain and consequent impacts on cognition. Overall, support for a causal relationship between maltreatment and cognition was found among institutional samples, as well as two high quality longitudinal studies of community samples of maltreated children.

## **Discussion**

This systematic review sought to critically evaluate the evidence for an association between maltreatment and cognition in children under 12 years. Evidence for poor cognition in maltreated children compared to controls, and a dose-response relationship between timing and duration of maltreatment, as well as the quality of the neglectful environment was found. Findings in relation to specific areas of cognition were mixed; while evidence was found for worse performance

across measures of executive functioning, attention, language and memory in maltreated children compared to controls, these findings were not consistently replicated across all the included studies.

Following Howick, Glasziou and Aronson's (2009) guidelines for assessing causality, this review found direct, mechanistic and parallel evidence that maltreatment causes cognitive impairment in children. Evidence for an association was demonstrated in cross-sectional studies, with worse general cognitive performance in maltreated children compared to controls established, but with mixed findings in relation to specific areas of cognition. Notably, when considering causality, the evidence from cross-sectional studies is weak, as the direction of causality could be from maltreatment to cognitive problems or vice versa. However, direct evidence for causality was also demonstrated in longitudinal studies, which by their design provide higher quality evidence with regards to causality; the longitudinal studies in the review were generally assessed as being of higher quality. Firstly, longitudinal studies of children maltreated in a family setting and those raised in institutional environments demonstrate that abuse and/or neglect is associated with poor cognitive performance over time. Notably, causality should not be assumed on temporal order alone, and the findings from Danese and colleagues (2016) would suggest that cognitive dysfunction can precede maltreatment. However, studies of both institutionalised children and community samples also provide evidence for a dose-response relationship between timing and duration of maltreatment and cognitive outcomes, as well as evidence for cognitive catch-up once children were removed from maltreating environments. Finally, one randomised controlled trial, representing the highest quality evidence in assessing causality, has shown that institutionalised care causes cognitive impairment and placement in family foster care is effective in reducing difficulties. Notably, Glowinski (2011) cautions against generalising evidence from the BEIP and ERAS populations to maltreated children in community samples as the former represent populations who experienced extreme depriving conditions.

Given the heterogeneity in both the agent of maltreatment (i.e. experiences of abuse, neglect, or both) and cognitive outcomes (i.e. specific neuropsychological functions or IQ), caution must be exercised when evaluating the evidence for causality. The institutionalised samples may reflect 'purer' experiences of neglect, compared to the community samples for whom experiences are likely to have been more diverse. This factor could go some way to explaining the greater evidence for a causal association found in the institutionalised studies. Indeed, in both the institutionalised samples and community samples of neglected children, effect sizes tended to be larger than in samples comprising a mixture of maltreatment experiences, lending support to this argument.

An important study that did not meet the inclusion criteria for this review is relevant to consider. Danese and colleagues (2016) used the UK E-Risk study (n = 2,232) and the New Zealand Dunedin study (n = 1,037) to examine the association between childhood violence victimisation and cognitive functioning in childhood, adolescence and adulthood. Although the authors found impairment in cognitive functioning among those exposed to childhood victimisation, this impairment was largely explained by cognitive difficulties that pre-dated victimisation exposure and confounding genetic and environmental factors. Indeed, among the studies in this review, Scarborough, Lloyd and Barth (2009) demonstrated that parent cognition was one of several variables that was associated with child cognition, and a significant limitation of most studies was that such heritable factors were not controlled for. However, the results of studies that did control for this confounding variable in analysis (1), or a proxy variable such as family household income (2, 6, 11, 14, 18) echo those of studies that did not, offering tentative support to the hypothesis that maltreatment itself impacts upon cognition over and above genetic factors. Nevertheless, future research should aim to further explicate the relationships among genetic factors, maltreatment experiences, and cognition.

Not all included studies explored the mechanisms by which maltreatment and cognition may be

associated. Those that did focused on the impact of chronic stress on the developing brain, in line with discussions in previous reviews on this topic (e.g. Pechtel & Pizzagalli, 2011; Kavanaugh, Dupont-Frechette, Jerskey & Holler, 2017). Evidence from this review lends further support to this argument; Bosquet Enlow and colleagues (2012) demonstrated that maltreatment occurrence in infancy but not preschool was significantly associated with cognitive impairment, and Cowell, Cicchetti, Rogosh and Toth (2015) found that those who were maltreated in infancy exhibited worse cognitive outcomes than those who were maltreated later. These results suggest that maltreatment during periods when the brain may be more sensitive to stress may lead to cognitive impairment. Moreover, Bosquet Enlow and colleagues (2012) reflect that the nature of maltreating parent-child relationships may also impact upon child cognition. Maltreatment at an earlier stage of development might result in greater exposure to such pathological social experiences; further, such experiences might occur both within a maltreating environment but also as a result of social, behavioural and affective difficulties demonstrated in this population (e.g. Maguire et al., 2014) possibly arising both due to and in combination with cognitive impairment. These experiences could result in a ‘vicious cycle’ of negative experiences and difficulties accessing education (e.g. Romano, Babchishin, Marquis & Frechette, 2014), with further deleterious consequences for cognition.

Another model that may be helpful in understanding the findings reviewed here is the latent vulnerability model (McCrorry & Viding, 2015), which conceptualises changes in neurocognitive functioning as adaptations to neglectful or maltreating environments. In this way, heightened threat perception, which is an adaptive calibration to a maltreating environment, could have negative implications for overall cognitive development, thus becoming maladaptive in the long-term. This model might offer a more nuanced means by which to understand cognitive outcomes in maltreated populations.

Research in institutionalised populations has shown that iron deficiency as well as duration of

institutional care is independently associated with cognitive outcomes in children (e.g. Doom et al., 2014) and that malnutrition status impacts rate of cognitive improvement (e.g. Park et al., 2011). The developmental catch-up observed in the ERAS can hence be compared with studies of community maltreated populations where similar results are not observed; for example, analysis of cognitive development among maltreated children (n = 32) aged 1-6 years recruited from the community to an intervention for children in foster care demonstrated only slight improvements over 30 months (personal communication of unpublished data). It is possible that several heritable and environmental factors interact in the relationship between maltreatment and cognition, with data from community and institutionalised samples reflecting a spectrum of experiences and outcomes.

Parallel evidence for an association between maltreatment and overall cognitive development/IQ in children was found, with results consistently suggesting poorer outcomes in maltreated children compared to controls. The evidence in relation to specific areas of cognition is less coherent, with results not consistently replicated across studies. Such differences in findings may be related to differences across samples and study methodologies e.g. tasks used to measure cognitive outcomes. More work examining specific profiles of abuse and neglect as well as the timing and chronicity of maltreatment in relation to specific profiles of cognition is indicated.

## **Limitations**

The assessment of causality used in this review comprises guidelines and does not suggest unequivocal evidence for causation between child maltreatment and cognition; caution must be used when evaluating such evidence (Howick, Glasziou & Aronson, 2009). Furthermore, this review examined evidence only in children under 12 years of age; longitudinal studies reporting follow-up findings beyond this age were excluded. Such findings nevertheless have important implications for our understanding of the ways in which child maltreatment impacts upon

cognition and related variables into adulthood. Finally, due to the heterogeneity of included articles, it was not possible to conduct a meta-analysis. Standardising methodologies in this area (e.g. with regards to measurement of cognition) would facilitate the conduction of a meta-analysis in order to determine effect sizes and spur research to address existing gaps.

## **Conclusions and implications**

In accordance with previous reviews in this area, this review demonstrates that maltreated children under 12 years demonstrate significantly poorer cognitive outcomes than their non-maltreated counterparts. This review shows some evidence that maltreatment causes cognitive impairment in the general population, and strong evidence that the extreme deprivation of institutionalisation causes cognitive impairment. More research teasing apart the complex relationships between heritable and environmental factors and specific cognitive outcomes in this population should be conducted. Standardising approaches to studying this area with regards to data collection methodologies would facilitate the conduction of meta-analyses and help to further advance the field. Regardless of the aetiology of difficulties, the wealth of evidence demonstrating that maltreated children experience cognitive difficulties, and the problem this poses for accessing education and peer relationships, highlights the need for a comprehensive cognitive assessment of young children who have been exposed to maltreatment. Identifying an individual profile of strengths and weaknesses as early as possible – and continuing to monitor outcomes – could help to support children to access educational and social environments in order to mitigate against further difficulties throughout the lifespan.

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## Chapter 2: Major Research Project

Behavioural differences observed in an unfamiliar setting between primary-school-aged typically developing children, children with symptoms of Disinhibited Social Engagement Disorder, and children with Autism Spectrum Disorder

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## **Plain English Summary**

### **Background**

Disinhibited Social Engagement Disorder is a disorder involving overfriendliness towards strangers observed in children who have been neglected. To help clinicians in diagnosing the disorder, the Waiting Room Observation Scale, a tool which uses measures of children's behaviour in a waiting room to identify symptoms of Disinhibited Social Engagement Disorder, was developed (McLaughlin et al., 2010).

Autism spectrum disorder is a developmental condition which also involves difficulties with social relationships. Children with Autism Spectrum Disorder and Disinhibited Social Engagement Disorder show similar behaviours (Davidson et al., 2015) and it is not clear whether the Waiting Room Observation Scale can discriminate between the two conditions. However, understanding more about differences between behaviours across the two conditions may be helpful for differential diagnosis. This is important because treatments for children with Disinhibited Social Engagement Disorder and Autism Spectrum Disorder are different.

This study compared behaviours of primary-school-aged children with Disinhibited Social Engagement Disorder, Autism Spectrum Disorder, and those with no diagnosis (typically developing) in an unfamiliar setting to get a better understanding of the differences in behaviour between these groups of children.

### **Aims**

1. To identify whether behavioural differences can be observed between typically developing children; children with a diagnosis of Autism Spectrum Disorder; and children with symptoms of Disinhibited Social Engagement Disorder, of primary school age.

2. To identify possible changes that could be made to the Waiting Room Observation Scale to improve differentiation between Disinhibited Social Engagement Disorder and Autism Spectrum Disorder.

## Methods

Secondary analysis of Waiting Room Observation data previously gathered on three groups of children (151 typically developing children, 54 children with symptoms of Disinhibited Social Engagement Disorder, and 10 children with Autism Spectrum Disorder) was conducted, supplemented by detailed participant/video observations as follows:

- Seven children with no diagnosis of Autism Spectrum Disorder or Disinhibited Social Engagement Disorder recruited from the community e.g. after school clubs
- Six children with a diagnosis of Autism Spectrum Disorder recruited from a third sector organisation for carers
- Five children with symptoms of Disinhibited Social Engagement Disorder - one recruited from NHS clinicians, and four who took part in a previous study, whose caregivers gave permission for their data to be used again, and whose video data was observed.

Children were observed in an unfamiliar setting (clinic room or waiting room) with their caregivers. Their behaviour towards their caregivers and the researcher (a stranger) was noted by the researcher, and the Waiting Room Observation Scale was completed. Caregivers completed questionnaires measuring the children's functioning.

The observations of children's behaviour were analysed to identify differences between the groups. Children's scores on the Waiting Room Observation Scale (using both the existing samples and observational sample) were analysed to see which items on the scale best discriminate between children with Autism Spectrum

Disorder and with symptoms of Disinhibited Social Engagement Disorder. Possible improvements to be made to the scale were identified from the behavioural observations.

### **Main findings and conclusions**

Both the observations of children and the analysis of Waiting Room Observation scores showed that a key difference between children with Autism Spectrum Disorder and with Disinhibited Social Engagement Disorder symptoms is the nature of their interaction with strangers. Children with Disinhibited Social Engagement Disorder symptoms showed a desire to be near to and talk to strangers. Children with Autism Spectrum Disorder only talked to strangers about their special interest, and only approached strangers if they were reaching for toys beside the stranger. Adding these details to the Waiting Room Observation Scale could help clinicians to think about these differences when understanding a child's difficulties.

## **Abstract**

*Background:* Disinhibited Social Engagement Disorder (DSED) is a psychosocial disorder associated with child social neglect characterised by indiscriminate friendliness towards strangers. Autism Spectrum Disorder (ASD) is a neurodevelopmental condition characterised by impaired communication, fixed interests and repetitive behaviour. Problems with social relationships presenting in children with these diagnoses may appear superficially similar, yet there are differences in the quality of social interactions between groups which may be best identified via behavioural observation.

*Objective:* This study examined the ability of an existing tool (The Waiting Room Observation Scale, WRO), designed to aid diagnosis of DSED, to differentiate between children with DSED symptoms and with ASD.

*Methods:* Secondary analysis involving multinomial regression was conducted on existing data from typically developing children (n = 158), children with DSED symptoms (n = 59) and children with ASD (n = 16). Suggested improvements to the WRO were identified via qualitative behavioural observations of typically developing children (n = 7), children with symptoms of DSED (n = 5), and children with diagnoses of ASD (n = 6) in an unfamiliar setting.

*Results:* Behavioural observations demonstrated that while children with symptoms of DSED showed interest in strangers, children with ASD only interacted with strangers for specific reasons, e.g. to talk about their special interest or to reach for a toy. This difference was reflected in the analysis of the WRO: a lack of shyness with strangers was one of only two items that predicted DSED symptoms but not ASD group membership.

*Conclusions:* Adding descriptive details outlining key differences between children presenting with ASD and with symptoms of DSED to specific WRO items could help clinicians to reflect upon these differences when formulating a child's difficulties with social relationships or considering differential diagnosis.

## Introduction

Children who have experienced maltreatment (abuse or neglect) are at risk of developing disorganised attachments and difficulties with social relationships (e.g. Doyle & Cicchetti, 2017). Disinhibited Social Engagement Disorder (DSED) is a psychosocial disorder associated with child social neglect, first identified by Tizard and Rees (1975) in children adopted from British institutions who demonstrated ‘overfriendliness’ towards strangers compared to children raised in the family home. Such indiscriminate behaviours have subsequently been observed in children raised in institutional contexts (Chisholm, 1998; O’Connor & Rutter, 2000; Zeanah et al., 2002; Groark et al., 2011) and in community samples of maltreated children (Bennett et al., 2009; Kay & Green, 2013). Historically, DSED was a disinhibited subtype of Reactive Attachment Disorder (RAD). Both conditions share the aetiology of childhood serious social neglect and are diagnosed in this context. However, DSED is characterised primarily by indiscriminate friendliness towards strangers whereas RAD is characterised by inhibited symptoms, i.e. emotional withdrawal and failure to seek comfort from attachment figures (Diagnostic Statistical Manual, 5<sup>th</sup> Ed, 2013). While RAD is a disorder of attachment, DSED is considered a social impairment disorder (e.g. Zeanah et al., 2016), and is a separate disorder from RAD in the DSM-5.

To aid clinician diagnosis of RAD/DSED, McLaughlin and colleagues (2010) developed an observational measure of children's behaviour towards parents/caregivers and strangers in an unfamiliar setting (the Waiting Room Observation scale; WRO), based on qualitative observations of eight RAD/DSED cases and eight controls. The measure was found to be highly discriminatory between children with RAD/DSED and controls with no psychiatric diagnoses (McLaughlin et al., 2010).

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition involving impaired communication and interaction, fixed interests, and repetitive behaviour (Diagnostic Statistical

Manual, 5<sup>th</sup> Ed, 2013). One of the behavioural aspects may be a limited understanding of personal boundaries and impaired skills in following social rules. Since both DSED and ASD involve difficulties with social relationships and pragmatic language problems (Sadiq et al., 2012), some behavioural overlap across the two profiles can be observed. Davidson and colleagues (2015) examined assessment features that discriminate between children aged 5-12 years with ASD (n = 58) and RAD/DSED (n = 67). They found that although the social relationship problems in these populations may present as superficially similar, there is a difference in the quality of social interactions between these groups of children that is best discriminated via behavioural observation. The WRO may therefore be a helpful tool in aiding differential diagnosis, but it is not yet known whether the WRO is able to differentiate between ASD and DSED.

Many children presenting with ASD or DSED symptoms will likely also meet criteria for other diagnoses. Gillberg (2010) argues that co-existence of disorders, as well as the sharing of symptoms across disorders, is the rule rather than the exception in children presenting with neurodevelopmental vulnerabilities. It has since been demonstrated in epidemiological and twin studies that in addition to symptomatic overlap, there is also a common genetic aetiology across the different neurodevelopmental disorders (Pettersson et al., 2013). The population of children with a history of abuse/neglect may be especially likely to meet criteria for several diagnoses; Kocovska and colleagues (2012) conducted neuropsychiatric assessments on children with maltreatment histories presenting with indiscriminate friendliness, finding that 70% had possible or likely ASD and 85% had possible or likely Attention Deficit Hyperactivity Disorder (ADHD). Establishing the WRO's discriminatory ability across different neurodevelopmental disorders is important; this study focused on ASD rather than ADHD due to previous research suggesting that behavioural observation may be the best means by which to detect differences in these presentations (Davidson et al., 2015).

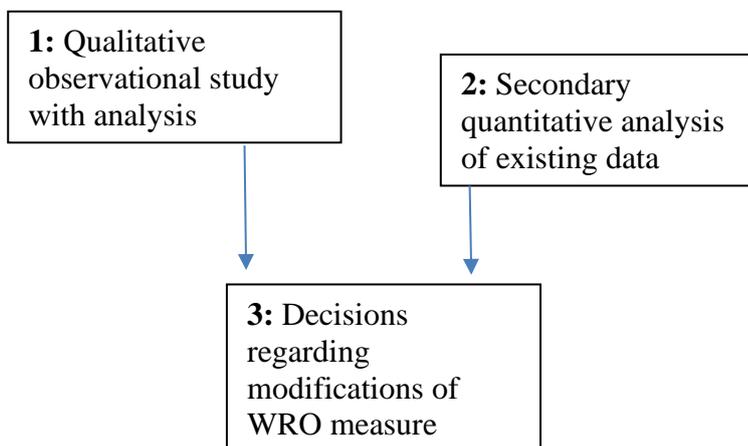
Woolgar (2013) calls attention to a problematic tendency among clinicians to assume the presence of RAD/DSED in maltreated children, which can be detrimental in that children do not receive evidence-based treatments for more typical difficulties if RAD/DSED are perceived to be the primary difficulty. As such, differential diagnosis is important, and to this end it is necessary to establish that diagnostic tools are sufficiently sensitive and specific. The limitations in social functioning associated with DSED may limit the potential for children to develop appropriate attachment relationships, potentially resulting in secondary co-morbidities. Indeed, individuals who have experienced child abuse/neglect experience high rates of mental health difficulties (Nemeroff, 2016). Similarly, children with ASD are vulnerable to poor mental health (e.g. Ryzewska et al., 2018). Interventions to support children with RAD/DSED and ASD differ. While treatment for children with RAD/DSED involves strengthening the relationship between the child and their primary caregiver (Zeanah, Chesher & Boris, 2016), supporting children with ASD may involve behavioural, educational, or psychosocial interventions (Volkmar et al., 2013). It is therefore important to deepen our understanding of behavioural differences between children with DSED symptoms and with ASD to aid differential diagnosis to support timely and appropriate intervention. Indeed, both Gillberg's (2010) and Woolgar's (2013) arguments draw attention to the importance of comprehensive formulations and multidisciplinary team involvement in the treatment of children presenting with these difficulties. Improving diagnostic tools is a helpful step in aiding such ways of working. The WRO is therefore conceptualised as part of a repertoire of tools for assessing children and tailoring an intervention as appropriate.

This study used a mixed methods cross-sectional design to examine behavioural profiles of primary-school-aged children (typically developing; those with symptoms of DSED, and those with ASD) with strangers and their caregivers in an unfamiliar setting. The aims of the study were twofold: primarily, to identify whether behavioural differences can be observed between typically developing children, children with symptoms of DSED, and children with ASD; and

secondly, to identify potential improvements to the WRO to differentiate between DSED symptoms and ASD.

## Method

Secondary analysis of WRO data previously gathered on typically developing (TD) children; children with DSED symptoms; and children with ASD was conducted to investigate the WRO's ability to differentiate between these groups of children. Additionally, an observational study of TD children; children with DSED symptoms; and children with ASD was conducted to identify improvements to be made to the WRO. Figure 2 illustrates the separate components of the study.



*Figure 2: Separate components of the study*

Ethical approval to conduct the secondary analysis of existing data and to conduct the observational study was granted by the National Health Service (NHS) West of Scotland Research Ethics Committee (Appendix 7). For the observational study, informed consent was sought from caregivers and assent was sought from children (Appendices 8-17).

## Participants

A power calculation indicated that, to obtain a difference of 1 WRO scale point between the groups a sample size of 24 in each group would be required. However, because the aims of this

study were to explore and improve the WRO's discriminatory ability, and not related to mean differences in WRO scores, the power calculation was used to give a broad idea of an appropriate sample size, rather than to determine a required sample size.

The secondary analysis of existing WRO data involved the following samples, previously recruited by the research team:

1. Children with ASD (n = 10) recruited via NHS clinicians and third sector organisations to an ongoing study of DSED and ASD.
2. Children with symptoms of DSED (n = 54) recruited to studies of DSED/RAD via schools, social workers, NHS clinicians and third sector organisations (Kocovska et al., 2012; Minnis et al., 2009; Minnis et al., 2013).
3. Typically developing children (n = 151) recruited to a study to generate general population norms for the WRO via schools and the community.

For the observational study, three groups of children aged 4-12 years were recruited by the author:

1. Typically developing (TD) children (n = 7) were recruited via the community. Approximately 250 information packs outlining the study and inviting interested families to take part were distributed via representatives from after school clubs in Greater Glasgow and Clyde.
2. Children with symptoms of DSED and no diagnosis of ASD were recruited employing previously used techniques that successfully identified children with DSED (Kocovska et al., 2012). One child was recruited via Child and Adolescent Mental Health Services (CAMHS) clinicians. Clinicians identified and approached families with a child displaying indiscriminate friendliness before providing contact details of consenting families to the researcher. Information about the study was also distributed via Scottish Attachment in Action, a third sector organisation's website and annual conference. The

COVID-19 pandemic, which necessitated the cessation of data collection before an adequate sample size had been reached, resulted in a change to the protocol. Secondary analysis of video data of children ( $n = 4$ ) interacting with their caregivers/strangers during a 15-minute play session as part of another study (Minnis et al., 2016) was conducted using the same methodology as for the other samples. Children were included if their caregivers had consented to their data being used in further studies, they were in the appropriate age range and had a Disturbances of Attachment Interview (DAI) non-attached/disinhibited subscale score of  $>5$  (rated based on audio recordings of interviews by research nurses trained to good inter-rater reliability), indicating the presence of disinhibited symptoms.

3. Children with ASD ( $n = 6$ ) were recruited via a third sector organisation providing support to family carers. Information about the study was distributed via email. Children were eligible to participate if they had a diagnosis of ASD, attended a mainstream school or language unit within a mainstream school and did not have a maltreatment history, i.e. no involvement with child protective services.

Typically developing children were recruited to participate in these procedures only. Children with ASD or symptoms of DSED were invited to participate in a second part of the study following participation in the procedures outlined above (Appendices 14 and 16). Both parts of the study were covered by a single ethics application (Appendix 7). Consent was sought to retain families' contact details in order to invite participation in the second part of the study.

## **Observational study procedure**

Children and their caregivers attended a clinic waiting room for approximately 15 minutes. Caregivers completed two measures (Strengths and Difficulties Questionnaire, SDQ, and Relationship Problems Questionnaire, RPQ) and children were invited to play with toys. For some observations (TD group  $n = 2$ ; ASD group  $n = 3$ ; DSED group  $n = 1$ ), two researchers were

present in the waiting room: one (author) completed detailed qualitative observations of the child, and the other, who was blinded to the child's group membership, completed the WRO. The researchers compared their observations following the procedure. For the remaining observations, one researcher (author) completed qualitative observations of the child, followed by the WRO. Neither researcher invited interaction with the child but responded if the child interacted with them. For some observations, participants' siblings or other strangers attending the clinic were also present in the waiting room. Once the caregiver completed the questionnaires, both the caregiver and the child were debriefed. Participants were reimbursed travel expenses and paid £10 for their participation.

The video data depicted a play session with the child and their caregiver. The child and caregiver were seated in a clinic room and a researcher (stranger) provided a box of toys before leaving the room for approximately 15 minutes. The stranger then returned with lunch for the child and caregiver; inviting the child to help to tidy away the toys and leaving the caregiver and child to have lunch. Researcher(s) re-entered the room occasionally during the play session e.g. to provide the caregiver with expenses. This procedure facilitated observation of key elements similar to the waiting room procedure, including the child's behaviour in an unfamiliar setting in the presence of their caregiver and stranger(s). Qualitative behavioural observations were taken during the recorded interaction and the WRO was completed.

## **Measures**

Strengths and Difficulties Questionnaire (SDQ) (Goodman, 1997): a 25-item behavioural screening questionnaire completed by caregivers, assessing emotional, conduct, hyperactivity and peer problems. The measure has good internal consistency and satisfactory sensitivity and specificity (Goodman, 2001). Scores range from 0-40, with a score of 17-40 considered in the 'abnormal' range.

Relationship Problems Questionnaire (RPQ) (Minnis et al., 2007): a 10-item questionnaire for DSED symptoms completed by caregivers. The measure has good internal consistency (Minnis et al., 2007). Scores range from 0-30, with a higher score indicating more disinhibited symptoms.

Waiting Room Observation Scale (WRO) (McLaughlin et al., 2010) (Appendix 18): a 17-item observation measure of children's behaviour with a parent/caregiver and stranger completed by a third-party observer. The measure has good internal consistency, moderate sensitivity and good specificity in differentiating between children with DSED/RAD and controls with no diagnosis (McLaughlin et al., 2010). Scores range from 17-34, with a lower score indicating more disinhibited behaviour.

Disturbances of Attachment Interview (DAI) (Smyke & Zeanah, 1999) (used to identify high DSED symptom scores in the video data sample): a 12-item semi-structured interview of children's attachment behaviours completed with caregivers. Strong internal validity and inter-rater reliability have been found for this measure (Smyke et al., 2002). For the non-attached/disinhibited subscale, scores range from 0-8, with a higher score indicating more disinhibited symptoms.

## **Analysis**

All analyses were conducted by the author. Although the qualitative analysis was conducted prior to the quantitative analysis, the quantitative analysis will be presented first in correspondence with the study aims.

### **Quantitative analysis**

Descriptive statistics were generated to describe each sample.

The WRO data generated from the observational study was added to existing WRO data held within the research team (described above), resulting in the following sample:

- Six new cases added to data from children with ASD (n = 10)
- One new case combined with existing data on children with DSED (n = 58)
- Seven new cases added to data from typically developing children (n = 151).

Multinomial regression was conducted via SPSS (version 26) to determine the ability of each WRO item to independently predict group membership of cases with ASD and with symptoms of DSED (TD cases were the reference category). For each item, a score of 'no' was the reference category, apart from four items which are reverse scored in the measure (*exhibits noticeable caution or shyness with stranger; warmth to child-carer relationship; responds reciprocally with carer; preferential interest of carer's attention*); for these items, a score of 'yes' was the reference category.

The assumptions of multinomial logistic regression include no significant outliers and no multicollinearity between predictor variables. As the data were categorical, it was not necessary to identify or remove outliers. In order to test for multicollinearity, a linear regression using each WRO item as predictor variables was run in order to obtain tolerance and Variance Inflation Factor (VIF) statistics. Tolerance values less than 0.1 (Menard, 1995) and VIF values greater than 10 (Myers, 1990) indicate a problem with multicollinearity. As the sample size was small, there may be the possibility of type two error (i.e. over-interpreting the absence of a difference). As such, results should be interpreted with caution.

## **Qualitative analysis**

Initially, a grounded theory approach was considered to analyse the qualitative data. However, due to the presence of a priori hypotheses related to the quantitative data, a thematic analysis was considered more appropriate. Therefore, qualitative thematic analysis of notes taken during observations, noting emerging behavioural themes was conducted (Braun & Clarke, 2006). Observations were compared both within and between groups to generate themes that characterized the similarities and differences between each group.

## **Reflexivity**

Due to the recruitment procedures, the researcher was not blinded to the group membership of participants during observations. This phenomenon, combined with the researcher's immersion in the research team and clinical work, may have influenced the interpretation of behaviours under observation. For at least one out of every group of participants, a second researcher (who was blinded to participant group) was present during the observation, and the two researchers compared findings. The researcher's role within and interpretation of observations was further reflected on within regular supervision sessions.

Both qualitative and quantitative findings contributed to recommendations for possible modifications to be made to the WRO and suggestions for items to improve discrimination between DSED symptoms and ASD.

## **Results**

This study aimed to:

1. Identify whether behavioural differences between children with symptoms of DSED, with ASD, and typically developing controls in an unfamiliar setting can be observed.
2. Identify whether any modifications can be made to the WRO to improve its ability to discriminate between DSED symptoms and ASD.

Aim 1 is addressed by the quantitative results, which will be presented first. Aim 2 is addressed by both the quantitative and qualitative results; the latter will be presented second.

## WRO items as predictors of group membership

Table 4 outlines the demographic characteristics of the samples used in the regression analyses (new cases plus existing data). The SDQ and RPQ were used to describe the samples. Higher mean SDQ and RPQ scores in the groups of children with ASD and with symptoms of DSED suggest a greater degree of psychosocial difficulties generally in these samples compared to the typically developing group.

*Table 4: Demographic characteristics of the samples used in regression analyses*

	<b>TD group</b> (n = 158)	<b>ASD group</b> (n = 16)	<b>DSED group</b> (n = 59)
<b>Gender</b>	N = 92 females N = 66 males	N = 3 females N = 13 males	N = 22 females N = 36 males N = 1 missing data
<b>Age</b> Mean (SD)	7.9 (1.9)	8.1 (2.4)	7.4 (2.4)
<b>SDQ total score</b> Mean (SD)	6.6 (4.9)	24.2 (6.0) N = 10 missing data	20.7 (7.8)
<b>RPQ total score</b> Mean (SD)	*Caregiver rated 1.2 (2.4)	*Teacher rated N = 10 4.4 (5.0) *Caregiver rated N = 6 13.3 (6.7)	*Caregiver rated 11.3 (7.6)
<b>WRO total score</b> Mean (SD)	31.8 (1.8)	30.0 (2.7)	28.8 (3.9)

Each WRO item was entered into a multinomial regression to ascertain the ability of each item to independently predict group membership (ASD diagnosis or symptoms of DSED; TD was the reference group). Tests to see if the data met the assumption of collinearity indicated that multicollinearity was not a concern (Appendix 19).

*Table 5: WRO items as independent predictors of group (ASD or DSED symptoms) membership*

<b>Group</b>	<b>WRO item</b>		<b>Odds ratio</b>	<b>95% confidence interval of odds</b>
-ASD	Looks at stranger to invite conversation	Yes	0.69	0.12 – 4.46
		No (reference)	-	-
	Interrupts conversation between stranger and carer	Yes	0.76	0.09 – 6.53
		No (reference)	-	-
	Initiates conversation with stranger	Yes	6.31	0.77 – 51.38
		No (reference)	-	-
	Moves towards stranger	Yes	13.49*	1.84 – 98.94
		No (reference)	-	-
	Makes physical contact with stranger	Yes	2.74	2.74-2.74
		No (reference)	-	-
	Displays noticeable caution or shyness with stranger	Yes (reference)	-	-
		No	0.53	0.11 – 2.63

Warmth to child-carer relationship	Yes (reference)	-	-
	No	0.67	0.10 – 5.05
Makes spontaneous comments in presence of stranger	Yes	0.82	0.16 – 4.19
	No (reference)	-	-
Refuses or ignores request from carer	Yes	1.85	0.22 – 15.47
	No (reference)	-	-
Exhibits hypercompliance to request from carer	Yes	1.68	0.000 - -
	No (reference)	-	-
Responds reciprocally in conversation with carer	Yes (reference)	-	-
	No	15.43*	2.26 – 105.33
Displays rapid shifts in emotional expression	Yes	12.20	0.12 – 1361.17
	No (reference)	-	-
Adopts role of babyish child	Yes	137.87*	6.95 – 2735.26
	No (reference)	-	-
Appears superficially charming	Yes	3.82	0.000 - -
	No (reference)	-	-
Tries to exert control over environment	Yes	0.49	0.00 – 71.42
	No (reference)	-	-

	Displays insatiable desire for attention	Yes	0.32	0.01 – 20.82
		No (reference)	-	-
	Preferential interest of carer's attention	Yes (reference)	-	-
		No	0.18*	0.03 – 0.99
-DSED	Looks at stranger to invite conversation	Yes	1.26	0.45 – 3.56
		No (reference)	-	-
	Interrupts conversation between stranger and carer	Yes	0.23	0.05 – 1.06
		No (reference)	-	-
	Initiates conversation with stranger	Yes	1.68	0.36 – 7.72
		No (reference)	-	-
	Moves towards stranger	Yes	8.01*	1.55 – 41.33
		No (reference)	-	-
	Makes physical contact with stranger	Yes	2.98	0.000 - -
		No (reference)	-	-
	Displays noticeable caution or shyness with stranger	Yes (reference)	-	-
		No	3.15*	1.29 – 7.71
	Warmth to child-carer relationship	Yes (reference)	-	-
		No	2.82	0.95 – 8.32

Makes spontaneous comments in presence of stranger	Yes	0.71	0.28 – 1.78
	No (reference)	-	-
Refuses or ignores request from carer	Yes	5.41*	1.25 – 23.36
	No (reference)	-	-
Exhibits hypercompliance to request from carer	Yes	1.90	0.14 – 25.93
	No (reference)	-	-
Responds reciprocally in conversation with carer	Yes (reference)	-	-
	No	0.45	0.09 – 2.12
Displays rapid shifts in emotional expression	Yes	0.93	0.05 – 18.67
	No (reference)	-	-
Adopts role of babyish child	Yes	16.43*	1.08 – 250.31
	No (reference)	-	-
Appears superficially charming	Yes	0.35	0.01 – 8.60
	No (reference)	-	-
Tries to exert control over environment	Yes	0.92	0.12 – 6.82
	No (reference)	-	-
Displays insatiable desire for attention	Yes	5.15	0.81 – 32.83
	No (reference)	-	-

	Preferential interest of carer's attention	Yes (reference)	-	-
		No	0.18*	0.06 – 0.50

\*p <0.05

Six items were significant in predicting group membership, with *moves towards stranger, does not respond reciprocally in conversation with carer, adopts role of babyish child* and *does not show preferential interest of carer's attention* predicting having ASD compared to Typically Developing group membership, and *moves towards stranger, does not display noticeable caution or shyness with stranger, refuses or ignores request from carer, adopts role of babyish child*, and *does not show preferential interest of carer's attention* predicting having symptoms of DSED compared to Typically Developing group membership (Table 5). The model explained 56.9% (Nagelkerke R<sup>2</sup>) of the variance in group membership and correctly classified 82.0% of cases.

## Observational study

Table 6 outlines the demographic characteristics of the observational study sample. Higher mean SDQ and RPQ scores in the groups of children with ASD and with symptoms of DSED suggest a greater degree of psychosocial difficulties generally in these samples compared to the typically developing group.

Table 6: Demographic characteristics of the observational study sample

	<b>TD group</b> (n = 7)	<b>ASD group</b> (n = 6)	<b>DSED group</b> (n = 5)
<b>Gender</b>	N = 1 male N = 6 females	N = 6 males	N = 2 males N = 3 females

<b>Age in years</b> Mean (SD)	7.6 (1.6)	9.5 (2.2)	5.6 (2.6)
<b>SDQ total score</b> Mean (SD)	3.1 (2.4)	24.2 (6.0)	21.0 (5.2)
<b>RPQ total score</b> Mean (SD)	0.4 (0.8)	13.3 (6.7)	Video data DAI score: 6.5 (1)  In person observation RPQ score: 24.0
<b>WRO total score</b> Mean (SD)	32.7 (1.4)	28.7 (3.3)	25.8 (2.6)

Table 7 outlines the themes identified from the qualitative analysis on behavioural observations.

See Appendix 20 for a full description of each theme.

*Table 7: Themes identified from qualitative analysis of behavioural observations*

<b>Theme</b>	<b>Group</b>	<b>Description</b>
Child-caregiver interaction	TD	Remained close to caregiver, often leaning into them while completing forms. Often whispered and giggled together.
	ASD	Mostly sat by themselves and only came close to caregiver when it was functional to do so i.e. to complete a form. Laughed and smiled together.
	DSED	Disorganised i.e. seeking proximity and then pushing caregiver away. Laughing and reciprocal interaction around toys but children also controlled direction of play or disagreed with caregivers.
Child's exploration of environment	TD	Some children approached toys straight away whereas some only did so when prompted by caregiver. Some did not move from beside the caregiver. Most moved around the room more over time.

	ASD	Some did not move around room at all. Those that did approach the toys and move around did so straight away with no prompting from caregiver.
	DSED	Most moved around room with no prompting from caregiver. Some were asked by caregivers to return to seat due to interaction with items in room other than toys.
Child-stranger(s) interaction	TD	One sibling group made comments to stranger at beginning of interaction. Majority did not attempt to make eye contact but smiled and looked away if eye contact was made; invited more interaction over time e.g. making eye contact.
	ASD	Some made no attempt to interact with stranger(s) but came physically close to stranger(s) e.g. to retrieve a toy. Two invited interaction with the stranger straight away e.g. talking about special interests or family.
	DSED	Majority interacted with stranger(s) immediately, e.g. asking questions about them or approaching them to play. Some sought out stranger(s) when not present in the room e.g. asking where they were or going to find them.
Child's spontaneous comments/interruptions in stranger(s)' presence	TD	Minority made spontaneous comments in stranger(s)' presence but tended to whisper if they did so. Some provided commentary on their activity/play, often if interacting with a sibling.
	ASD	Some made no comments at all. Some made frequent spontaneous comments related to procedures of the study or later in the day. Some provided commentary on their activity/play. Often shouted or played loudly with toys (e.g. slamming toys). Some interrupted caregiver while distracted.
	DSED	All made spontaneous comments in presence of stranger(s). Often shouted or played loudly (e.g. slamming toys). Some interrupted caregiver while distracted.

## WRO modifications

Modifications to be made to the WRO to improve its ability to discriminate between children with ASD and with symptoms of DSED were suggested based on an integration of the results from the regression analysis and the qualitative analysis.

*Does not display noticeable caution or shyness with stranger* and *refuses or ignores request from carer* predicted DSED symptoms but not ASD group membership, suggesting that a lack of inhibition with strangers, as well as a lack of reference to the caregiver in an unfamiliar setting (i.e. not taking direction/guidance from them despite being in a stressful situation) are key factors in discriminating between DSED symptoms and ASD.

Several items predicted both ASD and DSED symptoms group membership. However, the qualitative analysis revealed important distinctions in the quality of these behaviours that should be noted.

- *Moves towards stranger*. Children with DSED symptoms did so in the pursuit of an interaction with the stranger, e.g. to ask them a question or to engage in play with them. Children with ASD did so in pursuit of their own endeavor, e.g. to reach a toy, with a limited awareness of personal space as opposed to approaching the stranger to interact.
- *Does not show preferential interest for carer's attention*. Children with DSED symptoms showed an interest in interacting with the stranger. While some children with ASD showed a similar interest, this was exclusively for the purpose of talking about their special interest. Others with ASD showed no interest in interacting with anyone at all, and hence no preference for their carer's attention. Notably, *does not respond reciprocally with carer* predicted having ASD, which reinforces the lack of interaction generally in this group.
- *Adopts role of babyish child*. This was noted in both groups and may be an area of genuine overlap among children with ASD/DSED symptoms.

The key difference discriminating between ASD and DSED symptoms appears to be the purpose of the interaction with strangers. In children with ASD, the stranger appears irrelevant, with

children pursuing their own non-social agenda and interacting with the stranger (and sometimes the caregiver) only if it is helpful to that agenda. By contrast, children with DSED symptoms appear to cope with the unfamiliar situation by making social approaches to the stranger. Adding caveats outlining these differences to these items in the WRO may help to guide clinicians in scoring the WRO to best discriminate between ASD and DSED symptoms. For example:

- *Moves towards stranger*. For a score of ‘yes’, child’s approach to stranger must be accompanied by social eye contact/interaction with stranger, as opposed to e.g. reaching for an item near the stranger.
- *Preferential interest of carer’s attention*. For a score of ‘no’, child must show preferential interest in the stranger(s)’ attention compared to that of their carer, as opposed to no interest in either carer or stranger’s attention.

## Discussion

This study aimed firstly to identify whether behavioural differences can be observed between children with symptoms of DSED, with ASD, and typically developing controls in an unfamiliar setting. Compared to typically developing children, both children with symptoms of DSED and children with ASD appeared to show less hesitancy in interacting with strangers, with both groups moving towards strangers and showing a lack of preference for their caregiver’s attention over that of the stranger’s. Two WRO items predicted DSED symptoms but not ASD group membership, which indicates that displaying a lack of shyness with strangers and refusing to comply with caregivers’ requests may be features that are particular to those with DSED symptoms. The significance of the former item highlights the subtleties in the nature of interactions among children with DSED symptoms and with ASD; while some children with ASD do interact with strangers in this paradigm, this appears to serve a means to an end, such as talking about a special interest. Similarly, although some children with ASD enter the stranger’s

personal space, this appears to be functional, e.g. due to reaching for a toy. In contrast, children with DSED symptoms simply appear to interact indiscriminately, approaching and speaking to strangers. This finding is in line with theory in that children with ASD display typical attachment behaviours (Teague et al., 2017) but may display abnormal social interactions in that their shyness in an unfamiliar setting may be overridden by factors such as cues related to their special interest. The item *refuses to comply with caregiver's request* may capture a weak attachment with the caregiver among children with DSED symptoms; in the unfamiliar setting, children with DSED symptoms do not reference the caregiver but instead take control of the social aspects of the situation; something which typically developing children are too inhibited by the stressful nature of the situation to do. Indeed, both typically developing children and children with ASD exhibited attachment behaviours to varying degrees in this situation, such as sticking closely to the caregiver, or taking direction when given.

The confidence intervals for several of the WRO items in the regression analyses are large, suggesting a high level of variation in responses to WRO items across the samples; as such, the quantitative findings described here should be approached with caution. The qualitative findings pinpoint differences identified in the quantitative results, and as the qualitative analysis was completed prior to the regression analysis, this result is not subject to a confirmation bias. Nevertheless, there are notable issues surrounding the qualitative analysis in relation to reflexivity and reliability; as the researcher was not blinded to group membership prior to completing the qualitative analysis, and was the only person from the research team present for a significant proportion of the observations, it is possible that the researcher's knowledge of each individual's group membership influenced the findings. The qualitative findings should therefore also be approached with caution.

These findings can be viewed in the context of previous research on the differentiation of DSED and ASD. In a sample of children ( $n = 102$ ) with borderline or mild intellectual disability, Giltaj, Sterkenburg and Schuengel (2015) found no association between disinhibited social engagement

behaviour and ASD symptoms, arguing that RAD/DSED and ASD symptoms may be distinct or comorbid forms of aberrant social behaviour. In a study aiming to identify symptoms that discriminate between ASD and RAD/DSED through the Checklist for Autism Spectrum Disorder, Mayes and colleagues (2016) found that restrictive and repetitive interests was among the symptoms that were unique to children with ASD, and that children with ASD were more likely to be self-absorbed and in their own world than children with DSED. These results complement the findings of this study in potentially identifying the features of ASD that explain the behavioural profile observed, i.e. interacting with the stranger in pursuit of their own interests.

There may be notable differences in the presentation of children with DSED symptoms in different developmental stages; while this study focused on children of primary school age, the datasets contributing to the regression analyses contained children with DSED symptoms aged 13 years ( $n = 3$ ). Excluding these children from analysis resulted in the same findings, with an additional WRO item predicting having DSED symptoms: *a lack of warmth to the child-caregiver relationship*. This finding needs further exploration in larger samples, but perhaps suggests that patterns of behaviour may shift during different developmental periods (Lehmann et al., 2018); establishing differences in behavioural patterns within and between children with DSED symptoms and ASD during different phases (e.g. childhood compared to adolescence) is an area that warrants further research.

In some cases, children in this study were observed in the presence of their siblings, which may have affected the quality of the interaction; for example, children may have felt more confident interacting with a stranger or exploring their environment in conjunction with another child. Data on the presence of siblings was not collected for all the additional samples, so it was not possible to conduct a sensitivity analysis to determine whether the presence of a sibling impacted on results. Future research should consider whether the presence of siblings impacts upon behavioural presentations in an unfamiliar setting. This is important because this measure is

considered for use as part of a clinical assessment and children presenting to CAMHS may be accompanied by siblings for appointments.

There is evidence that a significant number of children with a maltreatment history may also meet criteria for neurodevelopmental vulnerabilities such as ASD (e.g. Kocovska et al., 2012; Mayes et al., 2016). As such, it is possible that a proportion of the sample with symptoms of DSED analysed here would also meet criteria for ASD, or indeed for other diagnoses. However, the purpose of the WRO is to aid clinicians' thinking in cases that are diagnostically difficult, including when symptoms of different diagnoses co-occur.

An additional aim of this study was to identify improvements to be made to the WRO to enable differentiation of DSED symptoms and ASD. Previous findings have demonstrated the WRO's ability to discriminate between typically developing children and those with DSED symptoms (McLaughlin et al., 2010). As the measure performs adequately in differentiating between these groups, supplementary notes to be added to specific items, rather than significant modifications, are proposed to aid clinicians' thinking around the key differences between children with ASD and DSED symptoms observed here. As well as discriminant validity, excellent inter-rater reliability has been found for the WRO among raters who received minimal training (e.g. five minutes of explanation) (personal communication of unpublished data). Further, the measure can be completed in a waiting room setting by a range of professionals prior to a clinic or research appointment and scored within 5-10 minutes. It is hence an efficient tool that has promise in forming part of a multi-informant assessment for DSED symptoms in both clinical and research settings.

A next step in validating the use of this tool is to collect data on the measure, modified as per the suggestions above, with samples of children with ASD, DSED symptoms and typically developing controls, to ascertain whether the suggested modifications are effective in discriminating between children with ASD and DSED symptoms. Furthermore, as co-existence and overlap between neurodevelopmental vulnerabilities is common (Gillberg, 2010; Pettersson

et al., 2013), an important further step is to provide further supplementary notes to the WRO informed by data on the tool's ability to discriminate between DSED symptoms and other neurodevelopmental disorders. In a clinical sample ( $n = 124$ ) of home-reared preschool children, Scheper and colleagues (2019) found that higher parent rated disinhibited social engagement behaviour was associated with ADHD (but not ASD); the authors argue that symptoms of DSED could be overshadowed by comorbid ADHD symptoms, leading to selective treatment. Modifying the WRO further to include consideration of ADHD could result in an observational tool that primarily identifies symptoms of DSED but also prompts thinking around other diagnoses such as ASD or ADHD. In this way, the measure could be used to aid both differential diagnosis and individual formulations around a child's difficulties with social relationships, and to inform interventions accordingly.

## **Limitations**

Due to the recruitment procedures, it was not possible for the researcher to be blinded to group membership while completing behavioural observations. As this could have introduced bias into the observations, this is a key limitation of the study. However, for at least one observation out of every group, a second researcher who was blinded to group membership was present and completed the WRO separately from the qualitative observations, allowing triangulation of the qualitative data with the WRO. In these cases, a high degree of agreement was identified between the two researchers.

A further limitation is the use of video data alongside in-person observations. Recruiting children with symptoms of DSED to the study proved to be difficult; this phenomenon reflects the rarity of the condition and systemic complexity of these cases. This difficulty, combined with the COVID-19 pandemic, necessitated the use of video data to complete the study. Although the video data depicts a different procedure from the waiting room procedure, the key elements of the interaction remain the same, i.e. the child is in an unfamiliar setting in the presence of both

their caregiver and stranger(s), and the caregiver is at points distracted from the child. As such, the qualitative data obtained from both procedures are comparable.

Finally, the qualitative sample size, as well as the regression sample of children with ASD, were small. As such, there is a danger of type two error (i.e. over-interpreting the absence of a difference). Future research should replicate this study with a larger sample. However, DSED is a rare disorder (Zeanah & Gleason, 2010), so obtaining a large sample of this population may be difficult. Indeed, previous studies in this area have used small samples of children with DSED symptoms; for example, Mayes and colleagues (2016) report findings from a sample of twenty children with RAD/DSED, and McLaughlin and colleagues (2010) developed the WRO from observations of eight RAD/DSED cases.

## **Conclusion**

Both qualitative behavioural observations and quantitative analysis of WRO items that predict ASD or DSED symptoms group membership indicate that a key difference between the two groups is the nature of the child's interaction with stranger(s). While for children with symptoms of DSED this is related to a desire for an interaction with the stranger(s) in and of itself, for children with ASD the stranger appears to be irrelevant, but their typical shyness in an unfamiliar setting can be overridden by their desire to pursue their own non-social agenda, e.g. to talk about their special interest. Supplementary notes outlining these differences could be added to relevant WRO items in order to improve its ability to aid differential diagnosis and contribute to a formulation of a child's difficulties with social relationships.

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# Appendix 1: Journal of *Child Abuse & Neglect* instructions for authors



**CHILD ABUSE & NEGLECT**  
The International Journal

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### DESCRIPTION

*Child Abuse & Neglect* is an international and interdisciplinary journal publishing articles on child welfare, health, humanitarian aid, justice, mental health, public health and social service systems. The journal recognizes that child protection is a global concern that continues to evolve. Accordingly, the journal is intended to be useful to scholars, policymakers, concerned citizens, advocates, and professional practitioners in countries that are diverse in wealth, culture, and the nature of their formal child protection system. *Child Abuse & Neglect* welcomes contributions grounded in the traditions of particular cultures and settings, as well as global perspectives. Article formats include empirical reports, theoretical and methodological reports and invited reviews.

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##### General points

- Make sure you use uniform lettering and sizing of your original artwork.
- Embed the used fonts if the application provides that option.
- Aim to use the following fonts in your illustrations: Arial, Courier, Times New Roman, Symbol, or use fonts that look similar.
- Number the illustrations according to their sequence in the text.
- Use a logical naming convention for your artwork files.
- Provide captions to illustrations separately.
- Size the illustrations close to the desired dimensions of the published version.
- Submit each illustration as a separate file.
- Ensure that color images are accessible to all, including those with impaired color vision.

A detailed [guide on electronic artwork](#) is available.

**You are urged to visit this site; some excerpts from the detailed information are given here.**

#### Formats

If your electronic artwork is created in a Microsoft Office application (Word, PowerPoint, Excel) then please supply 'as is' in the native document format.

### Appendix 3: Systematic review search strategy

<b>Ovid Embase 1996 to 2019</b>		<b>Results</b>
S1	(Cognit* OR intellectual* OR neurocognit*) ADJ4 (impair* OR deficit* OR dysfunction OR function* OR performance OR outcome)	27,2631
S2	Child* ADJ4 (abus* OR neglect* OR maltreat* OR institutional* OR postinstitutional*)	36,822
S3	S1 AND S2	703
<b>Ovid Medline 1996 to 2019</b>		
S1	(Cognit* OR intellectual* OR neurocognit*) ADJ4 (impair* OR deficit* OR dysfunction OR function* OR performance OR outcome)	123,612
S2	Child* ADJ4 (abus* OR neglect* OR maltreat* OR institutional* OR postinstitutional*)	23,795
S3	S1 AND S2	332
<b>Ebsco PsycINFO</b>		
S1	MM "Child Abuse" OR MM "Battered Child Syndrome" OR MM "Child Neglect"	25,120
S2	MM "Neurocognitive Disorders" OR MM "Neurodevelopmental Disorders" OR MM "Developmental Disabilities" OR MM "Intellectual Development Disorder" OR MM "Neuropsychology" OR MM "Executive Functioning Measures" OR MM "Cognitive Ability" OR MM "Cognitive Impairment" OR OR MM "Mathematical Ability" OR MM "Reading Ability" OR MM "Spatial Ability" OR MM "Verbal Ability" OR MM "Cognition" OR OR MM "Neuropsychological Assessment"	106,559
S3	S1 AND S2	231

# Appendix 4: Crowe Critical Appraisal Tool (1.4) form

**Crowe Critical Appraisal Tool (CCAT) Form (v1.4)** Reference  Reviewer

This form must be used in conjunction with the CCAT User Guide (v1.4); otherwise validity and reliability may be severely compromised.

Citation	
<input type="text"/>	Year <input type="text"/>

Research design <small>(add if not listed)</small>	
<input type="checkbox"/> Not research	Article   Editorial   Report   Opinion   Guideline   Pamphlet   ...
<input type="checkbox"/> Historical	...
<input type="checkbox"/> Qualitative	Narrative   Phenomenology   Ethnography   Grounded theory   Narrative case study   ...
<input type="checkbox"/> Descriptive, Exploratory, Observational	A. Cross-sectional   Longitudinal   Retrospective   Prospective   Correlational   Predictive   ... B. Cohort   Case-control   Survey   Developmental   Normative   Case study   ...
<input type="checkbox"/> Experimental	<input type="checkbox"/> True experiment: Pre-test/post-test control group   Solomon four-group   Post-test only control group   Randomised two-factor   Placebo controlled trial   ... <input type="checkbox"/> Quasi-experiment: Post-test only   Non-equivalent control group   Counter balanced (cross-over)   Multiple time series   Separate sample pre-test post-test [no Control] [Control]   ... <input type="checkbox"/> Single system: One-shot experimental (case study)   Simple time series   One group pre-test/post-test   Interactive   Multiple baseline   Within subjects (Equivalent time, repeated measures, multiple treatment)   ...
<input type="checkbox"/> Mixed Methods	Action research   Sequential   Concurrent   Transformative   ...
<input type="checkbox"/> Synthesis	Systematic review   Critical review   Thematic synthesis   Meta-ethnography   Narrative synthesis   ...
<input type="checkbox"/> Other	...

Variables and analysis		
Intervention(s), Treatment(s), Exposure(s)	Outcome(s), Output(s), Predictor(s), Measure(s)	Data analysis method(s)
<input type="text"/>	<input type="text"/>	<input type="text"/>

Sampling					
Total size	Group 1	Group 2	Group 3	Group 4	Control
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Population, sample, setting	<input type="text"/>				

Data collection <small>(add if not listed)</small>	
<b>Audit/Review</b> a) Primary   Secondary   ... b) Authoritative   Partisan   Antagonist   ... c) Literature   Systematic   ...	<b>Interview</b> a) Formal   Informal   ... b) Structured   Semi-structured   Unstructured   ... c) One-on-one   Group   Multiple   Self-administered   ...
<b>Observation</b> a) Participant   Non-participant   ... b) Structured   Semi-structured   Unstructured   ... c) Covert   Candid   ...	<b>Testing</b> a) Standardised   Norm-ref   Criterion-ref   Ipsative   ... b) Objective   Subjective   ... c) One-on-one   Group   Self-administered   ...

Scores					
Preliminaries	Design	Data Collection	Results	Total [/40]	
Introduction	Sampling	Ethical Matters	Discussion	Total [%]	

**General notes**

Appraisal checklist for the synthesis of the research design scores, not against other research designs.

Category Item	Item descriptors [ ] Present; [x] Absent; [ ] Not applicable	Description [Important information for each item]	Score [0-5]
<b>1. Preliminaries</b>			
Title	1. Includes study aims and design		
Abstract (assess last)	1. Key information 2. Balanced and informative		
Text (assess last)	1. Sufficient detail others could reproduce 2. Clear/concise writing, table(s), diagram(s), figure(s)		
<b>Preliminaries [ /5 ]</b>			
<b>2. Introduction</b>			
Background	1. Summary of current knowledge 2. Specific problem(s) addressed and reason(s) for addressing		
Objective	1. Primary objective(s), hypothesis(es), or aim(s) 2. Secondary question(s)		
<b>Is it worth continuing?</b>			<b>Introduction [ /5 ]</b>
<b>3. Design</b>			
Research design	1. Research design(s) chosen and why 2. Suitability of research design(s)		
Intervention, Treatment, Exposure	1. Intervention(s)/treatment(s)/exposure(s) chosen and why 2. Precise details of the intervention(s)/treatment(s)/exposure(s) for each group 3. Intervention(s)/treatment(s)/exposure(s) valid and reliable		
Outcome, Output, Predictor, Measure	1. Outcome(s)/output(s)/predictor(s)/measure(s) chosen and why 2. Clearly define outcome(s)/output(s)/predictor(s)/measure(s) 3. Outcome(s)/output(s)/predictor(s)/measure(s) valid and reliable		
Bias, etc	1. Potential bias, confounding variables, effect modifiers, interactions 2. Sequence generation, group allocation, group balance, and by whom 3. Equivalent treatment of participants/cases/groups		
<b>Is it worth continuing?</b>			<b>Design [ /5 ]</b>
<b>4. Sampling</b>			
Sampling method	1. Sampling method(s) chosen and why 2. Suitability of sampling method		
Sample size	1. Sample size, how chosen, and why 2. Suitability of sample size		
Sampling protocol	1. Target/actual/sample population(s): description and suitability 2. Participants/cases/groups: inclusion and exclusion criteria 3. Recruitment of participants/cases/groups		
<b>Is it worth continuing?</b>			<b>Sampling [ /5 ]</b>
<b>5. Data collection</b>			
Collection method	1. Collection method(s) chosen and why 2. Suitability of collection method(s)		
Collection protocol	1. Include date(s), location(s), setting(s), personnel, materials, processes 2. Method(s) to ensure/enhance quality of measurement/instrumentation 3. Manage non-participation, withdrawal, incomplete/lost data		
<b>Is it worth continuing?</b>			<b>Data collection [ /5 ]</b>
<b>6. Ethical matters</b>			
Participant ethics	1. Informed consent, equity 2. Privacy, confidentiality/anonymity		
Researcher ethics	1. Ethical approval, funding, conflict(s) of interest 2. Subjectivities, relationships with participants/cases		
<b>Is it worth continuing?</b>			<b>Ethical matters [ /5 ]</b>
<b>7. Results</b>			
Analysis, Integration, Interpretation method	1. A.1.1. method(s) for primary outcome(s)/output(s)/predictor(s) chosen and why 2. Additional A.1.1. methods (e.g. subgroup analysis) chosen and why 3. Suitability of analysis/integration/interpretation method(s)		
Essential analysis	1. Flow of participants/cases/groups through each stage of research 2. Demographic and other characteristics of participants/cases/groups 3. Analyse raw data, response rate, non-participation/withdrawal/incomplete/lost data		
Outcome, Output, Predictor analysis	1. Summary of results and precision for each outcome/output/predictor/measure 2. Consideration of benefits/harms, unexpected results, problems/failures 3. Description of outlying data (e.g. diverse cases, adverse effects, minor themes)		
<b>Results [ /5 ]</b>			
<b>8. Discussion</b>			
Interpretation	1. Interpretation of results in the context of current evidence and objectives 2. Draw inferences consistent with the strength of the data 3. Consideration of alternative explanations for observed results 4. Account for bias, confounding/effect modifiers/interactions/imprecision		
Generalisation	1. Consideration of overall practical usefulness of the study 2. Description of generalisability (external validity) of the study		
Concluding remarks	1. Highlight study's particular strengths 2. Suggest steps that may improve future results (e.g. limitations) 3. Suggest further studies		
<b>Discussion [ /5 ]</b>			
<b>9. Total</b>			
Total score	1. Add all scores for categories 1-8		
<b>Total [ /40 ]</b>			

# Appendix 5: Journal of *Developmental Child Welfare* instructions for authors

## 1.1 Aims & Scope

Before submitting your manuscript to *Developmental Child Welfare*, please ensure you have read the journal's [Aims & Scope](#).

## 1.2 Article Types

*Developmental Child Welfare* considers the following kinds of article for publication:

1. Regular research articles reporting new empirical findings
2. Research reviews
3. Research translation articles, including social policy analysis
4. Opinion articles and debate

*Developmental Child Welfare* does not publish 'Letters to the Editor' or 'Book reviews'.

The manuscript should conform to APA publishing style, and must include an abstract containing a maximum of 250 words. All manuscripts should be clearly organized, with a clear hierarchy of headings and subheadings (3 weights maximum). Regular research articles should not exceed 7,500 words (including references, tables and figures, but excluding the abstract), and review articles should not exceed 9,000 words. Unless negotiated with the Editor, other types of articles should not exceed 7,500 words. The journal can host additional 'supplementary materials' online (see section 4.3 below).

## 1.3 Writing your paper

The SAGE Author Gateway has some general advice and on [how to get published](#), plus links to further resources.

### 1.3.1 Make your article discoverable

When writing your paper, think about how you can make it discoverable. The title, keywords and abstract are key to ensuring readers find your article through search engines such as Google. For information and guidance on how best to title your article, write your abstract and select your keywords, have a look at this page on the Gateway: [How to Help Readers Find Your Article Online](#).

## 2. Editorial policies

### 2.1 Peer review policy

*Developmental Child Welfare* operates a strictly anonymous peer review process in which the reviewer's name is withheld from the author and, the author's name from the reviewer (see section 4 below). Each new submission is carefully read by the Editor to decide whether it has a reasonable chance of being published in DCW. Manuscripts are screened for their fit with the journal's aims and scope, as well as the quality of the reported research and readability. Those that have a reasonable chance of being published will be reviewed by two or more independent reviewers. The Editor may encourage authors to re-submit a manuscript after making specific changes.

As part of the submission process, authors are asked to provide the names of three scholars who could be called upon to review the manuscript. Recommended reviewers should be experts in their fields and should be able to provide an objective assessment of the manuscript. Please be aware of any conflicts of interest when recommending reviewers. Examples of conflicts of interest include, but are not limited to:

- The reviewer should have no prior knowledge of your submission
- The reviewer should not have recently collaborated with any of the authors
- The reviewer should not belong to the same institution as any of the authors

Please note that the Editor is not obliged to invite any of the corresponding authors' recommended reviewers to assess their manuscript.

### 2.2 Authorship

All parties who have made a substantive contribution to the article should be listed as authors. Principal authorship, authorship order, and other publication credits should be based on the relative scientific or professional contributions of the individuals involved, regardless of their status. A student is usually listed as principal author on any multiple-authored publication that substantially derives from the student's dissertation or thesis.

### 2.3 Acknowledgements

Acknowledgements should be appended to the manuscript following acceptance for publication.

All contributors who do not meet the criteria for authorship should be listed in an Acknowledgements section. Examples of those who might be acknowledged include a person who provided purely technical help, or a department chair who provided only general support.

Any acknowledgements should appear first at the end of your article prior to your Declaration of Conflicting Interests (if applicable), any notes and your References.

### 2.4 Funding

Developmental Child Welfare requires all authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit the [Funding Acknowledgements](#) page on the SAGE Journal Author Gateway to confirm the format of the acknowledgment text in the event of funding, or state that: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

### 2.5 Declaration of conflicting interests

Developmental Child Welfare requires authors to include a declaration of any conflicting interests and recommends you review the good practice guidelines on the [SAGE Journal Author Gateway](#). This should be included in the final (i.e. accepted) version of your manuscript, after any acknowledgements and prior to the references. If no conflict exists, please state that 'The Author(s) declare(s) that there is no conflict of interest'. For guidance on conflict of interest statements, please see the ICMJE recommendations [here](#).

### 2.6 Research ethics and patient consent

Medical research involving human subjects must be conducted according to the [World Medical Association Declaration of Helsinki](#).

Submitted manuscripts should conform to the [ICMJE Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals](#), and all papers reporting animal and/or human studies must state in the methods section that the relevant Ethics Committee or Institutional Review Board provided (or waived) approval. While the manuscript should initially exclude the institution's name to allow for blind peer review, the final accepted article should include the full name and institution of the review committee, in addition to the approval number. An example of how to deal with this in the submitted manuscript is "The study design was approved by the University of [name withheld for blind peer review] Human Ethics Research Committee, approval # HE43524."

For research articles, authors are also required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal.

Information on informed consent to report individual cases or case series should be included in the manuscript text. A statement is required regarding whether written informed consent for patient information and images to be published was provided by the patient(s) or a legally authorized representative.

Please also refer to the [ICMJE Recommendations for the Protection of Research Participants](#).

### 3. Publishing Policies

#### 3.1 Publication ethics

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### 4. Preparing your manuscript for submission

#### 4.1 File format

The preferred format for your manuscript is Word. LaTeX files are also accepted. Word and (La)Tex templates are available on the [Manuscript Submission Guidelines](#) page of our Author Gateway.

#### 4.2 Artwork, figures and other graphics

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's [Manuscript Submission Guidelines](#).

Figures supplied in colour will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

#### 4.3 Supplementary material

This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc) alongside the full-text of the article. For more information please refer to our [guidelines on submitting supplementary files](#).

#### 4.4 Reference style

Developmental Child Welfare adheres to the APA reference style. View the [APA](#) guidelines to ensure your manuscript conforms to this reference style.

#### 4.5 Blinding for peer review

To facilitate blind peer review, authors should make all reasonable efforts to ensure that their manuscript does not reveal their identities to reviewers. Where a reviewer might reasonably infer that a cited publication is the authors' previous work (e.g. "... In our previous study ..."), the work should be cited in text as [author citation withheld for peer review], and it should be temporarily withheld from the reference list. Similarly, depending on the field of research, details of the author's institution or city might reasonably identify a manuscript's authorship. To ensure blind peer review, Acknowledgements, Funding information and Declarations of conflicts of interest (see sections 2.3, 2.4 and 2.5) should only be inserted into the final version of the manuscript, following acceptance for publication.

There will of course be situations in which a study's authorship cannot be shielded from reviewers, which may warrant a discussion between the corresponding author and editor.

#### 4.6 English language editing services

Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal's specifications should consider using [SAGE Language Services](#). Visit SAGE Language Services on our Journal Author Gateway for further information.

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**IMPORTANT:** Please check whether you already have an account in the system before trying to create a new one. If you have reviewed or authored for the journal in the past year it is likely that you will have had an account created. For further guidance on submitting your manuscript online please visit ScholarOne Online Help.

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### 5.2 Information required for completing your submission

You will be asked to provide contact details and academic affiliations for all co-authors via the submission system and identify who is to be the corresponding author. These details must match what appears on your manuscript. At this stage please ensure you have included all the required statements and declarations and uploaded any additional supplementary files (including reporting guidelines where relevant).

### 5.3 Permissions

Please also ensure that you have obtained any necessary permission from copyright holders for reproducing any illustrations, tables, figures or lengthy quotations previously published elsewhere. For further information including guidance on fair dealing for criticism and review, please see the Copyright and Permissions page on the [SAGE Author Gateway](#).

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## 6. On acceptance and publication

### 6.1 SAGE Production

Your SAGE Production Editor will keep you informed as to your article's progress throughout the production process. Proofs will be sent by PDF to the corresponding author and should be returned promptly. Authors are reminded to check their proofs carefully to confirm that all author information, including names, affiliations, sequence and contact details are correct, and that Funding and Conflict of Interest statements, if any, are accurate. Please note that if there are any changes to the author list at this stage all authors will be required to complete and sign a form authorising the change.

### 6.2 Online First publication

Online First allows final articles (completed and approved articles awaiting assignment to a future issue) to be published online prior to their inclusion in a journal issue, which significantly reduces the lead time between submission and publication. Visit the [SAGE Journals help page](#) for more details, including how to cite Online First articles

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Publication is not the end of the process! You can help disseminate your paper and ensure it is as widely read and cited as possible. The SAGE Author Gateway has numerous resources to help you promote your work. Visit the [Promote Your Article](#) page on the Gateway for tips and advice.

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## 7. Further information

Any correspondence, queries or additional requests for information should be sent to the Editor, Professor Michael Tarren-Sweeney, Email: [michael.tarren-sweeney@canterbury.ac.nz](mailto:michael.tarren-sweeney@canterbury.ac.nz)

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## **Appendix 6: Major Research Project Proposal**

**Name of assessment:** Major Research Project Proposal

**Title:** Behavioural differences observed in a clinic waiting room between primary-school-aged typically developing children, children with Disinhibited Social Engagement Disorder (DSED), and children with Autism Spectrum Disorder (ASD)

**Matriculation number:** 2167084

**Date of submission:** 13/05/2019

**Version number:** 2

**Actual word count:** 3,274

**Maximum word count:** 3,000

**Research Title**

Behavioural differences observed in a clinic waiting room between primary-school-aged typically developing children, children with symptoms of Disinhibited Social Engagement Disorder (DSED), and children with Autism Spectrum Disorder (ASD)

**Abstract**Background

Disinhibited Social Engagement Disorder (DSED) is a psychosocial disorder associated with child maltreatment. Autism Spectrum Disorder (ASD) is a neurodevelopmental condition. Both conditions are characterised by difficulties with social relationships and social communication. An observational tool was developed to identify children with DSED (the Waiting Room Observation scale, WRO) but it is not yet known whether the tool can discriminate between DSED and ASD.

Aims

To identify behavioural differences between DSED and ASD and possible modifications that could be made to the WRO to better differentiate between the two conditions.

Methods

Observations of three samples of primary-school-aged children (those with a diagnosis of ASD, n = 10; those with symptoms of DSED and a maltreatment history, n = 10; and typically developing controls, n = 10) will be conducted during a visit to a Child and Adolescent Mental Health Services (CAMHS) clinic waiting room. All observations will include one child at a time. Qualitative analysis will be conducted to establish behavioural differences observed between samples and develop hypotheses regarding discriminatory items/modifications to be made to the WRO. Multinomial logistic regression will be applied to previously collected WRO data to determine which items perform well and which should be modified.

Application

The challenge of differential diagnosis between DSED and ASD may add to families' waiting times before intervention. Correct diagnosis is vital to support appropriate intervention. Early intervention in ASD/DSED may reduce the prevalence of secondary co-morbidities. The WRO is an assessment tool that can aid differential diagnosis.

**Brief Introduction**

Children who have experienced maltreatment (abuse or neglect) are at risk of developing disorganised attachments and difficulties with social relationships (e.g. Doyle & Cicchetti, 2017). Disinhibited Social Engagement Disorder (DSED) is a psychosocial disorder associated with child maltreatment, first identified by Tizard and Rees (1975) in children adopted from British institutions who demonstrated ‘overfriendliness’ towards strangers compared to children raised in the family home. Such indiscriminate behaviours have subsequently been observed in children raised in institutional contexts (Chisholm, 1998; O’Connor & Rutter, 2000; Zeanah et al., 2002; Groark et al., 2011) and in community samples of maltreated children (Bennett et al., 2009; Kay & Green, 2013). Historically DSED was considered to be a disinhibited subtype of Reactive Attachment Disorder (RAD). Both conditions share the aetiology of childhood maltreatment and are diagnosed in this context. However, DSED is characterised primarily by indiscriminate friendliness towards strangers whereas RAD is characterised by inhibited symptoms, i.e. emotional withdrawal and failure to seek comfort from attachment figures (Diagnostic Statistical Manual, 5<sup>th</sup> Ed, 2013). While RAD is considered to be a disorder of attachment, DSED is considered a social impairment disorder (e.g. Zeanah et al., 2016). Indeed, DSED is a separate disorder from RAD in the DSM-V.

To aid clinician diagnosis of RAD/DSED, McLaughlin et al. (2010) developed an observational measure of children's behaviour towards parents/caregivers and strangers in an unfamiliar setting (the Waiting Room Observation scale; WRO), based on qualitative observations of eight RAD/DSED cases and eight controls. The measure was found to be highly discriminatory between children with RAD/DSED and controls with no psychiatric diagnoses (McLaughlin et al., 2010).

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition involving impaired communication and interaction, fixated interests, and repetitive behaviour (Diagnostic Statistical Manual, 5<sup>th</sup> Ed, 2013). One of the behavioural aspects may be a limited understanding of personal boundaries and impaired skills in following social rules. Since both DSED and ASD involve difficulties with social relationships and pragmatic language problems (Sadiq et al., 2012), some behavioural overlap across the two profiles can be observed (Davidson et al., 2015). It is not yet known whether the WRO is able to differentiate between ASD and DSED.

Since DSED is associated with maltreatment, a diagnosis has significant child protection ramifications; it is thus important to establish that diagnostic tools are sensitive and specific in

order to accurately identify children with DSED. Moreover, the limitations in social functioning associated with DSED may limit the potential for children to develop appropriate attachment relationships, potentially resulting in secondary co-morbidities. Indeed, individuals who have experienced child maltreatment experience high rates of mental health difficulties (Nemeroff, 2016). Similarly, children with ASD are vulnerable to poor mental health (e.g. Rydzewska et al., 2018). Preliminary evidence suggests that interventions to support children with RAD/DSED and ASD may differ (e.g. Davidson et al., 2015). It is therefore important to deepen our understanding of behavioural differences between children with DSED/ASD to aid differential diagnosis to support timely and appropriate intervention.

This study will utilise data already being collected within the academic CAMHS department at the University of Glasgow to expand on the McLaughlin et al. (2010) procedure utilised to develop the WRO. Behavioural profiles of children (typically developing; with symptoms of DSED; and with ASD) with strangers and their caregivers in a waiting room setting will be compared. Additionally, data already held within the academic CAMHS department will be used to conduct a multinomial logistic regression to determine which items of the WRO are able to discriminate between DSED and ASD and which would benefit from modification, based on hypotheses drawn from data collected in the first part of the study.

## **Aims and Hypotheses**

### Aims

The primary aim is to identify whether behavioural differences can be observed between typically developing children; children with a diagnosis of ASD; and children with symptoms of DSED, of primary school age.

The secondary aim is to identify possible modifications that could be made to the WRO to differentiate between DSED and ASD by conducting multinomial logistic regression on data collected using the existing tool and comparing this data to qualitative behavioural observations.

### Hypotheses

As the first component of the study is qualitative, there are no formal hypotheses relating to these aims. However, we anticipate that there will be clear behavioural differences observed between typically developing children and those with symptoms of DSED, or ASD (e.g. presence or absence of caution/shyness with strangers), and that there will be subtle behavioural differences

observed between children with ASD and those with symptoms of DSED (e.g. nature of social interaction with strangers).

With regards to the second component of the study, the null hypothesis is that all the regression coefficients in the model are equal to zero. The null hypothesis will be rejected if the p-value is less than 0.05.

## **Plan of Investigation**

### Design

A cross-sectional, mixed methods design, involving participant observations of primary-school-aged children and their caregivers, and secondary analysis of existing data.

### *Part one:*

### Participants

Recruitment of the following participants will occur in tandem.

Primary-school-aged children (n = 10 per sample) and their caregivers:

- Typically developing children.
  - Included if they are of primary school age (5-11 years), do not have a diagnosis of ASD, and do not attend CAMHS.
  - Recruited from the community (e.g. after school programmes). Information sheets describing the study will be distributed to relevant groups. Families who are interested in participating will be invited to return their contact details and their consent to be contacted in a provided freepost envelope.
- Children with a diagnosis of ASD.
  - Included if they are of primary school age; have a diagnosis of ASD; attend a mainstream primary school or a language unit within a mainstream primary school, and do not have a maltreatment history.
  - Recruited as part of an ongoing study (overseen by Claire Davidson) via NHS clinicians and national autism charities.
- Children with symptoms of DSED.
  - Included if they are of primary school age; have been referred to NHS clinicians with symptoms of indiscriminate behaviours towards strangers and have a suspected or confirmed maltreatment history.
  - Recruited as part of an ongoing study (overseen by Claire Davidson) via NHS clinicians and charities such as Adoption UK and Scottish Attachment in Action.

As the DSED/ASD samples will be recruited via NHS clinicians, these samples may be skewed towards more complex presentations. However, as complex cases will likely be harder to diagnostically discriminate, this is considered appropriate given the aims of the study.

### Measures

Following the McLaughlin et al. (2010) procedure, qualitative behavioural observations of children will be taken under the following headings: child-stranger interaction, exploratory behaviour, child-carer interaction, and general behavioural characteristics.

Additionally, the following measures will be completed:

- Strengths and Difficulties Questionnaire (SDQ) (Goodman, 1997): a 25-item behavioural screening questionnaire completed by caregivers, assessing emotional, conduct, hyperactivity and peer problems. The measure has good internal consistency and satisfactory sensitivity and specificity (Goodman, 2001).
- Relationship Problems Questionnaire (RPQ) (Minnis et al., 2007): a 10-item questionnaire for DSED symptoms completed by caregivers. The measure has good internal consistency (Minnis et al., 2007).
- Waiting Room Observation Scale (WRO) (McLaughlin et al., 2010): a 19-item observation measure of children's behaviour with a parent/caregiver and stranger completed by a third party observer. The measure has good internal consistency, moderate sensitivity and good specificity in differentiating between children with DSED/RAD and controls with no diagnosis (McLaughlin et al., 2010).

### Research procedures

Caregivers will be telephoned and informed of the rationale and procedure of the study. Children will then attend a clinic waiting room with their caregivers. The trainee and a second researcher from the Academic CAMHS team will already be seated in the waiting room. Caregivers will be provided with consent forms and two measures (SDQ, RPQ) to complete. There will be toys available for the children to play with, and there may or may not be other strangers present. The trainee will unobtrusively observe the child's behaviour, including any interactions with the caregiver/trainee/strangers, and take detailed qualitative notes. If the child engages strongly with the trainee, it may be difficult to take notes. In this event, the trainee will complete notes immediately following the observation period. Caregivers' knowledge of the rationale of the study may influence their interactions with their child; to guard against this as far as possible, caregivers will be encouraged to interact as they would normally with their child prior to participating. To avoid biasing observations, the trainee will not be directly involved in the

recruitment of the DSED/ASD samples and will therefore be blinded to sample within the clinical samples during the observation period. The trainee will be unblinded to the clinical samples following the qualitative analysis. The second researcher will unobtrusively observe the child's behaviour to complete the WRO. After approximately ten minutes, a clinician will enter the waiting room and escort children in the ASD/DSED samples to a clinic room to complete an assessment as part of a wider ongoing study. As children in the typically developing sample will not take part in these assessments, following the observation period the trainee will debrief the children and their caregivers, and escort them to the exit. To establish inter-rater reliability, the trainee will complete a second WRO form, compare scores with those of the second researcher, and discuss any differences in interpretations of behaviour.

### Data analysis

Qualitative thematic analysis (Braun & Clarke, 2006) of notes taken during observations, noting emerging behavioural themes e.g. whether child exhibits caution or shyness in the presence of strangers will be conducted. Observations will be compared both within and between groups; in order to facilitate the introduction of new codes based on new observations, a grounded theory approach will be utilised, involving constant comparisons between observations. The coding framework will thus develop iteratively. Dr Sara McDonald – a lecturer in primary care with expertise in qualitative research – will advise on this analysis. A multi-disciplinary reflective group involving the trainee, a child psychiatrist (Professor Helen Minnis) and speech and language therapist (Claire Davidson) – both experts in the field – will be held after every few observations to discuss emerging behavioural themes. The qualitative observations will be used to generate hypotheses regarding which items on the WRO best discriminate between ASD and DSED.

Descriptive statistics for the SDQ and RPQ data will be generated to more thoroughly describe the ASD, DSED and typically developing samples.

### *Part two:*

The WRO data collected in Part One will be added to WRO data held within the academic CAMHS team, as follows:

- Children with ASD (n = 15) recruited to the wider study overseen by Claire Davidson, via NHS clinicians and charities.

- Children with symptoms of DSED (n = 59) recruited to studies of DSED/RAD via schools, social workers, NHS clinicians and charities (see Kocovska et al., 2012; Minnis et al., 2009; Minnis et al., 2013).
- Typically developing children (n = 153) recruited via schools and the community, e.g. after school clubs, to a study to establish general population norms for the WRO. Findings from this study are emerging.

Multinomial logistic regression will be conducted on this data via SPSS to determine which items perform best in discriminating between DSED and ASD. Possible modifications to be made to poorly performing items will be identified via the qualitative analysis conducted in Part One.

### Justification of sample size

As the primary aim is qualitative, a formal power calculation for this component of the study is inappropriate. McLaughlin et al. (2010) conducted qualitative analysis on observations of eight children with suspected DSED and eight controls. As the aims and design of this study are similar, ten observations per group is considered sufficient.

For the second aim, a power calculation using the descriptive statistics on the WRO in Davidson et al. (2015) was conducted. To obtain a difference of 1 WRO scale point between the groups a sample size of 24 in each group is required. The proposed sample size in Part Two (ASD n = 25; DSED n = 69; controls n = 163) would therefore provide adequate power.

### 2-Sample t Test

Testing mean 1 = mean 2 (versus  $\neq$ )

Calculating power for mean 1 = mean 2 + difference

$\alpha = 0.05$  Assumed standard deviation = 1.2

#### Sample Target

Difference	Size	Power	Actual Power
1	24	0.8	0.806767

### Settings and equipment

The study will take place in Glasgow clinic waiting rooms. Required equipment includes the measures and toys. The measures are freely available, and toys are available within the

Academic CAMHS team. A second researcher will be required to complete the WRO while the trainee completes qualitative behavioural observations. This will be a member of the Academic CAMHS team.

## **Health and Safety Issues**

### Researcher safety issues

The research will take place within a clinic waiting room which is routinely attended by families. There will be no lone working and the population under investigation is of minimal risk.

### Participant Safety Issues

Attendance at a clinic waiting room, including completion of the measures, is not anticipated to be a distressing experience for children or caregivers. However, children – particularly those with ASD – may feel anxious coming to a new place. Children will be accompanied by a caregiver during participation. If children become distressed, their participation will be terminated.

## **Ethical Issues**

Participants will be children, some of whom may be vulnerable. Children will be accompanied by their caregivers throughout the study. Caregivers will be provided with information about the study prior to attending the clinic waiting room, and informed consent will be sought from caregivers prior to commencing the observation. Assent will be sought from children via an age-appropriate information sheet and assent form. Children and caregivers will be debriefed after the observation.

Data obtained during this study will be retained in a locked filing cabinet within the Academic CAMHS team, with access restricted to the research team.

Children with DSED/ASD will be recruited as part of an ongoing study which has NHS ethical and R and D approval. Typically developing children will be recruited from the community. An ethics amendment for this component of the study, as well as the secondary analysis of existing data, will be submitted.

## **Financial Issues**

No costs for equipment/measures will be accrued. Stationary costs will be accrued in recruitment of the typically developing group, including printing of information sheets, and for printing of

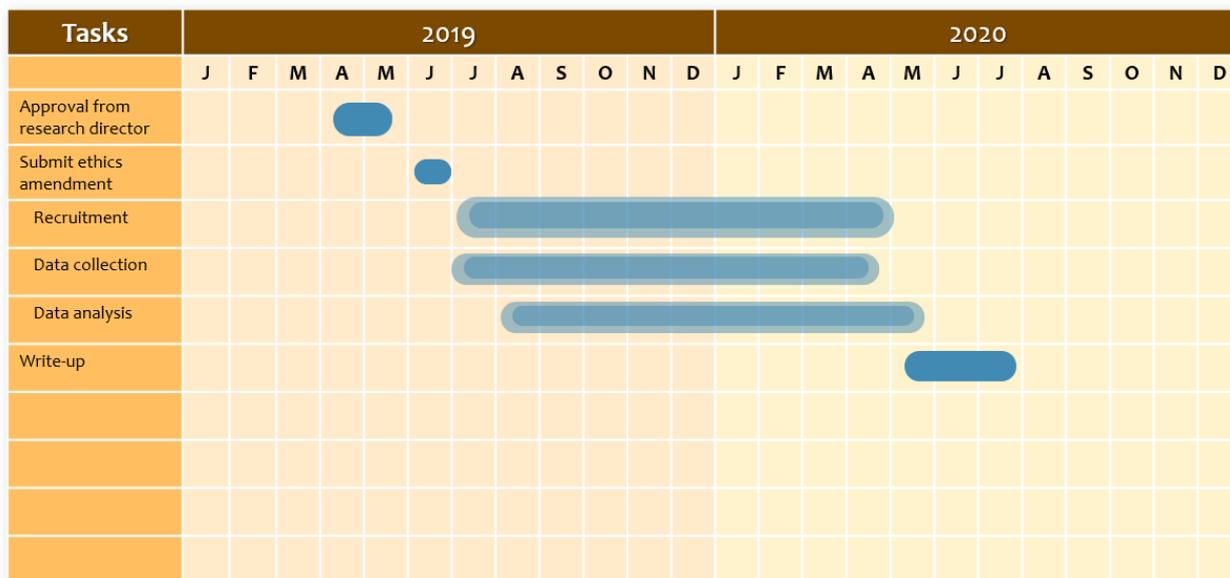
consent forms and measures for completion. This is anticipated to sum to approximately £10. Freepost envelopes (n = 10) will also be required in recruitment of the typically developing group. This is anticipated to sum to approximately £7.

Participants in the ASD/ DSED samples will be participating as part of an ongoing study. They will be paid travelling expenses and £20 for participation in the whole study, which includes three separate assessments, funded via the Castang foundation. Participants in the typically developing sample will participate in the waiting room observation only. In line with the payment given to participants in the other samples, we propose to pay these participants travelling expenses (anticipated to be maximum £10 per participant), plus £10 for participating. This will sum to a maximum of £200.

**Timetable**

See Figure 1. Following approval of the proposal, an ethics amendment will be submitted. Following ethical approval, data collection will commence and continue until April 2020. Data analysis and write-up will begin in May 2020, for submission on 31<sup>st</sup> July 2020.

Figure 1: Gantt chart



**Practical Applications**

Although the behavioural profiles associated with DSED and ASD may appear similar, they are distinct presentations requiring different interventions; differential diagnosis to facilitate appropriate support is crucial to avoid the development of secondary co-morbidities. The WRO is an assessment tool that can be used as part of a routine appointment; tailoring the measure to

aid differential diagnosis could support timely and appropriate intervention for children with either presentation.

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## **Appendix 7: Ethical and R&D approvals**

A substantial amendment to an existing ethical application was granted from the NHS West of Scotland Research Ethics Committee to conduct the secondary analysis of previously collected data and the observational study. Due to a change in the protocol related to staff sickness, a second substantial amendment to the same ethical application was granted from the same committee for these procedures. A non-substantial amendment to another existing ethical application was granted from the same committee to conduct qualitative observations on the video data.

**WoSRES**  
West of Scotland Research Ethics Service

Miss Claire Davidson  
DCFP, 4<sup>th</sup> Floor  
West Glasgow Ambulatory Care Hospital  
Yorkhill, Glasgow  
G3 8SJ



West of Scotland REC 3  
Research Ethics  
Clinical Research and Development  
Dykebar Hospital  
Grahamston Road  
Paisley PA2 7DE

Date 04 July 2019  
Direct line 0141 314 0211  
E-mail WoSREC3@ggc.scot.nhs.uk

Dear Miss Davidson

**Study title:** Discriminating symptoms of Autism Spectrum Disorder and Disinhibited Social Engagement Disorder via structured observation: the development of a clinical diagnostic tool.  
**REC reference:** 16/WS/0234  
**Amendment number:** 4 22/05/2019 (REC Ref AM05)  
**Amendment date:** 24 June 2019  
**IRAS project ID:** 211514

The above amendment was reviewed by the Sub-Committee in correspondence.

**Ethical opinion**

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

The sub-committee sought confirmation by email on 04 July 2019 that:

- the original study participants were informed of the Waiting Room Observation (WRO) aspect of the study
- if / how the researchers will be blinded to which set of participants they are observing

You responded to these concerns by email on 04 July 2019, and the sub-committee was satisfied with the response.

**Approved documents**

The documents reviewed and approved at the meeting were:

Document	Version	Date
Notice of Substantial Amendment (non-CTIMP)	4 22/05/2019 (REC Ref AM05)	24 June 2019
Other [Original REC Form]		
Other [TD Group Reply Slip (sub study)]	1	05 February 2019
Participant consent form [Assent Form TD Group Child (sub study)]	1	05 February 2019
Participant consent form [TD Group Parent (sub study)]	2	07 June 2019
Participant information sheet (PIS) [TD Group Child (sub study)]	1	05 February 2019
Participant information sheet (PIS) [TD Group Parent (sub study)]	2	07 June 2019
Research protocol or project proposal [Tracked]	7	07 June 2019

**Membership of the Committee**

The members of the Committee who took part in the review are listed on the attached sheet.

**Working with NHS Care Organisations**

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

**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.

**HRA Learning**

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities – see details at: <https://www.hra.nhs.uk/planning-and-improving-research/learning/>

16/WS/0234:	Please quote this number on all correspondence
-------------	--

Yours sincerely



For  
**Mrs Rosie Rutherford**  
Chair

*Enclosures: List of names and professions of members who took part in the review*

*Copy to: Miss Claire Davidson*

**WoSRES**  
West of Scotland Research Ethics Service



Miss Claire Davidson  
Research Fellow  
University of Glasgow  
Ward 4  
Fourth Floor  
West Glasgow Ambulatory Care Hospital  
Yorkhill  
Glasgow  
G3 8SJ

West of Scotland REC 3  
Research Ethics  
Clinical Research and Development  
Dykebar Hospital  
Grahamston Road  
Paisley PA2 7DE

Date 11 October 2019  
Direct line 0141 314 0211  
E-mail WoSREC3@ggc.scot.nhs.uk

Dear Miss Davidson

**Study title:** Discriminating symptoms of Autism Spectrum Disorder and Disinhibited Social Engagement Disorder via structured observation: the development of a clinical diagnostic tool.  
**REC reference:** 16/WS/0234  
**Amendment number:** REC Ref AM06  
**Amendment date:** 07 October 2019  
**IRAS project ID:** 211514

Thank you for submitting the above amendment, which was received on 11 October 2019. I can confirm that this is a valid notice of a substantial amendment and will be reviewed by the Sub-Committee of the REC at its next meeting.

**Documents received**

The documents to be reviewed are as follows:

Document	Version	Date
Notice of Substantial Amendment (non-CTIMP) [Notification of Substantial Amendment]	REC Ref AM06	07 October 2019
Participant consent form [Consent ASD]	V5	29 August 2019
Participant consent form [Consent DSED]	V6	29 August 2019
Participant information sheet (PIS) [Parent PIS DSED]	V5	29 August 2019
Participant information sheet (PIS) [Child PIS]	V5	29 August 2019
Participant information sheet (PIS) [Parent PIS ASD]	V5	29 August 2019
Research protocol or project proposal [Protocol]	V8	23 August 2019

**Notification of the Committee's decision**

The Committee will issue an ethical opinion on the amendment within a maximum of 35 days from the date of receipt.

**R&D approval**

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval for the research.

**HRA Learning**

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities – see details at: <https://www.hra.nhs.uk/planning-and-improving-research/learning/>

**16/WS/0234:****Please quote this number on all correspondence**

Yours sincerely



**Moyra Evans**  
**REC Manager**

Copy to:

*Miss Claire Davidson, University of Glasgow*

Dear Karen,

<b>Study Title:</b>	The Best Services Trial (BeST?): Effectiveness and cost-effectiveness of the New Orleans Intervention Model for Infant Mental Health
<b>EudraCT:</b>	N/A
<b>Sponsor:</b>	NHS GG&C
<b>Sponsor R&amp;D ref:</b>	GN14CO183P
<b>Chief Investigator:</b>	Prof Helen Minnis
<b>Amendment number</b>	NSA July 2020: New additions to research team

Thank you for submitting the above amendment to the NHS GG&C R&D office.

This amendment has been reviewed on behalf of the Sponsor. As you are adding two new researchers to the study team in NHS GG&C, but there is not a change to the study, I can confirm that it is a **non-substantial amendment** and does not require REC approval.

You WILL need confirmation of ongoing R&D management approval, and the researcher who does not have an NHS GG&C contract will require a letter of access to access the data as per SOP 52.005. As this researcher will have 'access to patient data (anonymised or identifiable) with no bearing on patient care' they will not require a research passport to be completed, a disclosure check or an occupational health check. They will only require a letter of access which Erin and I will issue.

Please contact me if you have any queries.

Dear Miss C Davidson,

**R&D Ref:** GN16NE540 **Ethics Ref:** 16/WS/0234

**Investigator and site(s):** Miss Claire Davidson (West Glasgow ACH)

**Project Title:** Discriminating symptoms of Autism Spectrum Disorder and Disinhibited Social Engagement Disorder via structured observation: the development of a clinical diagnostic tool.

**Protocol Number:** V7; 07/06/19

**Amendment:** Substantial Amendment 4 (REC ref AM05)

**Sponsor:** NHS Greater Glasgow and Clyde

I am pleased to inform you that R&D have reviewed the above study's Amendment and can confirm that Management Approval is still valid for this study.

Document	Version	Date
Notice of Substantial Amendment (non-CTIMP)	4 22/05/2019 (REC Ref AM05)	24 June 2019
Other [Original REC Form]		
Other [TD Group Reply Slip (sub study)]	1	05 February 2019
Participant consent form [Assent Form TD Group Child (sub study)]	1	05 February 2019
Participant consent form [TD Group Parent (sub study)]	2	07 June 2019
Participant information sheet (PIS) [TD Group Child (sub study)]	1	05 February 2019
Participant information sheet (PIS) [TD Group Parent (sub study)]	2	07 June 2019
Research protocol or project proposal [Tracked]	7	07 June 2019

I wish you every success with this research project.

Dear Miss C Davidson,

**R&D Ref:** GN16NE540 **Ethics Ref:** 16/WS/0234

**Investigator and site(s):** Miss Claire Davidson (West Glasgow ACH)

**Project Title:** Discriminating symptoms of Autism Spectrum Disorder and Disinhibited Social Engagement Disorder via structured observation: the development of a clinical diagnostic tool.

**Protocol Number:** V8 23/08/2019

**Amendment:** Substantial Amendment 3 (07.10.19)

**Sponsor:** NHS GGC

I am pleased to inform you that R&D have reviewed the above study's Amendment and can confirm that Management Approval is still valid for this study.

Document	Version	Date
Notice of Substantial Amendment (non-CTIMP) [Notification of Substantial Amendment]	REC Ref AM06	07 October 2019
Participant consent form [Consent ASD]	V5	29 August 2019
Participant consent form [Consent DSED]	V6	29 August 2019
Participant information sheet (PIS) [Parent PIS DSED]	V5	29 August 2019
Participant information sheet (PIS) [Child PIS]	V5	29 August 2019
Participant information sheet (PIS) [Parent PIS ASD]	V5	29 August 2019
Research protocol or project proposal [Protocol]	V8	23 August 2019

I wish you every success with this research project.

## Appendix 8: Information sheet for parents/caregivers of typically developing children



**Institute of Health and Wellbeing**

*Social Relationships Study 2.0*

*Researcher:  
Genevieve Young-Southward*



**University of Glasgow  
West Glasgow Ambulatory Care Hospital  
Yorkhill, Glasgow, G3 8SJ  
Tel: 0141 2019239**

### Parent/Guardian Information Sheet

You have been invited to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask if there is anything that is not clear or if you would like more information.

#### **Who is conducting the research?**

The research is being carried out by Genevieve Young-Southward, Trainee Clinical Psychologist, with the Institute of Health and Wellbeing at the University of Glasgow. Genevieve is carrying out this study as part of a Doctorate in Clinical Psychology, which is a clinical and research training qualification.

#### **What is the purpose of the study?**

The purpose of the study is to further develop the tools that we use to assess children with social relationship and communication problems. However, we would also like to recruit a comparison group of typically developing children who do not have social relationship problems. The benefits of investigating the social relationships of different groups of children are that it may help to improve our ability to make quick and **accurate** diagnosis for children who do have social relationship problems, so that the appropriate treatment can be provided.

#### **Why have I been invited?**

You have been invited to take part in this study because you have a child who is developing as would be expected for his/her age and no social relationship/communication problems have been identified.

#### **Do I have to take part?**

No. It is up to you and your child to decide. This information sheet will provide details of the study, but should you have further questions please get in touch. If you are interested in taking part

please contact the researcher (Genevieve Young-Southard) to express your interest using any of the following:

- via telephone on **0141 2019239**
- by email at **g.young-southward.1@research.gla.ac.uk**
- by **returning the enclosed reply slip** using the S.A.E provided.

On receiving your note of interest the researcher will contact you to discuss the study. You do not have to decide whether you want to participate in the study during this phone call. You can take time to think about it and the researcher can arrange to speak with you again, if required. If you do choose to participate in the study, your written consent will be taken by the researcher at the study appointment. Please note, you and your child are free to withdraw from the study at any time, without giving reason. This would not affect the standard of care your child receives or your child's future treatment.

### **What does taking part involve?**

An appointment will be made for you and your child to attend the clinic waiting room at the West Glasgow Ambulatory Care Hospital for approximately 15 minutes. There will be toys available in the waiting room for your child to play with. Two researchers (Genevieve and an additional researcher) will be present in the waiting room, and there may or may not be other people attending the clinic also present in the waiting room. Genevieve will provide you with consent forms and some questionnaires to fill in. These questionnaires will ask about your child's social relationship skills, communication and behaviours. While you fill in the questionnaires, Genevieve and the second researcher will observe your child's social behavior in the waiting room and make some notes. After 10-15 minutes, the observation will stop. Genevieve will discuss the study with you and answer any questions.

**We value your time and effort and are happy to pay for your transport to and from the clinic (taxi cost or mileage by car) and you will be given £10 as a thank you for your participation.**

Your identity and personal information will be completely confidential and accessed only by the researcher. All the information obtained will remain confidential and stored within a locked filing cabinet at the University of Glasgow. The questionnaires are anonymised through use of ID numbers rather than names, and all data are held in accordance with the Data Protection Act. This means that it is kept safely and cannot be revealed to other people, without your permission. Your data will be used only for the purposes of the research, unless there are concerns about child safety. In the unlikely event of such concerns, we would tell you of our concerns prior to contacting any other agencies.

### **What are the possible benefits of taking part?**

By taking part in this research, you will be providing valuable information about the social relationships and communication of different groups of children. Improving our understanding of these may help to improve assessment processes which, in turn, may lead to quicker treatment and management strategies. At the end of the study we will write to you and offer a summary report of the findings.

### **If you have a complaint about any aspect of the study:**

If you are unhappy about any aspect of the study and wish to make a complaint, please contact the researcher in the first instance. The normal NHS complaint mechanism is also available to you.

**Who has reviewed the study?**

This study has been reviewed by the NHS West of Scotland Research Ethics Service.

**If you have any further questions:**

We will give you a copy of the information sheet and signed consent form to keep. If you would like more information about the study and wish to speak to someone **not** closely linked to the study, please contact Dr Lucy Thompson, International Research Coordinator, at [lucy.thompson@abdn.ac.uk](mailto:lucy.thompson@abdn.ac.uk) and she will get in touch with you.

**Additional information about the use of your data:**

We **will keep your name and contact details confidential** and will not pass this information to the Sponsor (NHS Greater Glasgow & Clyde (GG&C)). **We will use this information as needed, to contact you about the research study, and to oversee the quality of the study.** Certain individuals from NHS GG&C and regulatory organisations may look at your child's medical and research records to check the accuracy of the research study. NHS GG&C will only receive information without any identifying information. **The people who analyse the information will not be able to identify you** and will not be able to find out your name or contact details. We will keep identifiable information about you from this study for 10 years after the study has finished. Information will be stored in accordance with the **Data Protection Act** and kept in confidence within the research team, except in the unlikely event of concerns about safety of the child or others. NHS Greater Glasgow and Clyde (NHS GG&C) is the sponsor for this study based in Scotland. We will act as the data controller for this study. This means that **we are responsible for looking after your information and using it properly.** NHS GG&C will keep identifiable information about you for **10 years** after the study has finished. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. **If you withdraw from the study, we will keep the information about you that we have already obtained unless you instruct us not to.** To safeguard your rights, we will use the minimum personally-identifiable information possible.

If you have any questions about the study, please don't hesitate to contact the researcher.

*Thank-you for your time*

**Contacts:**

**Researcher:** *Dr Genevieve Young-Southward*

**Supervisor:** *Professor Helen Minnis*



**Contact Genevieve or Helen at:**

**University of Glasgow  
West Glasgow Ambulatory Care Hospital  
Yorkhill, Glasgow, G3 8SJ**

**Tel: 0141 2019239**



# Appendix 9: Reply slip for parents/caregivers of typically developing children



**Institute of Health and Wellbeing**

*Social Relationships Study 2.0*

*Researcher:  
Genevieve Young-Southward*



**I have read the enclosed information sheet and I am interested to hear more about the Social Relationships Study 2.0. I would like the researcher to phone me on the following number to enable me to discuss the study with them. I understand that this does not mean that I have to take part in the study and although I may choose to participate in the study, I do not have to make my mind up during this phone call.**

**Name:** .....

**Please contact me on (telephone number)** .....

*Thank-you for your time*

**Contacts:**

**Researcher:** *Dr Genevieve Young-Southward*

**Supervisor:** *Professor Helen Minnis*



**Contact Genevieve or Helen at:**

**University of Glasgow  
West Glasgow Ambulatory Care Hospital  
Yorkhill, Glasgow, G3 8SJ**



**Tel: 0141 2019239**

## Appendix 10: Information sheet for typically developing children



Institute of Health and Wellbeing



*Social Relationships Study 2.0*

*Researcher:  
Genevieve Young-Southward*



University of Glasgow  
West Glasgow Ambulatory Care Hospital  
Yorkhill, Glasgow, G3 8SJ  
Tel: 0141 2019239

### Children's Information Sheet

You have been invited to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve. Please read this sheet carefully. Talk to your parent or guardian about the study. Ask if there is anything that you do not understand.

#### Who is doing the research?

The research is being done by Genevieve Young-Southward, Trainee Clinical Psychologist.

#### Why is the research being done?

The research is being done to give us more understanding about children who have problems with relationships.

We want to see lots of different children who do and do not have problems with relationships. This will help us understand how to help children who do have problems with relationships.



#### Why have I been asked?

You have been asked to take part in the study because you **do not** have any problems with relationships.

#### Do I have to take part?

No. It is up to you to decide.

### **What will happen if I take part?**



You will come to a room at the West Ambulatory Care Hospital with your parent or guardian to play with some toys. Your parent or guardian will fill in some forms, and there will be some other people in the room who will watch you play with the toys.

We will not tell anyone else that you took part in the study. All the information we keep from the study will be kept private.

If you have any questions, please ask!

#### **Contacts:**

**Researcher:** *Dr Genevieve Young-Southward*

**Supervisor:** *Professor Helen Minnis*



**Contact Genevieve or Helen at:**

**University of Glasgow  
West Glasgow Ambulatory Care Hospital  
Yorkhill, Glasgow, G3 8SJ**

**Tel: 0141 2019239**



# Appendix 11: Consent form for parents/caregivers of typically developing children



**Institute of Health and Wellbeing**

**Study ID:**

*Social Relationships Study 2.0*

## Parent/Guardian Consent Form

**Please INITIAL the box**

I confirm that I have read and understand the information sheet dated, 07/06/2019 (version 2) for the above study and have had the opportunity to ask questions.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my child’s medical care or legal rights being affected.

I understand that if I choose to withdraw from the study, I can request to have my data destroyed at any time.

I understand that all identifying and personal information is confidential and used only for the purposes of the research, unless there are concerns about child safety. All information collected is stored in accordance with the Data Protection Act.

I give permission for representatives from NHS Greater Glasgow and Clyde, to access personal information supplied, if they were undertaking an audit of the study.

I have explained to my child what is involved in the study and he/she understands. I give consent for my child to take part in the above study.

**Please sign below to give consent to participate in the study**

-----  
Name of participant (Child)      D.O.B (Child)      Date      Parent/guardian name

Parent/guardian signature-----

**Name of person taking consent:** .....

**Signature:** .....

**Date:** .....

**Researcher:**

*Dr Genevieve Young-Southward*

**University of Glasgow  
West Glasgow Ambulatory Care Hospital  
Yorkhill, Glasgow, G3 8SJ  
Tel: 0141 2019239**

## Appendix 12: Assent form for all children



Institute of Health and Wellbeing



*Social Relationships Study 2.0*

### ASSENT FORM FOR CHILDREN

**(To be completed by the child and their parent/guardian)**

Please circle your answers:

Have you read about, or been told about, the Social Relationships Study?



Yes



No

If you take part in the Social Relationships Study you will be asked to come to a clinic and play with some toys.

Is this okay?



Yes



No

Have you asked all the questions you want?



Yes



No

Do you understand that it's OK to stop taking part in the Social Relationships Study at any time?



Version 1



05.02.2019

Yes

No

Would you like to take part in the Social Relationships Study?



Yes

No

If you would like to take part, you can sign your name below

Your name \_\_\_\_\_

Signature \_\_\_\_\_

Date \_\_\_\_\_

The researcher, Genevieve, who explained this project to you needs to sign too

Print Name \_\_\_\_\_

Signature \_\_\_\_\_

Date \_\_\_\_\_

**Thank you for your help**

## Appendix 13: Information sheet for children with ASD or DSED



Institute of Health and Wellbeing



### *Social Relationships Study 2.0*

#### What is the Social Relationships Study About?



Hello, my name is Claire Davidson.

I would like to find out about how children get along with other people. This can involve talking to others and doing activities with other people. Some children find it easy to get along with people and others find it more difficult.

#### What will the Social Relationships Study involve?



You will come to a clinic waiting room with your parent or carer. You can play with some toys. Someone who works with Claire will be there. She will ask your parent or carer some questions.



You will come to the clinic again another day. You will be asked to try some games and puzzles. This helps us to learn about the things that are easier for children to do and the things that are more difficult. There are no right or wrong answers. The pictures show some of the games you will be asked to do.

#### Who would I do the puzzles with?



You will meet with Claire Davidson.  
You will meet with Claire in a private room.  
Claire will show you how to do the puzzles.

You will meet with Claire 2 times. The meetings will be on different days.

The meetings will last about 1 hour.

You will have a snack break at each meeting.

A person who works with Claire will come in the room for meeting 1.



### **What else do I need to know about the Social Relationships Study?**



We would like to video our meeting with you so we can look at it afterwards and think about what you said to us.



We would also like to ask your parents or carers some questions about how you get along with other people.

## **Thank You!**

## Appendix 14: Information sheet for parents/caregivers of children with ASD



*Researcher:  
Claire Davidson*

### *Social Relationships Study 2.0*

University of Glasgow  
Caledonia House  
Child and Adolescent Psychiatry  
West Glasgow Ambulatory Care Hospital  
Yorkhill, Glasgow, G3 8SJ  
Tel: 0141 2019239

### Parent/Carer Information Sheet

You have been invited to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask if there is anything that is not clear or if you would like more information.

#### **Who is conducting the research?**

The research is being carried out by Claire Davidson, Speech and Language Therapist (SLT), who is also a researcher with the Institute of Health and Wellbeing at the University of Glasgow. Claire is carrying out this study as part of a 3.5 year PhD, which is a research training qualification.

A small part of the research (Part One, see below) is being carried out by Dr Genevieve Young-Southward, Trainee Clinical Psychologist. Genevieve is carrying out this study as part of a doctorate in Clinical Psychology. Colleagues in NHS Greater Glasgow and Clyde will help by passing the information packs to parents of children eligible to participate in the study.

#### **What is the purpose of the study?**

The purpose of the study is to test a new assessment tool, developed by Claire and the research team. The new tool is designed to help clinicians with assessment of children with social relationship and communication problems. As *different* groups of children can present with similar social relationship problems but for very different reasons, the new tool is designed to help clinicians with their assessment. This, in turn, could lead to improved access to appropriate treatment and management. We would like to try the new tool with different groups of children who have social relationship and communication problems. This will help me to find out what works well and what works less well with the tool.

#### **Why have I been invited?**

You have been invited to take part in this study as you have a child who has some difficulties with social relationships and social communication.

#### **Do I have to take part?**

No. It is up to you and your child to decide. This information sheet will provide details of the study, but should you have further questions please get in touch and we will be pleased to answer them. I have also enclosed a child friendly information sheet to help you explain to your child what

they will be asked to do. If you are interested in taking part please contact us to express your interest using any of the following: via telephone on 0141 2019239, or by returning the enclosed reply slip using the S.A.E provided. On receiving your note of interest the researcher will contact you to discuss the study further. You do not have to decide whether you want to participate in the study during this phone call. You can think take time to think about it and the researcher can arrange to speak with you again, if required. If you do choose to participate in the study, your written consent will be taken by the researcher at the first appointment. Please note, you and your child are free to withdraw at any time, without giving reason. This would not affect the standard of care your child receives or your child's future treatment.

## **What does taking part involve?**

### **Part one**

#### **► Parents/carers:**

An appointment will be made for you and your child to attend the clinic waiting room at the West Glasgow Ambulatory Care Hospital for approximately 15 minutes. There will be toys available in the waiting room for your child to play with. Two researchers (Genevieve and an additional researcher) will be present in the waiting room, and there may or may not be other people attending the clinic also present in the waiting room. Genevieve will provide you with consent forms and some questionnaires to fill in. These questionnaires will ask about your child's social relationship skills, communication and behaviours. While you fill in the questionnaires, Genevieve and the second researcher will observe your child's social behavior in the waiting room and make some notes. After 10-15 minutes, the observation will stop. Genevieve will discuss the study with you and answer any questions.

**If you give permission, we will keep your contact details and you will be contacted at a later date with an invitation to take part in Part two of the study.**

### **Part two**

#### **► Parents/carers:**

Appointment 1: (approximately 1.5 hours) I, or my research colleague, would like to meet with you, on your own, to complete an interview with you about your child's social skills and communication. The researcher would be pleased to meet with you at your house to complete this interview, if preferred. Before we begin the interview, I will further explain the study and ask you to give written consent to participate.

#### **► Parents/carers & children:**

Appointment 2: I would like to meet with your child at the clinic where I will ask them to complete some picture tasks, read aloud a short story and then we will have a snack break. After the snack I will chat with your child about things that they enjoy i.e. about a favourite hobby. . My research colleague will be present during this 2<sup>nd</sup> task as I am interested to learn about children's social communication when interacting with more than one person During this time you will be asked to complete some questions in a booklet about your child's social relationships, communication and behaviour. This appointment will last approx. 1 hour.

Appointment 3: I would like to meet with your child again to complete some tasks about social relationship and communication skills. The appointment will last approximately 1 hour, and includes a snack break. Your child will be given the opportunity to play with toys (appropriate to their age), read books and play games with me and a colleague. The tasks will enable me to see your child's strengths and anything that they find more difficult. You will

be asked to complete a short interview with my colleague during this time and you can complete any remaining questions from the booklet during this time.

► **Video.** I would like to video the child's appointments so that I can look at them afterwards and take my time understanding more about your child's relationships. In order to help me with this I will ask an identified group of around 10 expert clinicians, who work in child services in the NHS, to view the video of the assessment and to give me independent feedback. This will provide the best possible and most accurate information. All clinicians are governed by client confidentiality and data protection rules and the clinicians will not be provided with any other information about your child, except from their age (**not date of birth**) and their level of language ability i.e. fluent speech with sentences, talks with single words etc. While I will not provide any other information to the clinicians, your child's first name may still be heard in the video.

► **Teacher.** I would like to send two short questionnaires to your child's current school teacher as this will help me to learn more about your child's social relationships when at school.

**We value your time and effort and are happy to pay for your transport to and from the clinic (taxi cost or mileage by car) and you will be given £20 as a thank you for your participation. You will be given £10 after Part One, and £10 after Part two.**

### **What happens to the information?**

Your identity and personal information will be completely confidential and accessed only by the researcher. All the information obtained will remain confidential and stored within a locked filing cabinet at Caledonia House, which is a Glasgow University building, where the researcher is based. Videos will be stored on in an encrypted file on the researcher's computer at her base only. The data is anonymised wherever possible through use of ID numbers rather than names, and all data are held in accordance with the Data Protection Act. This means that it is kept safely and cannot be revealed to other people, without your permission. Your data will be used only for the purposes of the research, unless there are concerns about child safety. In the unlikely event of such concerns, we would tell you of our concerns prior to contacting any other agencies. With your permission, we would let your child's GP know of the family's involvement in the study but would not pass on any study information to the GP. At the end of your involvement we will write a letter to the clinician who referred your child to the study and let them know the findings of all the information that we have gathered. They can share these findings with you.

### **What are the possible benefits of taking part?**

By taking part in this research, it will allow us to test a new assessment tool that could be valuable in improving the assessment of children who have difficulties with social relationships and social communication. The new assessment tool could enhance accuracy of diagnosis; improved assessment may lead to be a better patient experience, and may help access to appropriate treatment and management strategies. At the end of the study we will write to you and offer a summary report of the findings.

### **If you have a complaint about any aspect of the study?**

If you are unhappy about any aspect of the study and wish to make a complaint, please contact the researcher in the first instance but the normal NHS complaint mechanism is also available to you.

### **Who has reviewed the study?**

This study has been reviewed by the NHS West of Scotland Research Ethics Service.

### **If you have any further questions?**

We will give you a copy of the information sheet and signed consent form to keep. If you would like more information about the study and wish to speak to someone **not** closely linked to the study, please contact Dr Lucy Thompson, International Research Coordinator, at [lucy.thompson@abdn.ac.uk](mailto:lucy.thompson@abdn.ac.uk) and she will get in touch with you.

If you have any questions about the study, please don't hesitate to contact the researcher.

*Thank-you for your time*

**Contacts:**

**Researchers:** *Claire Davidson*



**Supervisor:** *Professor Helen Minnis*



*Dr Genevieve Young-Southward*

**Contact Claire, Genevieve or Helen at:**

**University of Glasgow  
Child and Adolescent Psychiatry  
West Glasgow Ambulatory Care Hospital  
Yorkhill, Glasgow, G3 8SJ**

**Tel: 0141 2019239**

# Appendix 15: Consent form for parents/caregivers of children with ASD



Institute of Health and Wellbeing



Researcher:  
Claire Davidson

## Social Relationships Study 2.0

### Parent Consent Form

**Please initial the BOX**

I confirm that I have read and understand the information sheet dated, 29.08.19 (version 5) for the above study and have had the opportunity to ask questions.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my child’s medical care or legal rights being affected.

I give my permission for my information to be held and for the researcher to contact me to participate in the part two of the study.

I understand that my child’s participation in the tasks with the researcher in part two of the study will be video recorded. The video recordings are for the purpose of the research study and will be accessed only by members of the research team. All video recordings will be treated as confidential and stored in accordance with the data protection act. I agree to my child being video taped during completion of the tasks.

I understand that all identifying and personal information is confidential and used only for the purposes of the research, unless there are concerns about child safety. All information collected is stored in accordance with the data protection act.

I give permission for representatives from NHS Greater Glasgow and Clyde, to access personal information supplied, if they were undertaking an audit of the study.

I have explained to my child what is involved in the study and he/she understands. I give consent for my child to take part in the above study.

I am happy to be contacted for future studies

I am happy for the research team to contact my child’s teacher to ask him/her to complete a short questionnaire about my child’s behaviour. If yes, please enter your child’s school contact details below:

Name of school \_\_\_\_\_  
 Class \_\_\_\_\_  
 Teacher \_\_\_\_\_

I am happy for the research team to contact my child’s GP to let him/her know of my child’s participation. If yes, please enter your GP’s contact details below:

Name \_\_\_\_\_  
 GP address \_\_\_\_\_

**Please sign below to give consent to participate in the study**

-----  
 Name of Participant (Child)      D.O.B (Child)      Date      Parent name (Printed)

Parent Signature-----

Best point of contact -----

2<sup>nd</sup> point of contact or email -----

**Researcher: *Claire Davidson***



**University of Glasgow  
 Caledonia House  
 Child and Adolescent Psychiatry  
 West Glasgow Ambulatory Care Hospital  
 Yorkhill, Glasgow, G3 8SJ  
 Tel: 0141 2019239**

## Appendix 16: Information sheet for parents/caregivers of children with DSED symptoms



Institute of Health and Wellbeing



Researcher:  
Claire Davidson



### *Social Relationships Study 2.0*

University of Glasgow  
Caledonia House  
Child and Adolescent Psychiatry  
West Glasgow Ambulatory Care Hospital  
Yorkhill, Glasgow, G3 8SJ  
Tel: 0141 2019239

#### Parent/Carer Information Sheet

You have been invited to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask if there is anything that is not clear or if you would like more information.

#### Who is conducting the research?

The research is being carried out by Claire Davidson, Speech and Language Therapist (SLT), who is also a researcher with the Institute of Health and Wellbeing at the University of Glasgow. Claire is carrying out this study as part of a 3.5 year PhD, which is a research training qualification.

A small part of the research (Part One, see below) is being carried out by Dr Genevieve Young-Southward, Trainee Clinical Psychologist. Genevieve is carrying out this study as part of a doctorate in Clinical Psychology. Colleagues in NHS Greater Glasgow and Clyde will help by passing the information packs to parents of children eligible to participate in the study.

#### What is the purpose of the study?

The purpose of the study is to test a new assessment tool, developed by Claire and the research team. The new tool is designed to help clinicians with assessment of children with social relationship and communication problems. As *different* groups of children can present with similar social relationship problems but for very different reasons, the new tool is designed to help clinicians with their assessment. This, in turn, could lead to improved access to appropriate treatment and management. We would like to try the new tool with different groups of children who have social relationship and communication problems. This will help me to find out what works well and what works less well with the tool.

#### Why have I been invited?

You have been invited to take part in this study as you have a child who has some difficulties with social relationships and social communication.

#### Do I have to take part?

No. It is up to you and your child to decide. This information sheet will provide details of the study, but should you have further questions please get in touch and we will be pleased to answer them. I have also enclosed a child friendly information sheet to help you explain to your child what they will be asked to

do. If you are interested in taking part please contact us to express your interest either via telephone on 0141 2019239, or by returning the enclosed reply slip using the S.A.E provided. On receiving your note of interest the researcher will contact you to discuss the study further. You do not have to decide whether you want to participate in the study during this phone call. You can think take time to think about it and the researcher can arrange to speak with you again, if required. If you do choose to participate in the study, we will invite you to complete a telephone interview about your child's social relationships. You will be asked to provide verbal consent over the telephone to participate in this interview. This does not mean that you have consented to participation in the full study and we will not collect any further information until we have met with you in person and obtained your written consent. You will be asked to give written consent at the first appointment. Please note, you and your child are free to withdraw at any time, without giving reason. This would not affect the standard of care your child receives or your child's future treatment.

## **What does taking part involve?**

### **Part one**

#### **► Parents/carers:**

An appointment will be made for you and your child to attend the clinic waiting room at the West Glasgow Ambulatory Care Hospital for approximately 15 minutes. There will be toys available in the waiting room for your child to play with. Two researchers (Genevieve and an additional researcher) will be present in the waiting room, and there may or may not be other people attending the clinic also present in the waiting room. Genevieve will provide you with consent forms and some questionnaires to fill in. These questionnaires will ask about your child's social relationship skills, communication and behaviours. While you fill in the questionnaires, Genevieve and the second researcher will observe your child's social behavior in the waiting room and make some notes. After 10-15 minutes, the observation will stop. Genevieve will discuss the study with you and answer any questions.

**If you give permission, we will keep your contact details and you will be contacted at a later date with an invitation to take part in Part two of the study.**

### **Part two**

#### **► Parents/carers:**

You will be asked to complete a telephone interview (approx. 30 mins-45 mins) with either myself or a colleague, as mentioned above, to hear about your child's social relationships. With your permission, I would like to audio record the interview to help with note taking. Following this, you will be asked to come into the clinic with your child to attend some appointments as described below. Your written consent to participate in the study will be sought at the first appointment.

Appointment 1: (approximately 1.5 hours) I, or my research colleague, would like to meet with you, on your own, to complete an interview with you about your child's social skills and communication. The researcher would be pleased to meet with you at your house to complete this interview, if this is preferred. Before we begin the interview, I will further explain the study and ask you to give written consent to participate.

#### **► Parents/carers & children:**

Appointment 2: I would like to meet with your child at the clinic where I will ask them to complete some picture tasks, read aloud a short story and then we will have a snack break. After the snack I will chat with your child about things that they enjoy i.e. a about favourite hobby. My research colleague will be present during this 2<sup>nd</sup> task as I am interested to learn about children's social

communication when interacting with more than one person. During this time you will be asked to complete some questions in a booklet about your child's social relationships, communication and behaviour. This appointment will last approx. 1 hour.

**Appointment 3:** I would like to meet with your child again to complete some tasks about social relationship and communication skills. The appointment will last approximately 1 hour, and includes a snack break. Your child will be given the opportunity to play with toys (appropriate to their age), read books and play games with me and a colleague. The tasks will enable me to see your child's strengths and anything that they find more difficult. You will be asked to complete a short interview with my colleague during this time and you can complete any remaining questions from the booklet during this time.

► **Video.** I would like to video the child's appointments so that I can look at them afterwards and take my time understanding more about your child's relationships. In order to help me with this I will ask an identified group of around 10 expert clinicians, who work in child services in the NHS, to view the video of the assessment and to give me independent feedback. This will provide the best possible and most accurate information. All clinicians are governed by client confidentiality and data protection rules and the clinicians will not be provided with any other information about your child, except from their age (**not date of birth**) and their level of language ability i.e. fluent speech with sentences, talks with single words etc. While I will not provide any other information to the clinicians, your child's first name may still be heard in the video.

► **Health & Social Care Records.** In order to learn more about other health or environmental circumstances, including any early adversities, which may influence your child's social relationships, I would, with your permission, like to check your child's information via access to routine health and social care databases/case notes. Please indicate on the consent form if you are happy for me to do this. Do not initial the box if you do not wish for this to happen.

► **Teacher.** I would like to send two short questionnaires to your child's current school teacher as this will help me to learn more about your child's social relationships when at school.

**We value your time and effort and are happy to pay for your transport to and from the clinic (taxi cost or mileage by car) and you will be given £20 as a thank you for your participation. You will be given £10 after Part One, and £10 after Part two.**

### What happens to the information?

Your identity and personal information will be completely confidential and accessed only by the researcher. All the information obtained will remain confidential and stored within a locked filing cabinet at Caledonia House, which is a Glasgow University building, where the researcher (Claire) is based. Videos will be stored on in an encrypted file on the researcher's computer at her base only. The data is anonymised wherever possible through use of ID numbers rather than names, and all data are held in accordance with the Data Protection Act. This means that it is kept safely and cannot be revealed to other people, without your permission. Your data will be used only for the purposes of the research, unless there are concerns about child safety. In the unlikely event of such concerns, we would tell you of our concerns prior to contacting any other agencies. With your permission, we would let your child's GP know of the family's involvement in the study but would not pass on any study information to the GP. At the end of your involvement we will write a letter to the clinician who referred your child to the study and let them know the findings of all the information that we gathered. They can share these findings with you.

### What are the possible benefits of taking part?

By taking part in this research, it will allow us to test a new assessment tool that could be valuable in improving the assessment of children who have difficulties with social relationships and social communication. The new assessment tool could enhance accuracy of diagnosis; improved assessment may lead to be a better patient experience, and may help access to appropriate treatment and management strategies. At the end of the study we will write to you and offer a summary report of the research findings.

**If you have a complaint about any aspect of the study?**

If you are unhappy about any aspect of the study and wish to make a complaint, please contact the researcher in the first instance but the normal NHS complaint mechanism is also available to you.

**Who has reviewed the study?**

This study has been reviewed by the NHS West of Scotland Research Ethics Service.

**If you have any further questions?**

We will give you a copy of the information sheet and signed consent form to keep. If you would like more information about the study and wish to speak to someone **not** closely linked to the study, please contact Dr Lucy Thomson, International Research Coordinator, at [lucy.thompson@abdn.ac.uk](mailto:lucy.thompson@abdn.ac.uk) and she will get in touch with you.

**Contacts:**

**Researchers:** *Claire Davidson*



**Supervisor:** *Professor Helen Minnis*



*Dr Genevieve Young-Southward*



**Contact Genevieve, Claire or Helen at:**

**University of Glasgow  
Caledonia House  
Child and Adolescent Psychiatry  
West Glasgow Ambulatory Care Hospital  
Yorkhill, Glasgow, G3 8SJ  
Tel: 0141 2019239**

# Appendix 17: Consent form for parents/caregivers of children with DSED symptoms



Institute of Health and Wellbeing



**Study Identification Number**

*Researcher:  
Claire Davidson*



## *Social Relationships Study 2.0*

### Parent Consent Form

**Please initial the BOX**

I confirm that I have read and understand the information sheet dated, 29.08.19 (version 5) for the above study and have had the opportunity to ask questions.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my child’s medical care or legal rights being affected.

I give my permission for my information to be held and for the researcher to contact me to participate in part two of the study.

I understand that my child’s participation in the tasks with the researcher in part two of the study will be video recorded. The video recordings are for the purpose of the research study and will be accessed only by members of the research team. All video recordings will be treated as confidential and stored in accordance with the data protection act. I agree to my child being video taped during completion of the tasks.

I understand that sections of my child’s medical notes and/or routine health databases will be looked at by the research team where it is relevant to my taking part in the research. I give my permission for the research team to have access to my child’s records.

I understand that all identifying and personal information is confidential and used only for the purposes of the research, unless there are concerns about child safety. All information collected is stored in accordance with the data protection act.

I give permission for representatives from NHS Greater Glasgow and Clyde, to access personal information supplied, if they were undertaking an audit of the study.

I have explained to my child what is involved in the study and he/she understands. I give consent for my child to take part in the above study.

I am happy to be contacted for future studies

I am happy for the research team to contact my child’s teacher to ask him/her to complete a short questionnaire about my child’s behaviour. If yes, please enter your child’s school contact details below:

Name of school \_\_\_\_\_

Class \_\_\_\_\_

Teacher \_\_\_\_\_

I am happy for the research team to contact my child’s GP to let him/her know of my child’s participation. If yes, please enter your GP’s contact details below:

Name \_\_\_\_\_

GP address \_\_\_\_\_

**Please sign below to give consent to participate in the study**

-----	-----	-----	-----
Name of Participant (Child)	D.O.B (Child)	Date	Parent name (Printed)

Parent Signature-----

Best point of contact -----

2<sup>nd</sup> point of contact or email -----

**Researcher:**

*Claire Davidson*



**University of Glasgow  
Caledonia House  
Child and Adolescent Psychiatry  
West Glasgow Ambulatory Care Hospital  
Yorkhill, Glasgow,  
G3 8SJ  
Tel: 0141 2019239**

## Appendix 18: Waiting Room Observation scale

### Waiting Room Observation

Additional observations/comments

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<u>Child stranger interaction</u>		YES	NO	Scoring Yes=0; No=1
1.	Does the child look at stranger(s) as if to invite conversation? (The child does not have to smile but, eye contact must be of a quality that would invite the stranger to communicate in a "normal" social setting.)	<input type="checkbox"/>	<input type="checkbox"/>	0
2.	Does the child interrupt conversation between the stranger(s) and his /her <u>carer</u> ?	<input type="checkbox"/>	<input type="checkbox"/>	0
3.	Does the child initiate conversation with the stranger(s) as if previously familiar?	<input type="checkbox"/>	<input type="checkbox"/>	0
4.	Does the child move towards and approach the stranger(s)?	<input type="checkbox"/>	<input type="checkbox"/>	0
5.	Does the child make physical contact with the stranger(s)?	<input type="checkbox"/>	<input type="checkbox"/>	0
6.	Does the child display noticeable caution or shyness with the stranger(s)?	<input type="checkbox"/>	<input type="checkbox"/>	1
<u>Child-carer interaction</u>				
7.	Is there a warmth to the carer-child relationship <del>eg</del> handholding, leaning in or cosy whispered chat, without parental irritation? (Does not have to include physical contact.)	<input type="checkbox"/>	<input type="checkbox"/>	1
8.	Does the child make spontaneous comment to his/her carer in the presence of the introduced stranger (researcher one)?	<input type="checkbox"/>	<input type="checkbox"/>	0
9.	Does the child refuse or ignore a request from his/her carer?	<input type="checkbox"/>	<input type="checkbox"/>	0
10.	Does the child exhibit hyper compliance (defined as complying immediately, without question; seemingly eager to please) to a request from his/her carer?	<input type="checkbox"/>	<input type="checkbox"/>	0
11.	Does the child respond reciprocally in conversation with his/her carer?	<input type="checkbox"/>	<input type="checkbox"/>	1
<u>General behaviours</u>				
12.	Does the child display rapid shifts in emotional expression (defined as sudden shifts to the extremes of emotion)?	<input type="checkbox"/>	<input type="checkbox"/>	0
13.	Does the child appear to adopt the role of playing a younger, "babyish" child either in voice or behaviour?	<input type="checkbox"/>	<input type="checkbox"/>	0
14.	Does the child appear superficially charming i.e. affection appears insincere or over the top (e.g. gives a false smile)?	<input type="checkbox"/>	<input type="checkbox"/>	0
15.	Does the child try to exert control over their environment (e.g. tries to be the boss)?	<input type="checkbox"/>	<input type="checkbox"/>	0
16.	Does the child display a seemingly insatiable desire for attention?	<input type="checkbox"/>	<input type="checkbox"/>	0
17.	Does the child show a preferential interest in his/her carer's attention over that of the stranger's?	<input type="checkbox"/>	<input type="checkbox"/>	1

## Appendix 19: Collinearity statistics for predictor variables entered into regression analysis

Variable (WRO item)	Tolerance	VIF
Looks at stranger to invite conversation	0.701	1.426
Interrupts conversation between stranger and carer	0.631	1.585
Initiates conversation with stranger	0.534	1.873
Moves towards stranger	0.530	1.886
Makes physical contact with stranger	0.724	1.381
Displays noticeable caution or shyness with stranger	0.804	1.243
Warmth to child-carer relationship	0.612	1.634
Makes spontaneous comments in presence of stranger	0.708	1.413
Refuses or ignores request from carer	0.511	1.958
Exhibits hypercompliance to request from carer	0.899	1.113
Responds reciprocally in conversation with carer	0.640	1.562
Displays rapid shifts in emotional expression	0.547	1.829
Adopts role of babyish child	0.572	1.749
Appears superficially charming	0.700	1.429
Tries to exert control over environment	0.385	2.600
Displays insatiable desire for attention	0.337	2.969

Preferential interest of carer's attention	0.853	1.173
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## **Appendix 20: Description of qualitative themes**

### **Child-caregiver interaction**

Typically developing children remained close to their caregivers, usually sitting beside them and leaning into them as they completed the questionnaires. There was clear evidence of warmth in these relationships, with children and caregivers whispering and giggling together. In contrast, children with ASD tended to sit by themselves, only approaching the caregiver when required, e.g. to complete the assent form. However, warmth was still evident in most of these relationships, with children and caregivers smiling or laughing at comments the other made.

Children with symptoms of DSED appeared more disorganised in their approach to the caregiver. Although there was evidence of warmth in the relationships, with children and caregivers laughing together and responding reciprocally in play, most children appeared controlling over the direction of play, refusing the caregiver's suggestions or pushing them away.

### **Child's exploration of environment**

Most typically developing children appeared hesitant to explore their unfamiliar surroundings when they entered the waiting room. Some remained next to their caregivers for the duration of the observation, while some moved away and interacted with the toys at their caregiver's prompting. In this way, children waited for an indication from their caregivers that it was safe or appropriate to play. A minority of children in this group interacted with the toys as soon as they entered the room. Most children in this group appeared to become more comfortable over the course of the observation, moving around the room more over time. Among the children with ASD, some did not move around the room at all, simply remaining in their seat for the duration of the observation. Those that did move around the room or play with the toys did so without any prompting from their caregiver. Children with symptoms of DSED also moved around the room without any prompting from their caregiver; indeed, the majority of these children were asked at

some point during the course of the observation to return to their seat because they were interacting with items in the room other than toys, e.g. a storage cupboard. In this regard, both the children with ASD and with symptoms of DSED demonstrated a lack of reassurance seeking from their caregiver in this unfamiliar setting compared to typically developing children.

### **Child-stranger interaction**

Although one sibling group in the typically developing group of children interacted with the stranger(s) straight away during the observation, the majority exhibited a degree of shyness. Most did not attempt to make eye contact with the stranger(s) but responded politely if eye contact was made, e.g. smiling and looking away. Most children appeared to become more comfortable over time with the presence of the stranger, looking towards them more often. Most children in this group did not speak to the stranger(s) unless prompted to by the caregiver, e.g. to say thank you and goodbye. There are parallels here to these children's exploration of the environment in that children waited to interact overtly with the stranger(s) until their caregivers indicated that it was safe and appropriate to do so.

Two distinct groups of children with ASD emerged in relation to this theme. The first made no attempts to interact with the stranger(s) at all. However, there were several occasions when children in this group moved physically close to a stranger, e.g. to retrieve a toy, but did not interact with them despite their physical proximity. These children hence appeared to be unaware of social norms around personal space. The second (smaller) group of children with ASD interacted with the stranger(s) straight away. Interestingly, this interaction appeared dependent on a visual prompt related to their special interest: one child was reported to have a special interest in hoovers and by chance a toy Hoover was present in the waiting room; a second was reported to have a special interest in babies and a baby doll was among the toys. In both cases the children spoke to the stranger(s) at length and without prompting about their special interests. In

this way, these children's desire to talk about their special interest appeared to override social norms around interacting with strangers.

Most children with symptoms of DSED interacted with the stranger(s) immediately, asking them questions about themselves or playing with them. Some children in this group sought out contact with the stranger(s), e.g. asking where they had gone if they had left the room or going to the doorway and calling to them. These children therefore did not appear to differentiate in their desire for attention from the caregiver/stranger(s).

### **Child's spontaneous comments/interruptions in stranger(s)' presence**

Few typically developing children made spontaneous comments in the presence of the stranger(s) but tended to whisper if they did so. Some children provided commentary on their play, often if they were playing with a sibling. No children in this group interrupted their caregiver while they were distracted talking to the researcher. Some children with ASD made no spontaneous comments throughout the observation. Others were loud in their play, e.g. shouting or slamming toys, and provided commentary on their play. Some made frequent interruptions while their caregiver was distracted talking to the stranger(s) or completing questionnaires; these interruptions were almost exclusively in relation to the procedures of the study (e.g. 'are we going into another room now?') or what would happen later in the day (e.g. 'are we going to McDonald's after this?'). In this regard, these children's urge to know what would happen next overrode the social norms of remaining quiet in the presence of strangers. Children with symptoms of DSED also played loudly and shouted. All these children made spontaneous comments in the presence of stranger(s) and often did so when their caregivers were distracted, e.g. shouting 'look at me'.