Are Early Adversities associated with traits resembling ASD in childhood?

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I confirm that I am submitting this work with the agreement of my Supervisor(s).’

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‘Yr wyf drwy hyn yn datgan mai canlyniad fy ymchwil fy hun yw’r thesis hwn, ac eithrio lle nodir yn wahanol. Caiff ffynonellau eraill eu cydnabod gan droednodiadau yn rhoi cyfeiriadau eglur. Nid yw sylwedd y gwaith hwn wedi cael ei dderbyn o’r blaen ar gyfer unrhyw radd, ac nid yw’n cael ei gyflwyno ar yr un pryd mewn ymgeisiaeth am unrhyw radd oni bai ei fod, fel y cytunwyd gan y Brifysgol, am gymwysterau deuol cymeradwy.

Rwy'n cadarnhau fy mod yn cyflwyno'r gwaith hwn gyda chytundeb fy Ngoruchwyliwr (Goruchwylwyr)

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Nelson Mandela said, *“Our children are our greatest treasure. They are our future. Those who abuse them tear at the fabric of our society...”* Thank you to all children and families who participated in this research, and I only hope it makes some positive contribution.

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**Abstract**

A rise in traits resembling Autism Spectrum Disorder (ASD) in children coincide with calls for less focus on diagnoses and more on understanding individual differences and needs. There is also growing recognition of the negative sequalae associated with adverse childhood experiences (ACEs). Results from studies exploring the associations between ACEs and ASD suggest that ACEs are associated with ASD traits but not ASD diagnoses. The current research seeks to confirm this reported association between ACEs and traits resembling ASD. It draws from a secondary dataset from a nationally representative longitudinal study (N = 332), the Cardiff Child Development Study (CCDS). The author coded and entered information from the available raw data, provided by parents recruited between Autumn 2005 and Summer 2007, to create new variables; a proxy ACE count and a measure of traits resembling ASD (N = 282). 60.3% of children in the subsample were coded as having had an ACE (i.e., abuse or household dysfunction) before the age of 7 years. Frequency of ACEs was not significantly different across gender though did occur more frequently in families with lower SES, *p* <0.05. The occurrence of traits resembling ASD was not significantly different across SES categories. Aspects of traits resembling ASD included impairments in communication, sociability, and flexibility, and were measured at three waves of the CCDS. Only the traits resembling ASD measured at Wave 6, when the children were 7 years of age, were considered reliable, α = 0.85. Wave 6 ASD measures were also valid due to their significant relationship with whether the child was referred for ASD, *p* = 0.004, and the items’ ecological validity. Traits resembling ASD were significantly different across ACE count categories, with higher impairments being associated with more ACEs. This difference only reached significance in relation to impaired sociability at Waves 4 and 6. Given its reliability and validity, the between-groups result in relation to the Wave 6 measure is of particular interest, *p* = 0.037. Relationships between ACEs and ASD traits reported in previous research were tentatively supported. Limitations included a potential for under-reporting some ACEs and over-reporting others, and a limited amount of available data related to ASD. In terms of clinical implications, results cautiously support the increased emphasis on children’s needs through a whole-systems approach. Clinicians may benefit from awareness that ACEs may be associated with impaired sociability.

**Chapter 1. Introduction**

**Early adversities and Traits resembling ASD in childhood**

* 1. **Understanding the rise in the number of children perceived to have traits resembling ASD**

Typically diagnosed in early childhood, Autism Spectrum Disorder (ASD) is a developmental and neurological condition manifesting through challenges in communication, social interaction, restricted interests, and repetitive behaviours (National Institute of Mental Health, 2023; Maphalala & Mathabela, 2022). ASD is termed a "spectrum" disorder due to the diverse range of symptoms and their severity experienced by individuals (National Institute of Mental Health, 2023). A plethora of recent reports suggest a continual rise in the number of children diagnosed with ASD in the UK (McConkey, 2020) and internationally (Zeidan et al., 2022). McConkey (2020) reported a rise of 154.1% of ASD pupils in England and 142.8% in Wales between 2010 and 2019. At the same time, there is a reported increase in numbers of referrals made to children’s mental health services in the UK (UK Government’s State of the Nation report, Oct 2020) and globally (WHO, 2022). This was already the case prior to the Covid-19 pandemic and is especially true since then (Lennon, 2021). A high level of co-morbidity between ASD diagnoses and mental health difficulties is well established. For example, an Autistica report found that 80% of adults with a diagnosis of autism also had mental health issues during their lifetime, Autistica (n.d.). This rise in referrals translates to an urgent priority to meet the needs of children and families, including those children referred based on traits resembling ASD, as efficiently as possible (Welsh Government, 2018, *Updated Delivery Plan*).

Explaining the rise in children and young people receiving ASD diagnoses over the last decade or two is not straightforward. It has been argued that the rise may be, in part, due to the broadening of the “ASD umbrella” term (Sigafood et al., 2009). Specifically, Sigafood et al. (2009) suggest that ‘the ASD tag’ has gained popularity, with a wider range of disorders now considered within the “spectrum” as opposed to when Leo Kanner defined childhood ‘autism’ in the 1940s (Sigafood et al., 2009).Alternatively, rising diagnoses may be the result of increased awareness of autism/ASD, along with improvements in the early identification of ASD (Zeidan, 2022).Still other work highlights how autism or ASD is essentially a social construct (Huws and Jones, 2015), which opens the possibility that the socio-political or economic context has some bearing on how many children or adults are considered to have ‘autism’. Considering these differing explanations, in the context of a rise in referrals, there are clear imperatives to increase understanding of the aetiology and nature of traits resembling ASD.

While the experience of children presenting with impairments in sociability, communication and flexibility is real, history tells us that ASD is a fluid, rather than a fixed, concept. Indeed, recent shifts in how ASD is conceptualised include an apparent moving away from deficit-based models, and to increasingly mainstream consideration of autism as a *difference* rather than a disorder (Dr. Cath Norton’s Introduction to the national ND Conference in Wales, 2022; NHS website, 2022; Harvey, 2018). In their alternative guide to psychiatric diagnoses, Johnstone and Boyle (2018) similarly referred to ASD and Asperger’s as a non-typical *way of being*. As Tamimi (2018) suggests, however, whether ASD is considered a difference or disorder may depend on perspective. He suggests that adults with a diagnosis prefer their neurodevelopmental profile to be considered “a difference” while parents of children with ASD may have a stronger incentive for the disorder perspective to be espoused *(*Tamimi, 2018*)*. In arguments advocating alternatives to psychiatric labels, ASD/autism is a label often exempt (Johnstone and Boyle, 2018), but the references to ASD as a ‘difference’ may signal the emergence of a reduced need for diagnosis and a wider acceptance of ASD traits. Indeed, Runswick-Cole, Mallet, & Timimi, (2016) challenged the assumption that the wide range of behaviours and hypersenstitives associated with ASD should share the same aetiology, course, treatment and outcome.

In line with emerging shifts in conceptualising ASD, a new planning tool for regional health boards in Wales, theNEST/NYTH framework (NHS Wales Health Collaborative, 2021) represents a proposed ‘step-change’ in how children and their wider families are supported. The authors of this framework propose that basing children’s referral criteria to mental health services on diagnosable disorders is; problematic, potentially stigmatising, and, at risk of precluding support for children where the root cause of their behavioural difficulties is relational or contextual. The NEST framework: When you need to know more (2021) presents an argument stating that there is a need for:

a move towards services responding to need rather than diagnosis or other tightly guarded referral criteria, and a more flexible matching of resources with what will be most helpful at a given point in time (p. 36)

The re-shift in focus, from understanding children through a diagnostic lens to that of flexibly responding to need, was publicly supported by the 2015 - 2022 Children’s Commissioner in Wales and echoed in policy in Wales in relation to NeuroDevelopmental (ND) concerns. Furthermore, responding to children’s needs with a whole-systems approach is advocated and increasingly preferred over diagnostic-led approaches or through some other closely guarded referral criteria. Importantly, the current research will focus on capturing traits resembling ASD in children, rather than on children who have received an ASD diagnosis.

In all, recent development in thinking regarding ASD seems to increasingly acknowledge the broader socio-political factors, adversities and environmental experiences at play in children’s lives. After the social and emotional deprivation that many children endured during the Covid 19 pandemic, it seems particularly timely to ask more about the nature of the relationship between early adversity and children’s presentations and traits. An increase in adverse events could be associated with the perceived rise in traits resembling ASD during childhood.

* 1. **Adverse childhood experiences (ACEs) and their association with later health outcomes**

DEFINITION OF ACEs and a SHORT CRITIQUE. Exposure to adverse childhood experiences (ACEs; childhood maltreatment and household dysfunction, e.g. substance use) in the first 18 years of life are associated with life-long negative outcomes for physical and mental health (Vig et al., 2020; Sheffler et al., 2020). For example, children exposed to four or more different types of ACEs show a nine-fold increased risk of self-harm or suicidality across their lifespan, compared to those with no ACE exposure (Hughes et al., 2018). ACEs are relatively common (usually around half the sample, from a general population, report they had one type of ACE and 14% of the population four or more different types, Felitti et al., 1998; Hughes et al., 2018) and there are concerns that the occurrence of ACEs increased during the C19 pandemic (Roumanou & Belton, 2020). In high-risk populations, such as prisoners and the homeless, rates of ACEs have been reported as consistently higher than in the general population (Takahashi et al., 2022; Radcliff et al., 2019). Both Welsh and UK Governments recognise the impact of ACEs, and have identified an urgent need to mitigate their potential detrimental association with later negative outcomes (e.g. Welsh Government, 2021; Welsh Government, 2018; Science and Technology Committee, UK Parliament, 2018).

Felitti et al. (1998) first highlighted the significant dose-response relationship between the number of ACEs types and a range of detrimental health outcomes, including later physical health conditions such as: ischemic heart disease, cancer and chronic bronchitis. Since this seminal work and ensuing series of studies, this dose-response finding has been fairly consistently replicated, at least for studies conducted with the general population, across several countries, including in the UK (e.g. Hughes et al., 2018).

While it’s important not to conflate correlation, between ACEs and detrimental health outcomes, with causation, several theories backed by evidence have been proposed to explain the consistent relationship between ACEs and negative outcomes. Felitti et al. (1998) proposed that secondary behaviour of the child/young person, which they engage in to cope with the experience of adversity, is what leads to the poorer health outcomes. They explain that “behavioural coping mechanisms”, such as smoking, are commonly used to lessen the mental impact of ACEs, and it is possibly these coping mechanisms that lead on to later health problems (illustrated in Figure 1.1). However, for the purpose of the current thesis, we are interested in the first step on the pyramid below, namely the “social, emotional & cognitive impairments” that are proposed to occur directly after the ACEs. It is of interest to explore (i.) whether these alleged impairments following ACEs resemble ASD traits and, (ii.) the nature of potential relationships between ACEs and impairments in communication, sociability and flexibility.

*Figure 1.1*

Depicting ACEs and Later Health Outcomes from Felitti et al.(1998)

Death

Early

Death

Area of interest in relation to the current research

Disease, Disability and Social Problems

Adoption of Health-Risk Behaviours

Social, Emotional, & Cognitive Impairment

Birth

Adverse Childhood Experiences

Reprinted with permission from “Relationship of Childhood Abuse and Household Dysfunction to Many of the Leading Causes of Death in Adults: The Adverse Childhood Experiences (ACE) Study” by V.J.Felitti, R.F. Anda, D. Nordenberg, D.F. Williamson, A.M. Spitz, V. Edwards, M.P. Koss, J.S. Marks, First Initial. Second Initial. Author Surname, 1998, American Journal of Preventative Medicine, 14(4), p.256.

* 1. **Autism and Traits Resembling ASD: A brief history**

A German Psychiatrist, Eugen Bleuler, apparently first used the term autismin 1911(Evans, 2013). At the time, according to Evans (2013), autistic thinking referred to fantasies and hallucinations that we may more closely align with our understanding of schizophreni*a* today. This 1911 definition of autism, referring to the “inner life” of adults and children (and not any observable outward difference) prevailed until the 1950s. This concept started to change in the 1940s, with child psychiatrist Leo Kanner’s paper on *‘autistic disturbances of affective contact’* (Kanner, 1943) in which he proposed that the signs of autism typically present in the first few years of life. In the paper, he described several cases of young children with an excellent relation to objects but an apparent failure to relate to other people, and with a very literal use of language (Kanner, 1943). It was not until the 1960s, in the process of validating child psychology as a science, that autism became more widely established to mean something more aligned to how it is viewed today. Indeed, as explained by Evans (2013), ‘autism’ became to mean the exact opposite of what it originally had in the sense that autism was now related to a deficiency in imagination/flexibility rather an excess of fantasy, and to outward behaviours rather than an ‘inner life’.

Interestingly and significantly, Kanner (1943)’s definition of autism was accompanied with him explaining that, in his group of patients, very few of the children had ‘warm hearted mothers and fathers’ (Kanner, 1943) and, in a later paper, he described how autistic children had seemingly been reared in ‘emotional refrigerators’ (Kanner, 1949). It appeared that these descriptions contributed to the ensuing emergence of judgement and ‘parent blaming’ in the context of childhood autism. That is, there became widespread belief that parental attitudes and child rearing practices gave rise to the development of this “emotional disorder”. As Wing and Potter (2002) explain, autism was not regarded as having any neurological basis at the time. From the 1960s onwards, however, parents in the USA and UK became vocal and active, rebelling against the idea that they were refrigerator parents or in any way to blame for their children’s autism (Wing and Potter, 2002).

During the 1960s also came a surge in the development of scientific research into autism (Wing and Potter, 2002). The concept of autism continued to shift, reflected in the different editions of the American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders (DSM) and the World Health Organization’s International Classification of Diseases (ICD) (Wing and Potter, 2002). Stemming from the Wing and Gould (1979) paper, what became known as “the triad of impairments” related to ASD was established. Wing and Gould (1979)’s sample consisted of 132 children under the age of 15 years selected because of impaired or absent social interaction and language along with the presence of repetitive, stereotyped activities. Wing and Gould (1979)’s work established that ASD consisted of abnormalities across the social, language and behavioural domains. This triad of impairments (in sociability, communication and flexibility) is still commonly referred to when describing ASD in clinical practice today. For the past couple of decades, it is also the case that autism has been mainly regarded as a disorder of the developing brain, largely genetic in origin, and increasingly as part of a wider *spectrum* of disorders (Wing and Potter, 2002).

Indeed, DSM- 5 (2013), dropped the separate diagnoses of Asperger’s Disorder and Autistic Disorder and introduced the central diagnosis of ‘autism spectrum disorder’ (ASD). To meet the DSM-5 criteria for ASD, a child or adult, from an early developmental period (the exact age of onset is not specified unlike earlier versions of DSM which required the symptoms to be present before 36 months of age), requires the presence of three things which are (i.) impairments in social communication and social interaction across contexts, (ii.) restricted and repetitive patterns of behaviours, interests or activities, and (iii.) impairment in social or occupational functioning. **These criteria can be met with or without language impairment (which must be specified) and can be compatible to one of three possible levels of severity. Thus, the triad of impairments (Wing and Gould, 1979) remain relevant, though language impairment is no longer necessarily required, beyond the impairment in ‘social communication’. While this slightly adapted** DSM-5 criteria came into force in the US from 2013, UK and European clinicians tended to comply with the ICD-10 (1994) definition of autism which continued to require impairments (before the age of three) in all three areas of ‘the triad’. That is, according to ICD-10 (1994), impairments in:

(i.) receptive or expressive language as used in social communication (ii.) the development of selective social attachments or of reciprocal social interaction, and (iii.) functional or symbolic play (pp. 147 - 149)

 However, the recently published ICD-11 (presented in 2019 and which came into effect in 2022) changed this and is now more aligned with DSM-5’s definition of ‘Autism Spectrum Disorder’. That is, ICD has also now replaced ‘autistic disorder’ and ‘Asperger’s disorder’ with ‘Autism Spectrum Disorder’ and dropped the requirement for a specific language impairment for a diagnosis (outside the impairment needed in social communication). Though the need for language impairment is now weakened in terms of receiving an ASD diagnosis, for the purposes of this thesis, traits resembling ASD are defined as perceived deficits in three areas; communication, social relationships and repetitive behaviours. These areas will specifically map onto the three domains included in the Detection of Autism by Infant Sociability Interview (DAISI), a guided interview between a Psychologist and the Parents of a child who may have autism, (Wimpory et al., 2000; Wimpory, 2013; Wimpory, 2016), further described in Chapter 3. According to the DAISI (Wimpory, 2016), the three domains are; Sociability, Communication and Flexibility of Thought and Behaviour. While estimates of prevalence for ASD range from around 1% (World Health Organisation, 2023), to 1.5% (Derweerdt, 2011) and 2.8% (National Center on Birth Defects and Developmental Disabilities, 2023) of the population, around 30% of people are considered to have some ASD traits (Derweerdt, 2011).

* 1. **ASD Traits and Attachment disorders**

While there have been reservations that DSM and ICD definitions of attachment disorders may not be keeping up with the latest evidence from attachment research (Howe, 2003), it is these definitions that broadly seem to hold most weight across clinical practice and research. Both the DSM-5 and ICD-11 identify two subtypes of attachment disorders, namely Reactive Attachment Disorder (RAD) and Disinhibited Social Engagement Disorder (DSED). Both need to occur before the age of 5 years with symptoms persisting for 12 months or more for a child to meet criteria. Presenting difficulties should not be better explained by ASD, and indications of significantly deficient care or neglect need to present. For a diagnosis of RAD, a child must exhibit an emotionally withdrawn or inhibited response specifically directed towards adult caregivers. Conversely, meeting criteria for DSED involves the absence of inhibition in interacting with and a willingness to accompany unfamiliar adults (ICD 11 and DSM 5).

The risk that clinicians may conflate ASD with attachment disorders in assessing children presenting with ASD traits has been relatively well recognised in clinical practice. This emerging dilemma (i.e. on whether a child should be diagnosed with ASD, attachment disorder or, arguably, both) was well documented and corroborated by the clinical psychologist Helen Moran in her 2010 paper on “The Coventry Grid” (Moran, 2010). The Coventry Grid, a table distinguishing between similar traits associated with either autism or attachment disorders respectively, has since become widely recognised as a guiding framework for clinicians to use alongside standardised assessment tools in clinical practice. Moran (2010) explained that, according to diagnostic criteria (from DSM- IV at the time), autism and attachment disorders are defined by almost identical deficits in social skills and relationships. When children have had adverse early experiences, she argues, it is extremely challenging for the clinician to distinguish between these differential diagnoses, with the clinician left to decide whether the presenting child has autism, an attachment disorder, or both (Moran, 2010).

Further to Moran (2010)’s work, Flakhill et al. (2017) devised a tool based on The Coventry Grid that clinicians can use to interview parents during the ASD assessment process (Flakhill et al., 2017). Furthermore, Davidson, Moran and Minnis (2022) sensitively explored the potentially complex process of delineating autism, reactive attachment disorder and disinhibited social engagement disorder. The latter two disorders, they explain, are believed to be the result of abuse and neglect, whereas autism is not (Davidson, Moran and Minnis, 2022). The authors further describe a mainly unstructured observational method used by the Scottish Centre for Autism, referred to as Live assessment. This method was recently developed to support clinicians in applying The Coventry Grid to practice and involves engaging the children with humour and social dilemmas (Davidson, Moran and Minnis, 2022). Davidson, Moran and Minnis (2022)’s preliminary findings suggest that this seems to be a helpful way of operationalising the resolution of the dilemma addressed by the Coventry Grid. In practice, however, at least based on the author’s clinical experience, children are diagnosed with ASD more commonly than with attachment disorders. Nevertheless, this body of work appears to point towards a link between difficult early experiences and later presentations that may be closely aligned to ASD traits.

**1.5. Early deprivation and traits resembling ASD in childhood**

The degree to which early experience may contribute to presentations consistent with ASD became a sensitive topic, arguably fuelled by the reference to ‘refrigerator parents’ by Kanner (1949) and the rebellion against it in the 1960s along with the understandable desire to move away from what was regarded as ‘parent blaming’. As Hoffman and Rice (2012) explain:

it may be that the mother-blaming/refrigerator-mother conceptions of the 1940s and 1950s have turned the mental health community, as well as parents, away from psychodynamic considerations in the treatment of ASD to treatments other than dynamic ones(p. 67).

However, as Sousa (2011) highlights, mothers of children with intellectual disabilities, which may include children with ASD, are perceived in a more positive light these days. Indeed Sousa (2011) described the perception of mothers as “warrior-heroes” rather than cold and overbearing ones (Sousa, 2011), but also acknowledged that this does not ease the social and emotional burdens placed upon them (or any primary caregiver) in practice. As Wales’ NEST framework emphasises (2021), the adults in the child’s life need empowering and supporting. It remains important to move away from any hint of parent-blaming in relation to children presenting with ASD-traits, especially given this history. At the same time, this avoidance of blame should not preclude a truthful exploration of how early adverse experiences may have contributed towards the child’s current perceived impairments in the areas of language, sociability and/or imagination (at least in some cases).

* 1. **The case of Quasi-autism**

Seemingly in contrast to the resistance to considering early child rearing experience as implicated in a child’s later presentation of ASD traits, studies based on Romanian orphanage children have consistently demonstrated a link between early institutional neglect and autistic traits (Rutter et al., 2007). As well as patterns appearing like autism being reported in children exposed to early institutional deprivation, other non-genetic factors, including being congenitally blind, have also been found to be associated with traits resembling ASD according to Rutter at al., 2007. Rutter et al. (2007)’s findings would again suggest that the early environment may have a role to play in the development of autistic traits, questioning whether autism should be considered a disorder as strongly influenced by genetics. The current research aims to explore the association between early adversity and traits resembling ASD in childhood, the results of which may strengthen the argument that environmental factors are relevant when assessing children presenting with traits resembling ASD.

Rutter et al. (1999) systematically studied 165 Romanian orphanage children who came to England before 42 months of age and were adopted into UK families. Rutter et al. (1999) reported that 6% of the children displayed “autistic-like” patterns of behaviours, and a further 6% displayed milder versions of the same profile of behaviours, compared to 0% of children in the comparison group who had been diagnosed with autism in early life. The authors eventually refer to these autistic-like behaviours exhibited as ‘Quasi-autism’. However, Rutter et al., (2007), later reported that the prognosis of the children with quasi-autism at 4- or 6- years of age was different from other children diagnosed with autism. Children with quasi-autism, in contrast to other children with autism, seemingly regained some social and linguistic skills at a later age and did initiate some social contact with others albeit in an unusual way. Children with quasi-autism were regarded as having much in common with children who had disinhibited attachment styles (Rutter et al., 2007). At the same time, however, the children with quasi-autism never lost their autistic traits completely, and Rutter et al. (2007) refer to “..the boundaries of the quasi-autistic pattern” not being “categorically clear cut” (Rutter et al., 2007, p.1205).

In considering how this finding could be explained, Rutter et al. (1999) refer to the evidence that early sensory deprivation can impede normal brain development. They hypothesise that early social deprivation may impede “developmental programming for aspects of psychological functioning relevant to the genesis of autism” (Rutter et al., 1999, p.543). This remains only a theory at present and while researchers/theorists tend to continue to regard quasi-autism as something quite different to “true” autism, these findings echo the need for tools such as the ‘Coventry Grid’ to solve a common dilemma in clinical practice. However, while discerning features of autism from features of attachment disorder may be needed, clinically, it is important to note that the variables created to represent traits resembling ASD in the current research has much in common with recognised symptoms of attachment disorder.

What these differing accounts proposed by previous research seem to have in common is that early adversities are linked to traits resembling ASD, but not to ASD itself. Based on these previous findings, this precise question (of whether early adversities are linked to traits resembling ASD) will be further explored in the current thesis, with consideration to the relevant clinical implications.

* 1. **Focus of the current thesis and chapter outline**

The current research will involve secondary analysis from an existing database derived from the longitudinal Cardiff Child Development Study (CCDS) (Hay et al., 2021). Firstly, raw data will be entered and coded to create new variables. Secondly, associations between ACEs and traits resembling ASD at different points in childhood will be explored. This study was limited to the number of families that had completed the questionnaire and interview items of interest, thus creating a subsample (N = 282) of the total number of nationally representative families who participated in the CCDS (N = 332). The following five chapters of this thesis cover the following:

 *Chapter II:* A literature review exploring the links between ACEs and ASD traits is followed by a consideration of potential clinical implications and a clear rationale for the current research. Finally, research questions and aims are presented.

 *Chapter III:* In this general methods chapter, the Cardiff Child Development Study (CCDS)’s general methodology is briefly introduced, and the process of coding and entering new raw data set-up for this study is explained.

 *Chapter IV:* The two new variables created (namely both an ACE count and a way of capturing ‘Traits resembling ASD in childhood’) are presented and explored. The validity and reliability of the new variables are considered, along with a consideration of their suitability for use in future analyses.

 *Chapter V:* In this results chapter, statistical analyses are conducted to test for between-group differences in Traits Resembling ASD across the ACE count categories, and statistical responses are given to the research questions posed.

 *Chapter VI:* The findings are summarised and considered in the context of the wider literature. A discussion ensues consisting of possible interpretations of the current findings, highlighting the limitations of the work and proposing possible direction for future research. Finally, clinical implications are further considered along with reflections on the work and an overall conclusion.

**Chapter II. Background, Rationale and Research Questions**

**2.1. Autism, ASD, ASD Traits and Traits Resembling ASD**

As highlighted at the end of the last chapter, there is a distinction in the literature between children or adults diagnosed with autism/ASD, and people considered to have ASD traits. Indeed, though there is evidence that both concepts, ASD diagnoses and ASD traits, are correlated, they are considered distinct. One cannot assume that an individual with ASD traits would meet criteria for an ASD diagnosis (Bhaumik et al., 2010). The distinction between ‘autism’ and ‘ASD’ is mainly historical, as discussed. From the publication of DSM-5 in 2013 onwards, the terms ‘autism’ and ‘Asperger’s disorder’ were increasingly replaced by ‘autism spectrum disorder’ (ASD). To have a diagnosis of ASD, a child or young person needs to have been assessed by a trained clinician, and this process should include a detailed developmental history and an observational and interactional assessment of the child noting features consistent with DSM-5 or ICD-11 criteria in both cases (NICE guidelines, 2017). In contrast, ASD traits can be measured by a standardised questionnaire (e.g. the Social and Communication Questionnaire; Rutter et al., 2007) and can apply to the whole population, in that everyone can be given a score in relation to ASD traits. Indeed, this is evident from work by Baron-Cohen (2001) in developing the Autism Spectrum Quotient (AQ) (Baron-Cohen et al., 2001). In their research on Quasi-autism and early neglect, Rutter et al. (2007) refer to ‘autistic-like features’. For the purposes of the current research, the traits captured are across the triad of impairments associated with ASD (Wing and Gold, 1979). However, as the current research does not involve the use of standardised measures or questionnaires designed to capture ASD traits (this was not the original aim of the CCDS), it can only be claimed that the traits coded resemble impairments known to be associated with ASD. Hence, the term ‘traits resembling ASD’ is used in relation to the current research and the terms ‘ASD traits’ and ‘ASD diagnoses’ used at other times referring to previous research or findings.

**2.2. Literature Review**

A computer-based literature search of peer-reviewed journal articles, restricted to the ten years prior (March 2012 until March 2022), was conducted on PsycINFO. The search terms used were *(ASD OR autism OR autistic) AND (ACEs OR adversity OR maltreatment).* This initially yielded some 600 papers. Titles and subsequently abstracts were scanned and reviewed to shortlist the final set of eight papers that needed to include statistical analyses on the relationship between early childhood adversity and either ASD traits or ASD diagnoses. This literature search could have been improved and refined by a wider use of search engines, considering papers written in languages other than English and finally by conducting forward and backward searchers (by reviewing citations and reference lists respectively) of the final shortlisted papers. It is therefore acknowledged that it is likely that other relevant academic papers are published but not included.

**2.3. ACEs and traits resembling ASD**

Over the past decade, several papers have been published exploring the relationship between early adversity and ASD traits and/or ASD diagnoses. The papers presented in Table 2.1, all published during the last 7-8 years, highlight the mixed results when exploring associations between early adversity (which can include ACEs or a narrower focus on Childhood Maltreatment, CM) and later autistic traits or diagnoses of autism. Three of the eight papers did not find any significant association between ACEs and ASD (Schneider et al., 2019; Hoch &Youseff, 2019; Mayes et al., 2019) whereas the other five did (Rigles, 2017; Dinkler et al., 2017; Berg et al., 2016; Kerns et al., 2017; Roberts et al., 2015). Though the use of ACEs items from the National Survey of Children’s Health (NSCH) were used across 4 of the 8 studies, there were variability in the way ACEs and/or CM were measured across studies. Six of the studies relied on parents’ reports of ACEs (Schneider et al., 2019; Rigles, 2017; Hoch and Youseff, 2019; Dinkler et al., 2017; Berg et al., 2016; Kerns et al., 2017), with one study drawing from multiple sources (Mayes et al., 2019) and one relying on adult women’s self-reporting (Roberts et al., 2015). Similarly, ASD traits and/or diagnoses were assessed in detail, using a wide battery of assessments, in certain studies (e.g. Mayes et al., 2019), whereas only the presence of a historical diagnosis of autism was recorded in others (e.g. Schneider et al., 2019). Collectively, the results certainly present an ambiguity about whether a true relationship between ACEs and traits resembling ASD should be expected. However, the weight from the study results presented in Table 2.1 tends to be in favour of an association between ACEs and ASD traits more so than between ACEs and ASD diagnoses.

*Table 2.1*

Summary of papers reporting on the relationship between ACEs and ASD traits

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Authors****and country** | **Sample Size** | **ACEs Measure** | **ASD Measure** | **Result** |
| **Berg et al. (2016)** The U.S. | 61 652 | Parents rated the NSCH nine (YES/NO) questions used above. | Parent-report ASD diagnosis. In the NSCH, they were asked:1. “Has a doctor or health professional ever told you that your child has autism?”, and 2. “Does this child currently have the condition?” | POSITIVE ASSOCIATION Children with ASD were at higher risk of 4 or more ACEs compared with typically developing peers, *p*<0.010, controlling for all covariates. |
| **Dinkler et al. (2017)** Sweden | 8,192 | Parents rated the occurrence of abuse and/or neglect on The Life-Stressor Checklist- Revised. If CM occurred, follow-up questions were asked. If one or more types of CM were indicated, the child was coded as having experienced CM. | Parents’ responses to questions in a screening tool, the Autism–Tics, AD/HD, and other Comorbidities inventory (A-TAC), were used to assess NDDs. | POSITIVE ASSOCIATIONIn the CM group, 24.1% had at least one NDD, compared with 5.5% in the non-CM group (p < .0001, φ = .16; Table 1). |
| **Hoch & Youseff (2019)** Minnesota, the U.S. | 7, 695 | Parent-rated trauma experiences of child during an interview with the researcher. Researcher then records responses on the Electronic Medical Record, choosing between drop-down options (e.g. “Car accident”, “Domestic violence”, “Emotional abuse”, “Fire”) as well as a free text form.  | ASD diagnosis based on a psychologist’s assessment using a battery of standardised assessments (e.g. the Autism Diagnostic Observation Schedule), interviews and questionnaires with the child and their caregiver(s).  | LOW/NO ASSOCIATIONResponses to trauma experiences were dichotomized into a present/absent variable.In the diagnostic regression, those with ASD showed the lowest likelihood of trauma diagnosis as compared to children with other types of Mental Health and/or developmental diagnoses.  |
| **Kerns et al. (2017)** The U.S. | 95,677 | Parents’ responses to 8 of the 9 NSCH ACEs items were included. The authors chose to exclude a ninth ACE item regarding racial discrimination. Primary outcomes were having ≥2 ACEs and ≥4 ACEs.  | The parents were asked the two questions previously described from the NSCH. | POSITIVE ASSOCIATIONMean number of ACEs for children with vs. without ASD: 1.3 (1.6) & 1.0 (1.4), *p* < 0.01. Children with ASD were more likely to report ≥ 2 ACEs and ≥4 ACES |
| **Mayes et al. (2019)** The U.S. | 789 | Multiple perspectives were captured in relation to children’s history of maltreatment (neglect and/or abuse) documented by caretakers, child protective services caseworker reports, and extracted from medical records. | ASD diagnoses based on a psychologist’s assessment using DSM diagnostic criteria and based on a comprehensive psychological evaluation of the child’s profile. | NO ASSOCIATION‘Checklist for Autism Spectrum Disorder’ scores were similar for the children; with autism not maltreated (21.6), with autism who were neglected (21.5), and with autism who experienced neglect and/or physical/sexual abuse (21.1).  |
| **Rigles (2017)** The U.S. | 56, 746 | Parent responses to the NSCH outlined above. Nine adverse childhood experiences (ACEs) were examined individually and as a combined score.  | Parent-report ASD diagnosis from the NSCH questions, coded 0 = “child does not have autism,” and 1 = “child has autism.” | POSITIVE ASSOCIATIONlogistic regression analyses revealed that children with autism had higher odds of experiencing certain ACEs. |
| **Roberts et al. (2015)** The U.S. | 1,077 | Women self-reported by responding to 5 questions from the Physical and Emotional Abuse Subscale of the Childhood Trauma Questionnaire (Bernstein et al., 1994). Two further questions queried unwanted sexual touching and forced or coerced sexual contact and coded as sexual abuse. Finally, a single item from a 2008 PTSD and trauma assessment was included to indicate childhood abuse. | Self-reported current autistic traits in mothers were measured using the 65-item Social Responsiveness Scale (SRS). The possible range of the SRS is 0 to 195, with higher scores indicating more autistic traits. | POSITIVE ASSOCIATIONWomen in the highest vs. lowest quintile of autistic traits were more likely to have; been sexually abused in childhood, experienced the highest quintile of physical/emotional abuse in childhood, been mugged, been pressured into sexual contact, but not to have been sexually harassed at work. |
| **Schneider et al. (2019).** The U.S. | 2, 083 | From the National Survey of Children’s Health (NSCH)\*Parents responded to questions on ACEs (e.g. poverty, separation, parent/guardian spending time in jail, and whether the child was treated unfairly based on ethnic or racial group) | The parents were asked the two questions previously described from the NSCH. | NO ASSOCIATIONParents of youth diagnosed with ASD reported similar rates of total ACEs (no statistically significant differences) compared with parents of children with no ASD diagnosis. |

From the studies presented in Table 2.1, two studies employed a range of standardised ASD measures, interviews and questionnaires to thoroughly assess whether the child participants met criteria for ASD (Hoch and Youseff, 2019; Mayes et al., 2019) similarly to the process of giving ASD diagnoses to children clinically. Two studies focused on ASD traits (Roberts et al., 2015; Dinkler et al., 2017), though the screening questionnaire employed by Dinkler et al. (2017) also had valid clinical cut-offs for different NDDs including ASD. The remaining four studies all relied on asking the parents of the child participants two questions in relation to whether their child had ever received a diagnosis of ASD, and thus had no measure of ‘ASD traits’ (Schneider et al., 2019; Rigles, 2017; Berg et al., 2016; Kerns et al., 2017). The two studies that gave their child participants ASD diagnoses following thorough assessments did not report significant relationships between early ACEs/CM and ASD diagnoses. In contrast, the two studies that focused on ASD traits did find significant relationships.

**2.3. Correlation or Causation?**

Though we may expect, from previous findings in the literature (Roberts et al., 2015; Dinkler et al., 2017), to find an association between number of ACEs and number of ASD traits, the potential causation implicated, is less clear. This was touched upon in a review of the association between adverse experiences and autism by Dodds (2020):

More recently, it has been discovered that trauma and adverse childhood experiences (ACEs) are more likely to occur in children with ASD than in neurotypical peers (Berg et al., 2016), but little is known about the directionality of ACEs and ASD, connections between traumatic experiences and ASD and the magnitude of the impact of adversity or trauma on people with ASD and their families. (pp. 1093- 1094)

Dinkler et al. (2017) found a link between CM and NeuroDevelopmental Disorders (NDDs) including ASD. But, from their carefully designed large twin-study, they understood this association as being mainly due to common genetic factors. They did not find any evidence to support the hypothesis that CM increases NDD load (Dinkler et al., 2017). This finding thus represented an attempt in the literature to establish the directionality of the relationship reported.

Drawing from data collected for the Cardiff IVF study, allowing them to distinguish in unique detail the degree of biological relationship between a mother and her offspring, Harold et al. (2013) found that the relationship between a child’s ADHD symptoms and the mother’s child-rearing practices was bi-directional. Specifically, the child’s early ADHD traits were found to influence the genetically unrelated mothers’ hostility, which in turn was then predictive of the child’s later ADHD traits (Harold et al., 2013). Though the author is not aware of an equivalent study in relation to ASD traits, it seems pressing to further explore the direction of potential association between ACEs and traits resembling ASD. Specifically, it would be useful to identify if one outcome influences the other, or if there is a bi-directional relationship between the two.

**2.4. Clinical implications**

Screening for ACEs has been useful for research purposes, but there are concerns that it could do more harm than good in clinical practice on an individual family basis (Finkelhor, 2018; UK Trauma Council, 2021). There is currently insufficient evidence to support the routine screening of ACEs in clinical practice (Gentry and Paterson, 2021). Gentry and Paterson (2021) reported that while ACEs screening was acceptable to patients and moderately predicted which newborn babies were at risk of later entering care, there was no evidence that routine enquire of ACEs improved the health of patients or reduced mortality (Gentry and Paterson, 2021).

Furthermore, there are warnings that an over-reliance on a person’s ACE score could preclude a clinician’s holistic understanding of a patient (UK Trauma Council, 2021), and that findings from large epidemiological studies cannot be meaningfully used to make inferences about individual patients (Anda et al., 2020). With these cautions in mind, the findings outlined in Table 2.1 suggest that there would be some clinical merit in sensitively and non-judgementally asking children and families about ACEs when a child is referred in relation to ASD traits. However, an over-reliance on giving individual children ACEs scores could be counter-intuitive, with efforts more valuably placed in educating clinicians about ACEs. As summarised in a report by the Early Intervention Foundation (2020- 2021), clinicians with increased awareness of ACEs report a general change in their practice. A knowledge of how common ACEs are, for example, could result in a clinician appreciating that many children have had their safety undermined in childhood (NEST framework, 2021) and therefore have a need to establish safety in clinical work. Indeed, the Welsh NEST Framework (NEST Framework, May 2021) outlines the need for a whole-system approach to children’s wellbeing, which includes an acknowledgement of the complex range and interaction of factors combining to impact a child’s presenting needs. Rather than a within-child or diagnostic response, a whole-system approach would involve responding to a child’s need across disciplines and agencies, working together with services and organisations (NEST Framework, 2021). This approach seems particularly pertinent when planning a response to a child presenting to services with impairments in aspects of the triad related to ASD, especially if an association between traits resembling ASD and ACEs is established. NEST framework thus provides the clinician with a guide of how he/she/they may respond holistically and in collaboration with other agencies to a child presenting with suspected ASD traits. Prioritising holistic understanding of the patient, responding non-judgementally, establishing safety, sensitively asking about ACEs, and considering a whole-system approach would all seem beneficial in relation to children referred due to traits resembling ASD.

In terms of implications for certain clinical populations, the potential findings of this study seem particularly relevant for children with developmental disabilities (Mehtar and Mukaddess, 2010), looked after or adopted children (Green et al., 2016) and children who experienced CM at an early age (Dinkler et al., 2017). Given the reported deterioration in social-communication skills and increases in stereotypes in their study following trauma in children between 6 and 18 years old with developmental disabilities, Mehtar and Mukaddes (2010) propose that clinicians should be aware of this potential link (with trauma) in children with ASD. Specifically, Mehtar and Mukaddess (2010) advise clinicians to consider trauma histories in children with developmental disabilities at periods which might otherwise be misunderstood as an exacerbation of symptoms of ASD (Mehtar and Mukaddes, 2010).

A study of British adopted children, with a history of abuse or neglect, found ASD rates for this group to be 10 times that of the general population (Green et al., 2016).It is therefore crucial to communicate these risks, clinically, when working with adoptive parents. Findings from the Green et al. (2016) study strengthens the rationale for providing intensive services and support to children and young people who have experienced acute neglect in their early development. For example, focused educational planning, by monitoring for changes in educational support needs, would be a helpful intervention for children who have experienced high rates of abuse or neglect (Green et al., 2016). At the same time, Dinkler et al. (2017) argued that children who were maltreated at an early age should always be investigated for NDDs, and Mayes et al. (2019) similarly had concerns that maltreated children miss out on diagnoses of autism (e.g. Mayes et al., 2019). Findings from Dinkler et al.’s (2017) study with twins supported their stance that having difficult early experiences should not be a barrier for children to access ND assessments or to being given a diagnosis when they meet criteria.

**2.5. The need to further explore the links between ACEs and Traits Resembling ASD**

As discussed, the likelihood of a relationship between ACE exposure and a diagnosis of autism seems mixed from previous findings. A relationship between ASD traits and ACE exposure appears clearer, however, though there remain unanswered questions. For example, are certain aspects of ASD traits more related to early adversity than others? Interestingly, the number of published papers exploring the links between ACE count and ASD traits, or diagnoses, appears to have surged in the past decade. It seems that there is a need to further establish the nature of this potential relationship. As discussed, confirming an association between ACE count and traits resembling ASD would have important clinical implications, including supporting arguments for a system-wide understanding of the potential early adversities children presenting with ASD traits may have experienced. At the same time, as discussed, it seems a clinical imperative to ensure that children exposed to multiple ACEs are given the same access to NDD assessments as other children.

The previous studies exploring the relationship between ACEs and ASD, as summarised in Table 2.1, largely focused on the presence of an autism diagnosis (e.g. Schneider et al., 2019), either past or present. In contrast, the main question, as discussed, focuses on whether traits resembling ASD (which may or may not reach threshold for diagnosis) are associated with early adversity. It is believed that exploring sub-threshold ASD traits has several advantages. Firstly, studies focusing on diagnosis of autism (Schneider et al., 2019) may have missed out on capturing degree of autistic traits, or traits resembling ASD. Children with a high number of ASD traits may not have been given a diagnosis for several reasons, such as long waiting lists and including (potentially) the presence of a traumatic or difficult early life. Indeed, childhood maltreatment is named as one of a number of ‘differential diagnoses’ that should be considered when assessing for ASD according to NICE guidelines (2017). It seems important therefore to capture the degree of autistic traits present, regardless of whether a diagnosis of autism has occurred. Secondly, this might tell us something about the relationship between ACEs and traits resembling ASD in the general community population rather than clinical samples. Thirdly, and more specifically, by exploring the triad of impairments, the relationship between ACEs and certain aspects of traits resembling ASD (i.e., communication, sociability, flexibility) can be further explored.

 Many studies on ACEs are retrospective in that they ask adults to recall childhood events, but the current work benefits from longitudinal data and a prospective record of ACEs collated as the child develops. It further builds on studies that relied on a parent-rating of their child’s ACEs (Schneider et al., 2019; Rigles,2017) by drawing from multi-informant perspectives in recording the presence of stressful events that inform the proxy ACE variable created. The CCDS was designed to have three-informants on each/most questionnaire items across the different waves of data collection (they were; the main caregiver- usually mother, a second parent- usually father, and a third person that knows the child well). Though we could not fully capitalise on this advantage for the purposes of the current research (see: discussion in sections 3.4.3. and 6.3), most proxy ACEs items used in this study are based on two informants, and the presence of traits resembling ASD is recorded from the teacher, parent and an observer perspective at the different waves. As far as is possible, the proxy measures for ACEs created for the current research will aim to resemble the types of ACEs originally defined by Felitti, Anda and colleagues (1998) and aligned to the Welsh Survey on ACEs (Hughes et al., 2018) for comparison purposes.

**2.6. Research Questions and Aims**

The main aim of the current research is firstly to create two variables of interest: a proxy measure of ACEs and a measure of traits resembling ASD, neither of which were intended to be captured directly when the CCDS was designed. Secondly, the research aims to explore the nature of the relationship between ACEs and traits resembling ASD when controlling for other relevant variables (such as SES). The research questions to be answered are:

1. Can an ACE count variable be created from CCDS data? If so, what was the prevalence of exposure to ACEs in the sample?
2. Can a valid and reliable method of capturing traits resembling ASD be achieved from CCDS data?
3. Is there a significant association between ACEs and traits resembling ASD? What is the influence of other confounders, such as SES, on this association?
4. Is this association different at different developmental stages?
5. Are certain aspects of traits resembling ASD (i.e. certain aspects of the triad) more closely related to ACEs?

To answer these questions, there is a need for a process of obtaining secure and ethical access to the data and setting up systems to code and enter raw data. There is also a need to create a new SPSS dataset and to create the variables needed, if possible, before testing their validity and reliability. Finally, there is a need to conduct suitable statistical analyses to answer research questions 3- 5. The methods and analyses used are discussed and presented in the chapters to follow.

**Chapter III. General Methodology**

**3.1. Design**

This research performs secondary analysis on a subsample of a pre-existing 6- wave longitudinal dataset generated through the Cardiff Child Development Study (CCDS). The focus of the CCDS was to explore the course of aggression over the first four years of life (see: Hay et al., 2021) and to identify early risk factors for later aggression (Waves 1 – 5). The study was extended to include the first 7 years of life with the creation of ‘Wave 6’, providing substantial data of interest for the current research. Figure 3.1 illustrates all the data collection waves included in the CCDS.

*Figure 3.1*

The Data Collection Waves of the Cardiff Child Development Study (CCDS)

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

Figure adapted from “Prosocial and Aggressive Behavior: A Longitudinal Study” by D.F.Hay, A.L. Paine, O. Perra, K.V. Cook, S. Hashmi, C. Robinson, V. Kairis, Rh. Slade, 2021, Monographs of the Society for Research in Child Development, 86 (2), p.22. Open access article, with permission to adapt.

**3.2. The author’s role in the CCDS**

The author previously worked as a full-time research assistant on the CCDS from February 2005 until October 2008. During this time, her duties included recruiting primiparous mothers and partners, often following their initial 12-week scan, and with the support of the midwifery team. The author was further involved in the development and design of some measures, and in collecting data through interview, questionnaire and child assessment processes across the earlier waves, pre-dominantly Waves 1, 2 and 3. This included managing her own caseload of families, arranging home visits and setting-up laboratory data collection. Laboratory sessions involved welcoming groups of three infants/toddlers and parents/carers into the School of Psychology at Cardiff and managing the assessment processes. The author also worked on her own independent research during this time, under the supervision of Professor Dale Hay, in relation to the early development of Mind Understanding (Roberts, 2010).

**3.3. CCDS Participants**

332 families were initially recruited to the CCDS between 1st November 2005 and the 31st July 2007. The pregnant women and their partners were either approached for participation by a research assistant at antenatal clinics across Cardiff & Vale and Gwent NHS Trusts or via their midwife working in a specialist team supporting pregnant women and girls at high social risk. Women and partners were asked if they would be happy to be called back by the project administrator to arrange a time for a first visit. Families were compensated for their time and received; (i.) £20 in gift vouchers per visit for their voluntary participation, (ii.) a DVD with highlights from their babies’ first three years and (iii.) birthday presents for the infants and toddlers at Waves 3 and 5. Further details on recruitment and related processes can be found in a number of publications stemming from the CCDS (e.g. Hay et al., 2021).

**3.4. Procedure**

Hypotheses were tested using longitudinal secondary data from the CCDS.

***3.4.1. Ethical Considerations***

All procedures involved with the CCDS had been formerly approved by the Cardiff University School of Psychology Research Ethics Committee and the U.K. National Health Service (NHS) MultiCentre Research Ethics Committee (MREC). Although the research is based on existing longitudinal data pre-approved by ethics committees, re-visiting this data, from Bangor University and running secondary analyses for new hypotheses created new ethical implications. An ethical consideration to be made was whether participating families had consented for their data to be used in future research (it being 17 years since the first families were recruited). Furthermore, how families might feel if new research outputs from Bangor University were published based on the data they originally provided to Cardiff University. Having worked as a research assistant on the CCDS for almost 4 years, the author’s knowledge and experience of the data, participating families and colleagues familiar with the work eased the process of considering the ethical permissions needed. The author was thus aware of the ethical permissions previously granted and had experience of dealing responsibly and sensitively with the dataset.

The current research, including access to the longitudinal dataset, was approved by Bangor University’s School of Psychology’s Ethics and Research committee on the 27th of August 2021 (Reference: 2021-16929-A14774) and by Cardiff University’s ethics committee (registered on their database, under the following reference number: EC.21.08.10.6388). With time, this enabled the author, an MRes student registered at Bangor University, to; set-up a Cardiff University account as a visiting researcher, remotely and securely access the shared drive where electronic data is saved and have physical access to the laboratory space at the School of Psychology, Cardiff where the raw data is stored.

***3.4.2. Arriving at variables relevant to ACEs and traits resembling ASD***

The CCDS was neither originally designed to capture ASD traits nor ACEs. However, the wealth of data collected across the waves of the study (See: Figure 3.1) offers the opportunity to create two sets of relevant variables that would enable the exploration of associations between them. Deciding on exact data points was a time-consuming process involving searching through each measure at every wave (accessed through the shared drive), and liaising with the CCDS’s P.I. Professor Emerita Dale Hay, Dr Cerith Waters and Dr Amy Paine, clarifying any other relevant data points that could be considered. Due to time constraints, there was only a limited amount of coding raw data that the author could undertake for the MRes, and it was thus decided that, apart from the newly processed Wave 6 interview data, only entered and available data would be included. Deciding on relevant data to be included was done in collaboration with the author’s supervisory team (Dr Dawn Wimpory and Dr Kat Ford).

***3.4.3. Coding and entering raw data***

Despite restrictions related to the Covid-19 pandemic impeding the work, the author visited the lab at Cardiff University on three separate occasions to meet with collaborators, and including 2-3 days’ work consisting of; organising office space, labelling and organising raw data, setting up systems and making a start at directly entering data. Significant parts of the relevant data (including Part 2 of the Wave 6 parent interviews) had not already been coded nor entered, and therefore meeting with Dr. Cerith Waters and Dr. Amy Paine, with Professor Dale Hay’s knowledge and approval, established a process by which to complete this in the timeframe given, and with respect to the Covid-19 restrictions operating at the time.

After physically setting up the office/lab space, writing a guide (see: Appendix 1), and organising cabinets, the author met with two Cardiff University students; one undergraduate student on a paid placement, Bethany Ireland, (under the supervision of Dr Cerith Waters); and one postgrad Masters student, Rhys Davies (under the supervision of Dr Amy Paine). The author then formed a working pattern where a series of (up to) 3-hour long sessions were arranged to process and enter the remaining raw data (for Part 2 of the Wave 6 parental interviews) into an SPSS file. This work was conducted virtually and in pairs (that is, the student would be physically in the office reading the participant’s response to questions, while the author entered the relevant codes on the SPSS document – displayed throughout the session on a shared screen). The author and student decided on a code together, and any uncertainty about ways of coding participants’ responses would be resolved through discussion. A summary of the main considerations is included in Appendix 2. Once Bethany’s and Rhys’s placements ended, a third student (Masters’s student, Emma Chubb, supervised by Dr Amy Paine) completed the data entry process with the author, and the same established process was adopted. The author was thus present and actively involved in every data coding/entering session. These sessions enabled the completion of data coding and entry for all available raw data from “Wave 6 parental interviews- Part 2”, not only the variables of interest for the purposes of the current research.

Aspects of the variables for use in the current research drew from data (e.g. Parental Questionnaires) previously entered and coded by academics working on the CCDS in SPSS documents. However, these often required further refinement in terms of, for example, labelling the individual SPSS variables coded. This work was done solely by the author, before merging the previously entered variables onto the author’s main MRes SPSS dataset file.

***3.4.4. Missing data***

It was ensured that each family included had data entered on the specific questionnaire and interview measures informing the newly created variables. This inevitably lessened the sample size, giving a maximum subsample of N = 282. The size of the subsample decreased for certain ACEs items which had missing values or were “not applicable” (see: Table 5.1 for a breakdown of differing sample sizes). The limitation of this approach is discussed in Chapter VI.

**Chapter IV**

**Creating Measures**

**4.1. Creating an Adverse Childhood Experiences (ACEs) variable**

Whilst the CCDS was not originally designed to collect information on exposure to ACEs, the data set includes measures for a number of data items which could be used as proxy measures for exposure to a number of ACE types. These are outlined in Table 4.1 below and included certain items in questionnaires relating to; parental mental health; use of drugs or alcohol; incarceration; separation; and beliefs about physical punishment at home, and others from parental interviews including relationship status, ways of disciplining your child and inter-parental arguments and/or violence. During the Wave 6 interviews with parents, interviewers routinely asked if the family received any involvement from health and social care services. If the answer was yes, then the interviewer would ask “why?” or “what for?”. Hence, there was a record of any families referred to social services, with associated reasons if known. The codes entered from these records were examined by the author, following a method similar to that used in other research studies to identify (as a proxy) ACE prevalence (see: Grey et al., 2019) and included in the final MRes data-set. It is understood, however, that the prevalence of types of abuse recorded in this way is likely to be an underestimation of the true prevalence occurring as it only included families referrals to social services with parents’ self-reporting the reason for that. The information gathered in this way was used to generate an individual’s ACE score, which, in line with international literature (e.g., Bellis et al., 2015), was then used to generate a proxy ACE count variable based on the ACEs defined by Bellis et al. (2015); Verbal Abuse, Physical Abuse, Sexual Abuse, Parental Separation, Domestic Violence, Mental illness, Alcohol Abuse, Drug Use, and Incarceration. The exact way in which these variables were pulled from the data is presented in Table 4.1, below:

*Table 4.1*

Formation of the ACEs count from CCDS raw data: Defining Individual ACEs

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

|  |  |  |  |
| --- | --- | --- | --- |
| **ACE** | **Source** | **Question** | **Qualifying Response** |
| **Parental Separation** | Wave6 ParentalInterview | Has there been a change in your relationship since we last talked to you, when *X* was 6 months old? IF YES: How has it changed? Has there been more than one change in your relationship since *X* was 6 months old?  | Parental separation was scored as present if the relationship status had changed since last time, and if one of the following responses were given:* Married, not to child’s other parent
* Cohabiting with new partner, not other parent
* In a relationship with a new partner, but not living together
* Living alone, (Single, widowed, divorced or separated)
* (Partner living elsewhere)
 |
| **Emotional Abuse** | Wave6 ParentalInterview | What do you do to discipline your child? Tell me about the last time. Was that fairly typical of what happens? Do you have to punish him/her often? Do you send X to their room or a cupboard? Do you lock the door? Have you told X that s/he is a bad girl/boy? Or told X that s/he is no good? Or stupid? Do you ever swear or curse at him/her? *If so, how often?* Has X ever made you so mad that you said you wished s/he had never been born? How often did this happen? Some children are easier to get along with than others. Which child in the family do you find it most difficult to get along with? | Emotional Abuse was scored as present when ***at least one*** of the following criteria were met in response to interview questions:* Parent HAS disciplined the child by locking him/her in a room, basement or cupboard
* Verbally dispraising (e.g. You are bad) statements by parent is characteristic
* Parent has verbally rejected child, by saying to them that that s/he wished child had never been born
* Target child is considered as being markedly ‘more difficult’ than siblings and subjected to different rules
 |
| **Physical Abuse** | Wave6 ParentalInterview | What do you do to discipline your child? Tell me about the last time you had to punish him/her. Was that fairly typical of what happens? Do you have to punish him/her often? Have you ever had to use spanking? If yes, did spanking occur with parent’s hand or with an instrument, and also whether any marks or bruises were left.  | Physical abuse was coded as present when ***both*** the following criteria was coded as present:* Spanking with hand OR spanking with an implement
* This did leave marks and/or bruises

In a small number of cases, Physical Abuse was alternatively coded as present due to this being noted elsewhere as ‘reasons for involvement of social services’ |
| **Domestic Violence** | Wave6 ParentalInterview | Have either one of you EVER hit the other one? When did this last happen? How often has this happened? Was anyone hurt? | Domestic violence was coded as present when:* Inter-parental physical aggression was present meaning that at least one incident of physical violence occurred
 |
| **Neglect** | Wave 6 interview | Interviewers routinely asked, “Do you receive any involvement from health and social care services?” If the parents responded “Yes”, the interviewer asked, “What for?”  | Noted as ‘Neglect’ under ‘reasons for involvement of social services’ |
| **Sexual Abuse** | Wave 6 interview | Interviewers routinely asked, “Do you receive any involvement from health and social care services?” If the parents responded “Yes”, the interviewer asked, “What for?” | Noted as ‘sexual abuse’ under ‘reasons for involvement of social services’ |
| **Mental Illness** | Both Mother and Father Questionnaires, Wave 6, Part 2 | “I’ve never threatened suicide or injured myself on purpose” (Not TRUE/ Somewhat TRUE/ Certainly TRUE) | Mental Health difficulties was coded as present when ***either*** parent responded to the Questionnaire item as follows:* Not True
 |
| **Alcohol Abuse**  | Both Mother and Father Questionnaires, Wave 6, Part 2 | How often do you drink alcohol? (Monthly or less, 2 to 4 times a month, 2 to 4 times a week, 4 or more times a week). How many units do you drink per week?  | Alcohol Abuse was coded as present if ***either*** parent met ***both*** criteria below from their self-reporting:* I drink 4 or more times a week
* I drink 14 units or more a week

In a small number of cases, ‘Alcohol Abuse’ was also coded as present when the parent had been arrested for drinking and driving. |
| **Drug Abuse**  | Both Mother and Father Questionnaires, Wave 6, Part 2 | Do you or have you used any of the following in the last year? CannabisEcstasyCocaineSpeedHeroinMorphineOther | Continued/prolonged use of any recreational drugORUse of Class A drug at least once |
| **Parental Incarceration** | Mother Wave 6 Questionnaire (Part 2)Father Wave 6 Questionnaire (Part 2) | Since the baby was born, have you or your partner ever been arrested? What was the arrest for? Were charges brought? Were either mother or father charged? Result of the Prosecution | Any time spent in prison by either parent (INC SUSPENDED SENTENCE/COMMUNITY SERVICE) |

**4.2. Creating an ‘ASD traits’ variable**

Items corresponding to traits resembling ASD (compatible with the triad of impairments, i.e. concerns about communication, sociability and flexibility) were identified from three data collection waves; Wave 3 (12 months), Wave 4 (21 months) and Wave 6 (84 months). These will be described separately.

 At Wave 3 (11- 15 months), the infant would visit the Social Development Laboratory with a parent/carer and attend a simulated ‘birthday party’. Following a short one-to-one recorded session with a research assistant, the parent-infant dyad would join two other pairs in a comfortable lounge which included sofas, and age-appropriate toys. Parents/carers were asked to interact as they would normally in a birthday party scenario. As this was somewhat more complex to bring together, for the purposes of the current research, the Wave 3 measures used are described in more detail in Table 4.2 below.

*Table 4.2*

Wave 3 lab items used to inform traits resembling ASD across the triad \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

|  |  |  |  |
| --- | --- | --- | --- |
| **Communication**  | **Sociability**  | **Flexibility**  | **Traits resembling ASD at W3** |
| Pointing is scored from observation of 12-month olds’ response to the Joint Attention (JA) task from the Early Social Communication Scales (ESCS) (Seibert, Hogan and Mundy, 1982, 1984, as cited by Roberts, 2010).Turn-taking is scored based on two individual tasks initiated by the researcher during the 12-month lab visit. One involved the sharing of rings with the infant and requesting them back, and the other involved rolling a ball to the infant and inviting the infant to roll the ball back to the experimenter.For the purposes of the current research, *impairment* was coded as follows:* Infant did NOT point during JA task
* Infant did NOT engage in any turn-taking across tasks
 | From observation of 12-month olds’ response to the Joint Attention (JA) task from the Early Social Communication Scales (ESCS) (Seibert, Hogan and Mundy, 1982, 1984, as cited by Roberts, 2010), *impairment* was coded as follows* Infant did NOT follow gaze during JA task
* Infant did NOT social reference (i.e. alternate gaze between person and object) during JA task
 | An in-depth study of the 12-month olds’ rocking and flapping behaviour was conducted by Fyfield (2014) and reported in her PhD thesis. Fyfield (2014) devised the Repetitive Behaviour Coding Scheme (RBCS). For the purpose of the current study, the author calculated the mean number of rocking and flapping observed and created the following dichotomous variables:* Infant flapped more often than the mean value
* Infant rocked more often than the mean value
 | The items across the three domains at 12-months (Wave 3) were summed together giving a total score of between 0 and 6 |

The Wave 4 items were derived from questionnaires completed by the main caregiver, and the Wave 6 items from questionnaires consisting of the child’s teacher’s responses to a questionnaire (as outlined in Table 4.4). Further to these items of interest, during the Wave 6 interview (age 7), parents/carers were asked whether their child has any developmental difficulties, which could include ASD traits (see: Table 4.3). The parents/carers were also asked whether they’ve seen a specialist about their concerns, and whether a diagnosis was given.

To ensure maximum precision in terms of the exact traits resembling ASD that should be mapped onto the triad of impairments, The Detection of Autism by Infant Sociability Interview (DAISI), an instrument developed by the author’s main supervisor (Dr. Dawn Wimpory), was consulted. The DAISI is a semi structured guided interview for use by experienced clinical psychologists for research and clinical purposes (Wimpory, 2016). It is designed to ease rapport and interaction between the psychologist and the parents of children who may have autism or related difficulties, with a specific focus on the first two years of life (Wimpory et al., 2000). Importantly, research in relation to the DAISI has highlighted the certain elements of communication, sociability and flexibility that are most closely associated with ASD (Wimpory et al., 2000), and thus certain traits resembling ASD should be considered to have more weighting. The DAISI focuses on elements of social engagement seen in typically developing infants which, as Wimpory et al. (2000) explain, may then “be specially revealing for what is abnormal in the case of autism” (Wimpory et al., 2000, p. 527). The main sections of the DAISI, “Early Development” and then “Current Development,” are each organised into three domains: Sociability, Communication and Flexibility of Thought & Behaviour (Wimpory et al., 2000). Consistent with the definition of the triad associated with ASD (Wing & Gould, 1979), it is these three domains that will form the basis of the framework for collating relevant data from the CCDS. Table 4.4 summarises how this was done, highlighting the questions asked to CCDS families that correspond to individual DAISI items and under what domain. The DAISI items which correspond to elements most closely associated with ASD are highlighted with an Asterix.

*Table 4.3*

General identification of ASD traits by the family and referral to services \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

|  |  |  |
| --- | --- | --- |
| **Source** | **Question** | **Qualifying response** |
| Wave 6 parent interview | Does X have any developmental difficulties such as dyslexia, dyspraxia, ADHD, developmental delay etc. ?(*There is a code for ASD*) Has X seen any specialists about these problems? | Yes, difficulties synonymous with ASD(with or without specialist) |

The precise way in which the variables capturing impaired communication, socialisation and flexibility was created from CCDS raw data is depicted in table 4.4. below:

*Table 4.4*

Measures created to capture traits resembling ASD across three waves of the CCDS

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

|  |  |  |  |
| --- | --- | --- | --- |
| **Corresponding DAISI items** | **TRAITS RESEMBLING ASD AT 12 MONTHS (WAVE 3)****Observational data** | **TRAITS RESEMBLING ASD AT 21 MONTHS (WAVE 4)****Questionnaire data** | **TRAITS RESEMBLING ASD AT 84 MONTHS (WAVE 6)****Questionnaire data** |
| **POSSIBLE IMPAIRED COMMUNCIATION**Gestures, e.g. Requesting picking up\*\*\* & Waving\* Pointing to request & show (Comprehension\*\*\*\* & Expression\*\*\*\*) Turn-taking with noises\*\*\* Vocalisations used communicatively\*\*\*\* Words used communicatively & with reciprocity | The sum of these two observational data items coded during the individual lab tasks:* Does NOT point (during JA task)
* Does NOT engage in ANY turn-taking across trials
 | The sum of four items (negatively skewed, where necessary, for the purposes of the current research) from the Questionnaire completed by the Primary Caregiver:* Does NOT say more than 10 words
* Does NOT use words to make wants known
* Does NOT point to ask
* Does NOT point to share interest
 | The sum of two items (negatively skewed, where necessary, for the purposes of the current research) from the Questionnaire completed by the child’s teacher:* Speech problems
* Unusually loud
 |
| **POSSIBLE****IMPAIRED SOCIABILITY**Active in Lap Games\*/ Turn-taking Eye Contact\*\*\*\* (including referential\*\*\*\*) Engagement socially, without toys\* Facial Expressions Greeting\*\* Imitation Offering & Giving\*\*\* Shared Experience Showing\*\* Sociability during play with toys\*\* Soothability from Crying Teasing | The sum of these two observational data items coded during the individual lab tasks:* Does NOT follow gaze
* Does NOT social reference
 | The sum of four items (negatively skewed, where necessary, for the purposes of the current research) from the Questionnaire completed by the Primary Caregiver:* Does not show objects
* Does not get upset when others are upset
* Does not offer toys to children
* Does not try to copy other people
 | The sum of two items (negatively skewed, where necessary, for the purposes of the current research) from the Questionnaire completed by the child’s teacher:* Avoids looking others in the eye
* Doesn’t get along with other children
 |
| **POSSIBLE****IMPAIRED FLEXIBILITY**Activity/ Favourite Toys Mannerisms Preoccupations/ Obsessions/ Routines Pretend Play Sensory avoidance/seeking | **The sum of these two observational data items coded using** The Repetitive Behaviour Coding Scheme (RBCS), (Fyfield, 2014):* Rocking is coded at above the mean
* Flapping is coded at above the mean
 | The sum of four items (negatively skewed, where necessary, for the purposes of the current research) from the Questionnaire completed by the Primary Caregiver:* Does NOT pretend
* Is restless/overactive/cannot sit still
* Constantly fidgeting or squirming
* Bites you or other people
 | The sum of two items (negatively skewed for the purposes of the current research) from the Questionnaire completed by the child’s teacher:* Disturbed by any change to routine
* Repeatedly rocks head or body
 |
| **TRAITS RESEMBLING ASD** | **Computed sum of “impaired communication”, “impaired sociability” and “impaired flexibility” from W3 variables.****Range (0 – 6)** | **Computed sum of “impaired communication”, “impaired sociability” and “impaired flexibility” from W4 variables.****Range (0 – 12)** | **Computed sum of “impaired communication”, “impaired sociability” and “impaired flexibility” from W3 variables.****Range (0- 6)** |

**Chapter V. ACEs and Traits resembling ASD in early and middle childhood: between-group differences, and associations**

**5.1. The prevalence of exposure to ACEs in the CCDS sample**

It was possible to create a proxy ACE count from the raw and entered data available through the CCDS. Only data points available at Wave 6 counted towards this ACEs variable, giving a total N of 282 (Male 56.4%; female 43.6%). The ACE count variable revealed that 39.7% of the subsample were coded as having zero ACEs, 37.6% as having one ACE and 22.7% as having two or more ACEs. To help verify how comparable these results were with other research on ACEs, prevalence figures were compared with results from a survey, N = 2,497, completed in Wales (Hughes et al., 2018). This comparison revealed a higher percentage of participants were found to have at least one ACE in the current study (60.3% compared to 49.9% reported by Hughes et al., 2018), and a lower percentage in the category of two or more (22.7% in the current study compared to 30.6% reported by Hughes et al., 2018). These comparisons are illustrated in Figure 5.1 below.

*Figure 5.1*

Comparing the current ACE count to the prevalence reported by Hughes et al.(2018)

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**5.2. Breakdown of ACEs by type**

In terms of different types of ACEs reported, the most common was for parental mental illness (39.7%), and the second most common was for the child to lose contact with a parent through death or separation (28.6%). The frequency of occurrence of all the ACEs types are reported in *Table 5.1.*

*Figure 5.2*

Percentage of children in the CCDS that had a parent who said at interview that they smack their children *and* left marks or bruises

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_



The breakdown of number and percentage of families reporting the separate ACEs are presented fully in the table below:

*Table 5.1*

Percentage of ACEs reported in CCDS sample, by category \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

|  |  |  |  |
| --- | --- | --- | --- |
| **ACE**  | **Number of positive cases** | **Sample size** | **Percentage from subsample reporting ACE %** |
| **Parental Separation** | **61** | **213** | **28.6%** |
| **Emotional Abuse** | **14** | **179** | **7.8%** |
| **Physical Abuse** | **10** | **213** | **4.7%** |
| **Domestic Violence** | **20** | **159** | **12.6%** |
| **Neglect** | **1** | **160** | **0.6%** |
| **Sexual Abuse** | **2** | **160** | **1.3%** |
| **Mental Illness** | **98** | **247** | **39.7%** |
| **Alcohol Abuse**  | **25** | **219** | **11.4%** |
| **Drug Abuse**  | **33** | **245** | **13.5%** |
| **Parental Incarceration** | **6** | **239** | **2.5%** |

Precise differences between the current findings and previous research in Wales (Hughes et al., 2018) are further discussed in Chapter VI.

**5.3. Reliability and Validity of traits resembling ASD variable**

Internal consistency of each “Traits resembling ASD” variable (i.e., at each of the three waves) was measured using Cronbach’s Alpha. The results are presented in the table below:

*Table 5.2*

Testing Internal Consistency between the individual items making up each composite “Traits Resembling ASD” variable across the different waves

|  |  |
| --- | --- |
|  | **Cronbach’s Alpha** |
| **Wave 3***6 individual items* | 0.17 |
| **Wave 4***12 individual items* | 0.20\* |
| **Wave 6***6 individual items* | 0.85 |

\* Would be 0.40 if the “Pretend” item was deleted.

The above analyses suggest that the items informing the Wave 6 Traits resembling ASD variable had high internal consistency, α = 0.85, whereas the equivalent items for the other waves were low (Wave 3) and (at best) ‘moderate’ (Wave 4). Internal consistency is a common measure of reliability (Laerd Statistics, 2013).

***5.3.1. Concurrent validity: Are impairments computed at each wave significantly related to the children later referred for ASD concerns?***

Within the current sub-sample of data, 8 out of the 282 (2.8%) parents asked at Wave 6 reported that their 7-year-old child had been referred for an ASD assessment. Although caution is required in the interpretation of these results, a number of Traits Resembling ASD, particularly those from Waves 3 and 6, were significantly associated with whether or not the child was referred for ASD, as displayed in the table (Spearman’s Rho) below, giving some reassurance of concurrent validity:

*Table 5.3*

Spearman’s Correlation Coefficient analyses testing the associations between children referred for an ASD assessment and the “Traits resembling ASD” captured

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

|  |  |  |  |
| --- | --- | --- | --- |
|  | **Sum of Impaired Communication, Impaired Sociability and Impaired Flexibility at W3** | **Sum of Impaired Communication, Impaired Sociability and Impaired Flexibility at W4** | **Sum of Impaired Communication, Impaired Sociability and Impaired Flexibility at W6** |
| **Was child referred for an ASD assessment, to our knowledge?** | r(282) = .254, p = .063.  | r(235) = .138, p = 0.389. | r(249) = .395\*\*, p = 0.004. |

***5.3.2. Ecological Validity***

In discussion with her first supervisor (Consultant Clinical Psychologist), the author (a Senior Clinical Psychologist) concluded that all ‘Traits resembling ASD’ items were considered to have good ecological validity. This appears to be especially the case for ‘Wave 6’ items which are based on teachers’ report informing an important part of ASD referrals in practice. Indeed, were a teacher to describe a child along the lines of the items included (e.g. problems with eye contact, unusually loud speech, and so on..), it is very likely, from our collective clinical experience, that this referral would be accepted for an ASD assessment.

**5.4. Potential Confounding variables: Sex and SES**

The author first checked to make sure there were no significant sex related differences in ACEs reported. A chi-squared goodness-of-fit test revealed no significant differences in number of ACEs experienced between male and female children, (X2(2) = 1.601, *p* = 0.449). Social adversity has been previously measured in the CCDS dataset (Perra et al., 2015). The current dichotomised variable used was informed by whether the mother’s occupation was classified as working or middle class according to the Standard Occupational Classification 2000 (SOC200; Elias, McKnight & Kinshott, 1999 as cited by Perra, 2015). From this, the author found that 150 of the families (53.2%) in the current sub-sample were coded as middle class (Standard Occupational Classification, SOC categories 1-3, as defined by the ONS) and 132 (46.8%) as working class (SOC categories 4-9). A chi-squared goodness-of-fit test was conducted to determine whether number of ACEs recorded differed significantly across socio-economic status and found that it did (X2(2) = 11.230, *p* = 0.004). The prevalence of two or more ACEs was higher for working class families compared to those classified as middle class. These differences are depicted in Figure 5.3.

*Figure 5.3*

Comparing the number of working class and middle-class families assigned to each ACE category

*\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_*



To further investigate whether it was SES driving any differences in traits resembling ASD across ACEs categories, bivariate analysis using chi-squared was conducted to determine whether traits resembling ASD differed significantly across socio-economic status. No significant association was found for traits resembling ASD at; Wave 3 (X2(4) = 4.43, *p* = 0.351), Wave 4 (X2(7) = 8.77, *p* = 0.270), or Wave 6 (X2(5) = 6.53, *p* = 0.258). To be as certain as possible, further chi-squared goodness-of-fit tests were conducted for each type of trait resembling ASD (i.e. impaired communication, impaired socialisation, impaired flexibility) across each of the three waves (9 sets of analyses in total), and the results were insignificant for each one, apart from ‘Wave 6 Impaired Communication’. The teacher reports of the speech or language difficulties when the child was 7 years old *was* associated with SES, (X2(2) = 7.52, *p* = 0.023), with higher rates of impairments scored for children from working class mothers. This finding may be important when considering the implications of any differences found in W6 impaired communication traits across ACEs categories.

**5.5. Are ACEs related to traits resembling ASD?**

If “ASD traits” is defined as a score of 2 or more on the impairments detailed in Table 4.4, then 22.5% scored at least 2 ASD traits at Wave 6, 43% at Wave 4 and 20.6% at Wave 3. None of the ASD Trait scores (at Waves 3, 4 and 6) were normally distributed across the 0, 1, or 2+ ACE= count categories, as assessed by Shapiro-Wilk’s test, *p* < 0.05, and all included a small number of outliers including one extreme outlier in the Wave 6 variable. The variables as they stand therefore violate the assumptions needed to be met for use of parametric analyses. Through inspection, the outlier did not appear to be from an error in entering data. Through discussion, it was decided to retain the outlier, not transform the data, and to employ non-parametric statistical analyses to test between group differences. The author is aware that employing non-parametric statistical analyses increases the risk of a Type II error, meaning that under-estimating any true associations is now more likely.

***5.5.1. ACEs and referral for an ASD assessment***

*Figure 5.4*

ACE count and referrals for an ASD assessment

*\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_*



As the number of participants known to have been referred to specialist services for an ASD assessment was low (2.8%), in line with population norms, the data lacked statistical power to calculate the significance of the relationship between ACEs and occurrence of ASD assessment. However, from the 8 participants referred to services, 6 (that is, 75% of children referred for an ASD assessment) had at least one ACE. This is depicted in Figure 5.4 above. Though differences in number of ASD referrals across ACEs categories were not statistically significant, by Chi-squared goodness of fit test (X2(2) = 0.52, *p* = 0.772), the finding is of interest. Further inspection of the data also revealed that the two children referred for ASD assessment with no ACEs had a particularly high number of missing data on ACEs (indeed all Wave 6 interview items on domestic violence, physical abuse and emotional abuse were missing), leaving the possibility open that the relationship between ACEs and referral for ASD assessments may be higher than implied by these results.

***5.5.2. ACEs and traits resembling ASD at 12, 21 and 84 months***

To answer the research questions in relation to whether the number of ACEs related to traits resembling ASD in childhood, between-group differences were statistically analysed with the Kruskal-Wallis non-parametric between-groups test (Kruskall and Wallis, 1952). The results were as follows (with significant results highlighted in yellow):

*Table 5.4*

Results of statistical differences in traits resembling ASD across ACEs categories

|  |  |  |  |
| --- | --- | --- | --- |
|  | **TRAITS RESEMBLING ASD AT 12 MONTHS (WAVE 3)****Observational data** | **TRAITS RESEMBLING ASD AT 21 MONTHS (WAVE 4)****Questionnaire data** | **TRAITS RESEMBLING ASD AT 84 MONTHS (WAVE 6)****Questionnaire data** |
| **IMPAIRED COMMUNCIATION** | **No significant differences across ACE count categories, H(2) = 0.18, p = 0.914 *n.s***. | **No significant differences across ACE count categories, H(2) = 2.485, p = 0.289 *n.s*.** | **No significant differences across ACEs categories, H(2) = 0.228, p = 0.892 *n.s*.** |
| **IMPAIRED SOCIABILITY** | **No significant differences across ACEs categories, H(2) = 1.930, p = 0.381 *n.s***. | **The Kruskal-Wallis test indicated that impaired sociability *did* differ significantly across ACEs categories, H(2) = 6.111, p = 0.047**  | **The Kruskal-Wallis test indicated that impaired sociability *did* differ significantly across ACEs categories, H(2) = 6.617, p = 0.037** |
| **IMPAIRED FLEXIBILITY** | **No significant differences across ACEs categories, H(2) = 1.089, p = 0.580 *n.s*.** | **No significant differences across ACEs categories, H(2) = 1.031, p = 0.597 *n.s*.** | **No significant differences across ACEs categories, H(2) = 3.619, p = 0.164 *n.s*.** |
| **TOTAL OF TRAITS RESEMBLING ASD** | **No significant differences across ACEs categories, H(3) = 1.098, p = 0.578 *n.s*.** | **No significant differences across ACEs categories, H(2) = 2.604, p = 0.272 *n.s*.** | **No significant differences across ACEs categories, H(2) = 4.142, p = 0.126 *n.s*.** |

As reported in Table 5.4, impaired sociability at both 21 and 84 months were *significantly* different across ACE count categories. To further understand this difference, pairwise comparisons were performed using Dunn’s (1964) procedure with a Bonferroni correction for multiple comparisons. Adjusted *p*-values are presented. This post hoc analysis revealed statistically significant differences in Wave 4 impaired sociability scores between the zero ACEs (*Mdn* = 1; x̅ = 0.10) and one ACE (*Mdn* = 1; x̅ = 0.24), *p* =0.041, but not between the ‘two plus ACEs’ (*Mdn = 1;*  x̅ = 0.17) or any other group combination. Further post hoc analysis revealed that statistically significant differences, at least at trend level, in Wave 6 sociability scores between the zero ACEs (*Mdn* = 1*;* x̅ = 0.24) and the one ACE (*Mdn = 1;* x̅ = 0.50) group, *p* = 0.061, though not between the zero ACEs and two plus ACEs (*Mdn* = 1*;* x̅ = 0.46) group or any other group combination. These differences are illustrated in Figure 5.5 below:

*Figure 5.5*

Significant differences in Impaired Sociability at Waves 4 and 6 across ACEs categories

*\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_*



***5.5.3. Associations between individual ACEs and Impairments in Communication, Sociability and flexibility in childhood***

Due to the amount of missing data on certain ACE types, there is insufficient power to explore each individual relationship. It was thus decided that any individual ACE variable with less than 20 positive cases (see: Table 5.1) would be excluded from further analysis. This resulted in the exclusion of; Emotional Abuse, Physical Abuse, Sexual Abuse, Neglect, Domestic Violence and Parental Incarceration. Thus, the correlation analysis suggesting a relationship between the number of Traits resembling ASD at Wave 4 and whether there was ‘Domestic Violence’ at home, *p* = 0.079, and the number of Traits resembling ASD at Wave 6 and whether the child was rated as having experienced ‘emotional abuse’, *p*= 0.097, is interesting but cannot be considered meaningful. No other significant relationships were found.

**Chapter VI. General Discussion**

The first aim of this research was met when the author created two new variables of interest from the existing CCDS dataset, an ACE count and a measure of traits resembling ASD. The work benefitted from drawing from an existing longitudinal dataset where ACEs were collected prospectively (rather than reported retrospectively as has been done in most studies on ACEs), and from which multiple perspectives on the early development of the children were available. The ASD traits investigated were well aligned with the traits emphasised as important within the triad of impairments related to ASD (Wing and Gould, 1979; Wimpory, 2013). From Wave 6 data, 2.8% of parents reported that their child had been referred for an ASD assessment, which, understanding that not all 2.8% would receive a diagnosis, appears comparable with the 1.5% of the population estimated to meet criteria for ASD at the time (Derweerdt, 2011). Though the methods of capturing traits resembling ASD were varied across the different waves (and therefore caution should be exerted whenever they are pooled together), the mean number of children scored as having 2 or more impairments (as defined in Table 4.4) was 28.7% which is comparable to the estimated 30% of the population who have ASD traits (Derweerdt, 2011).

The CCDS was not originally designed to capture either ACEs or traits resembling ASD, and creating the variables thus included revisiting aspects of raw data and posed certain challenges. These included higher than expected missing values in aspects of the ACEs variable, and a limited amount of available data that was relevant to ASD traits. Potential limitations of the current work will be further discussed before considering the possible clinical implications of the findings.

The second aim of the research was to explore the relationship between the two new variables created. From previous research (Roberts et al., 2015; Dinkler et al., 2017), it was expected that the proxy ACE variable created would be positively associated with the number of traits resembling ASD, and specifically that ASD traits would increase with the number of ACEs experienced by individuals. This expectation was met, at least in part, as findings demonstrated a positive association between ACEs and ASD traits at Wave 6 (7 years of age), *p* = 0.1, in the direction expected, and especially between impaired sociability and ACEs at Wave 6, *p* <0.05

**6.1. Summary of findings**

***6.1.1. Rates of ACEs reported***

Though certain types of ACEs recorded from the current dataset was similar to previously recorded rates (e.g. Emotional Abuse was recorded at 7.8% compared with 7.1% in the 2018 Welsh Survey), others were not. For example, there was a surprisingly high rate of parental mental health (i.e. parents’ reports of suicidality and/or acts of self-harm), at 39.7% as opposed to 17.9% in the Hughes et al. (2018) survey. The Hughes et al. (2018) study was a national study conducted in Wales and therefore one would anticipate a similar ACE prevalence. Possible reasons for the differences in rates of parental mental health are two-fold: firstly, the current study relied on data provided directly from the parents themselves about their own mental health as opposed to previous studies that have relied on adults recalling their own parents’ mental health when they were children. It is thus possible that previous surveys were an underestimation of true rates of parental mental health problems, with the parents possibly having concealed their difficulties from their children, or at least that their difficulties were not given a name or understood. Secondly, this particular ACE variable (parental mental health) only relied on one questionnaire item (asked to both mother and father/other parent), which was negatively skewed. That is, a response of “Not True” to the item “I’ve never threatened suicide or injured myself on purpose” indicated that the parent/carer *had* “threatened” suicide or self-harmed. The author is aware that, in a lengthy questionnaire, this item mayhave thus been inadvertently inaccurately responded to by a busy parent. Whilst it is possible to investigate this hypothesis, within the context of the CCDS that offers rich data on the parents’ mental health at certain waves (E.g. SCAN interview at Wave 1), this is outside the scope of the current MRes. This is considered a limitation due to its narrow focus when wider data was available, although not easily obtainable for the author at this time. However, it is something that could be explored in future studies utilising the CCDS data. Future studies should also word this question about self-harm and suicidality differently. In particular, the phrase ‘threatening suicide’ may be replaced by the potentially less stigmatising “attempted suicide” or “had suicidal thoughts” (Spunout, 2021). The rate of ACEs overall, in the current study, was higher than those reported in previous studies. Most strikingly, 60% of children in the current subsample were considered to have had at least one ACE, as opposed to around 50% of the population found in other studies (Felitti et al., 1998; Hughes et al., 2017).

The other main discrepancy between current findings and the Hughes et al. (2017) survey is related to lower rates of neglect and sexual abuse in the current study (0.6% and 1.3% respectively compared to 4.3% and 6.9% in the 2017 survey). It is strongly suspected that the rates recorded in the current study are an under-estimation as it solely relied on parents’ responses at interview in relation to whether they had involvement from social services and where reasons for the referral had been recorded by the interviewer. This method is therefore quite different to what was done in the 2017 survey which, again, had involved asking adults to recall neglect or sexual abuse from their own childhood; a method likely to result in higher accuracy of reporting. It is well documented that victims of sexual abuse typically take many years before disclosing what happened (Allnock and Miller, 2013).

 ***6.1.2. Findings related to traits resembling ASD***

 In terms of the variables corresponding to traits resembling ASD, those created from the Wave 6 data (specifically from the teacher’s questionnaire), as reported in Chapter V, had the highest internal consistency and concurrent validity. Teacher’s reporting on the child’s presentation is often relied upon in referrals to child neurodevelopmental (ND) services, and these items were thus considered to also have good ecological validity. There is a caution about assessing ASD in babies or toddlers and the result indicating that the Wave 6 measure was the only valid and reliable one may therefore reflect clearer, more consistent, differences in children with traits resembling ASD at Wave 6 compared to earlier waves.

 ***6.1.3. Associations between ACEs and traits resembling ASD***

In terms of between-group differences in traits resembling ASD in children across the proxy ACE count (i.e. in children with 0, 1 or 2+ ACEs), these were found and in the direction expected especially from the Wave 6 data. Despite the increased risk of a Type II error with the use of non-parametric analyses, these differences across ACEs categories reached significance for impaired “sociability” at waves 4 and 6 (at least between the zero and one ACE category), and close to significance in terms of overall traits resembling ASD at wave 6, *p*= 0.1. As Wave 6 ASD measures were considered valid and reliable, it seems fair to conclude, from the results, that impaired sociability is significantly associated with whether an ACE was reported to have occurred at the age of 7 years.

 ***6.1.4. Answering the Research Questions***

From the results presented in Chapter V, the research questions presented in Chapter II can now be answered as follows:

1. Can an ACEs count variable be created from CCDS data?

The current research has demonstrated that, from combining raw and previously entered data, each of the ten commonly reported ACEs (e.g. Hughes et al., 2017) can be captured, at least to a degree, from the dataset, despite this not being an original aim of the CCDS. However, the proxy ACEs measure created through this research has limitations as described in section 6.1.1. above. These are mainly in relation to the questions about capturing parental mental health, child neglect and child sexual abuse. Future work, including studies drawing from CCDS data, could improve on this proxy ACEs measure. For example, there is rich data regarding parents’ mental health available from other data collection waves which could be utilised to test the reliability and validity of parents’ responses to the Wave 6 questionnaire item about self-harm and suicidal intent. Further information about abuse and neglect may also be gleaned by listening to available audio recordings of the Wave 6 parental interviews (a technique outside of the scope of the current MRes project) rather than relying solely on the interviewers’ written notes. Improving accuracy on sexual abuse and neglect, however, could only realistically be done by conducting a new, ethically approved, study with the same participants and asking the now grown-up children to recall potentially abusive events.

1. Can a valid and reliable method of capturing traits resembling ASD be achieved?

Traits resembling ASD were captured from CCDS data, along the three dimensions of; impaired communication, impaired sociability and impaired flexibility. However, statistical analyses revealed that the measures capturing traits resembling ASD were not valid or reliable enough based on data from Waves 3 and 4, and for the purposes of the current study. In contrast to this, the Wave 6 (when the children were 7 years) measure of traits resembling ASD was found to be a sufficiently valid and reliable measure, from the data collected. It was thus disappointing (though understandable given the original aims of the CCDS, e.g. Hay et al., 2021) that traits resembling ASD could not be meaningfully compared across the differing developmental stages. At the same time, it was reassuring that traits resembling ASD at Wave 6 were considered sufficiently meaningful to be considered further in the interpretation of final results.

3a. Is there a significant association between ACEs and traits resembling ASD?

Problems with the distribution of the data (e.g. in terms of outliers) meant that the less powerful non-parametric analyses needed to be employed. This, along with the relatively small sample size, increased the risk of making a Type II error, thus under-estimating the magnitude of the possible association that may exist between traits resembling ASD and proxy ACE categories. However, a significant relationship between ACE count and sociability at Wave 4 and 6 was found, as well as trends not reaching significance, including between ACEs categories and the summation of all traits resembling ASD at Wave 6. Other tested associations were considerably weaker, suggesting that traits resembling ASD at 12-months are not different across ACEs categories and traits resembling ASD at 21-months only different across ACEs categories in terms of ‘impaired sociability’. However, as referred to earlier, the measures used at waves 3 and 4 were not considered sufficiently reliable and valid for the purposes of the current research. Hence, we can only meaningfully conclude that whether or not the 7-year old children had at least one ACE was significantly associated with impaired sociability (one aspect of traits resembling ASD).

3b. What is the influence of confounders, such as SES, on this association?

In terms of confounding variables that could be influencing the association of interest, a range of risk factors for ASD have been proposed which may be worth considering (Liu et al., 2016; Maphalala & Mathabela, 2022). These include; air and other types of pollutions and toxicants, having older parents, what time of year the child was born (prevalence of ASD higher in children born in Winter), psychological stress during pregnancy and in the early stages of life, having a sibling with ASD (Maphalala & Mathabela 2022), having a mother who is an immigrant, birth order (ASD prevalence higher in children born later), gender (ASD higher in males), and a range of nutritional factors (Liu et al., 2016). Some of these variables (e.g. mother being an immigrant, psychological stress in early life) are consistent with early adversity and with this thesis’ hypothesis. Other variables (e.g. environmental factors and nutrition) were not captured by the CCDS and therefore cannot be considered. Birth order is interesting, but this was at least constant in the CCDS sample (all 332 children were first-born, at least to the mother), and finally factors such as seasonal timing of the birth and age of the parent could be looked at in future, using CCDS data.

Despite some evidence for ACEs being higher in girls (Holcombe et al., 2023), there were no child gender differences between recorded rates of ACEs in the CCDS sample. However, families from working class backgrounds were significantly more likely to fall into a higher ACEs category. Although ACEs are known to occur across the social divide, this trend for more ACEs at lower SES levels has been previously reported (Walsh et al., 2019). This finding therefore called into question whether any differences in traits resembling ASD across ACEs categories could not be better explained by differences in socio-economic status (SES).

To ensure this wasn’t the case, any potential associations between traits resembling ASD and SES were explored. None were significant, apart from ‘impaired communication’ at Wave 6. It may be interesting that teacher’s ratings of speech problems were likely to be higher in children from working class families. However, for the purposes of the current research, as ‘impaired communication’ in any wave was not close to being significantly different across ACEs categories, the potential problem of SES being a confounding variable was avoided. Hence, there wasn’t a need to run a logistic regression (consisting of several binary comparisons) to explore the relationships in more detail.

1. Is this association, between ACEs and traits resembling ASD, different at different developmental stages?

The results initially suggested that the associations were different across the developmental stages, with most associations found at Wave 6 (age 7 years) and least seen at Wave 3 (age 12 months). However, while this could have suggested that capturing traits resembling ASD at 12 months is more challenging as it is developmentally too early for such differences to fully emerge, or that the ACEs reported may not have occurred yet, no firm conclusions can be drawn due to a lack of sufficiently valid and reliable measures in the lower waves.

1. Are certain aspects of traits resembling ASD (i.e. certain aspects of the triad) more closely related to ACEs?

Across the three waves, impaired sociability was the most closely associated with number of ACEs, this reaching significance at waves 4 and 6. Though the Wave 4 measures, as discussed, were not sufficiently reliable or valid, it is interesting to note the precise items included were parents’ rating their 21-month children as; not ‘showing’ objects to others, not being upset when others are upset, not offering toys to other children and not copying other people. In contrast, the reliable and valid Wave 6 measure of impaired sociability included the teachers rating their 7-year old pupils as; avoiding looking others in the eye and as not getting along with other children. Broadly speaking, these combined map on to the most heavily weighted ‘sociability’ items from the DAISI (Wimpory et al., 2000) which include; eye contact, offering and giving, and social engagement without toys. Coding the child’s use of facial expressions may have enhanced our knowledge about any apparent impairment in sociability, but this particular measure was not available within the current sub-dataset.

* 1. **Interpreting the results**

As referred to in chapter II (Section 2.3), a significant relationship between number of ACEs and aspects of impairments resembling ASD does not indicate causality or tell us anything about the direction of the relationship. The lack of sufficiently valid and reliable measures of traits resembling ASD at waves 3 and 4 still further lessened the possibility of exploring this question. Though the traits resembling ASD at Wave 6 were reports on the child’s current functioning, whereas the ACEs measured were capturing historical events, it still may be the case that pre-existing difficulties in child sociability may have increased the likelihood of an ACE occurring. Research aiming to discern directionality between ADHD symptoms and mother’s hostility found the relationship to be bi-directional (Harold et al., 2013). Similarly, Dinkler et al. (2013) found no causal relationship between CM and NDD load, despite there being an association. The current association could also be explained through a bi-directional relationship, i.e. the occurrence of an ACE contributed to impairments in sociability (similarly to the model proposed by Felitti et al., 1998, depicted in Figure 1.1), but also that these impairments in sociability, in turn, lead to an increase in the likelihood of an ACE happening. These questions could be explored in future research, as will be discussed in section 6.3.

 As discussed in Section 2.1 of Chapter II, there is a distinction in the literature between ASD traits and ASD diagnoses (e.g. Bhaumik et al.). Without the use of standardised measures, or questionnaires, the current study could only be considered to capture traits resembling ASD and the findings do not tell us whether ACEs are related to standardised ASD traits or ASD diagnoses. Tentatively, the relationship between impaired sociability at age 7 years and whether the child had an ACE at last tentatively support findings from previous studies linking ASD traits with early childhood adversities such as was reported by Roberts et al. (2015). The sample size was too small to draw meaningful conclusions from the few cases (n = 8) that were known to have been referred for an ASD diagnoses, reported in section 5.5.1. of Chapter V. From the Dodds (2020) review, we may have expected children referred for an ASD diagnoses to have more ACEs than children not referred. Although this did seem to be the case with the small sample, no meaningful conclusions can be drawn. In light of the C-19 pandemic, and concerns of a rise in ACEs in recent years (Lennon, 2021), it is possible that the rise in referrals seen to child MH and ND services could partially be explained by this impairment in sociability, possibly mediating the relationship between ACEs and referral to services.

As discussed in Chapter I, with the introduction of the term ASD came a broadening to the traditional definition of ‘autism’ originally proposed by Kanner (1943). It is possible that this broadening in definition could contribute to the rise in diagnoses of ASD given to children who have ‘quasi-autism’, reactive attachment disorder and who display impairments in communication, sociability and/or flexibility that may be related to ACEs. Further research, drawing from real clinical cases could help discern to what degree this is the case.

* 1. **Limitations and future research**

As noted, the created ACEs measure can only at best be described a proxy measure of ACEs. The narrow focus (i.e. one questionnaire item across two respondents) of the “mental health” ACE measurement, and the associated risk of error (i.e. some parents may have mistakenly marked “Not true” to mean that they never self-harmed or threatened suicide) was especially problematic. The rich raw data available within the CCDS records means that there is scope to further refine and improve upon this variable in future. Two questions should thus be asked in future; 1. Whether prospective studies on ACEs will truly discover higher than expected rates of parental mental health difficulties in the population, perhaps unearthed by the direct way parents were asked about these in the CCDS, and 2. If the current finding was most likely due to a potential error made in parents’ reporting on this particular questionnaire item? Either way, a broader measure of parental mental health, as is available via the CCDS dataset, would be advantageous in future studies.

Another significant limitation, as referred to in Section 6.1.1., is that neither parents nor children were asked directly about experiences of either neglect or sexual abuse. Given the sensitive nature of these experiences, coupled with the fact that capturing ACEs was not originally intended, it is easy and understandable to see why. In future, studies wishing to explore the incidence of these forms of childhood maltreatment prospectively may usefully consider seeking permission to access social services files (a technique used by McCrory et al., 2019) and, for research purposes, only record those incidents of abuse known to social services as being present. Alternatively, asking children directly about their potential experiences of abuse is possible but would need extremely cautious planning and permissions with appropriate safeguarding provisions in place. It would be wisest to use this technique with older children when sexual abuse is most likely to have occurred. To the author’s knowledge, this latter technique is not so widely used in research on ACEs which tends to rely on retrospective recall from adult participants, although emerging research is starting to look at ways to measure childhood abuse and ACEs with children (Bethell et al., 2017). As the current sample could not consider ACEs occurring from 7 years to 18 years of age, future prospective studies would benefit from considering ACEs across this wider age range.

As well as the above-described limitations in relation to the proxy ACEs measure, creating the variable for traits resembling ASD also involved some problems. One limitation was the lack of ability to meaningfully compare the incidence of traits resembling ASD across the three waves (or three developmental stages). This was due to the different ways of capturing the children’s presentations from the items considered across the different waves. Wave 3 relied on observational data coded by a researcher observing the 12-month-old in a lab setting. Wave 4 data relied on parents/carers rating of child’s developmental achievements, whereas Wave 6 relied on teacher’s reporting on the 7-year-old child’s presentation and any related concerns. As reported, only the Wave 6 measures were considered sufficiently valid and reliable measures of traits resembling ASD.

Indeed, whilst the focus of the current study was limited to considering the potential relationship(s) between proxy ACEs and indications of traits resembling ASDs at Wave 6, potential research employing the current data, was originally envisaged to consider interrelationships between early and later indicators of traits resembling ASDs. However, the internal consistency issues that arose with the early measure of traits resembling ASDs, and the limited size of the current study, mean that such developments could not be justified.

There are potential ways of improving some of these limitations within the CCDS dataset. For example, ensuring comparisons of the same items from developmental questionnaires across the waves where this is available. Unfortunately, these improvements were beyond the scope of the current research which focused, for time and practical reasons (as outlined in section 3.4.3.), only on relevant data already coded and entered. Further, any improvements to the current research using the CCDS dataset could only be limited as the CCDS was never designed to capture ASD traits. Other longitudinal studies, such as the Avon Longitudinal Study of Parents and Children (ALSPaC) have captured richer data in relation to the children’s ASD (Yeargin-Allsopp, M., 2008; Steer et al., 2010). Future work, drawing from such datasets, would thus have the scope to explore the current research questions more accurately.

In terms of the problems with a lack of sufficient validity and reliability in ASD measures at Waves 3 and 4, focusing on the Wave 6 measures of traits resembling ASD is a meaningful way of overcoming these. Indeed, associations reported involving Wave 6 data should thus be treated with higher regard. In future, it is possible that traits resembling ASD could further be captured via video recordings available at the different waves of the CCDS. Though, again, the original aim did not include capturing ASD traits, it is likely that factors such as eye contact, social gesturing and facial expressions could be coded in this way. Despite the Wave 6 measures being the strongest in the current study, relying solely on Teacher’s reporting of the child’s presentations seems limiting and potentially problematic (e.g. reporter’s bias).

 In terms of analyses and results, missing data, small sample size and the need to use non-parametric analyses further challenged the study’s scope to discover any real associations that may exist. Necessary caution was therefore practised in interpreting results. Further to this, of course, is the crucial warning that ‘correlation is not causation’, as discussed in section 6.2, and future studies need to continue with the work of establishing whether early adversity partially contributes to certain changes in the child’s development including impairments in communication, sociability and/or flexibility, or whether the relationship is bi-directional. ACEs contributing to early impairments would be consistent with Figure 1.1. (proposed by Felitti et al., 1998) and also to Rutter et al. (1999)’s theory in relation to early brain development outlined in section 1.5 (and supported by more recent studies, e.g., Park et al., 2021; Kiatmura et al., 2021). Given the rise in referrals of children and young people presenting with traits resembling ASD, and the debate about whether ASD is a difference or disorder, it seems particularly useful and timely for future research to take up these questions, and thus potentially further our understanding of the aetiology of traits resembling ASD.

* 1. **Clinical implications**

In light of the rise in number of children referred to MH and ND services, and rise in diagnoses of ASD, this research supports the value of formulating each individual’s child presenting difficulties. That is, focus on attempting to understand a child’s impairment in any aspect of the triad in the context of challenges or adversities in their lives. Interpretations of the current findings specifically suggest that this should be done where the presenting difficulties include impairments in sociability (i.e. in eye contact and making friends), at around 7 years of age. Especially designed tools, such as those devised by Moran (2010) and Flakhill et al. (2017), could aid the clinician in formulating the child’s presenting difficulties from a diagnostic viewpoint.

As Dinkler et al. (2017) highlight, it is the case that children with experience of maltreatments are more likely to meet criteria for ASD and they should not be denied an assessment because of their experience of maltreatment (Dinkler et al., 2017). It is thus important that children with known ACEs, or those who disclose CM, are not precluded from having an assessment or diagnosis of ASD because of these earlier experiences (Dinkler et al., 2017). Alternatively, the clinician and service may decide to respond from a needs-based rather than a diagnostic-led standpoint and could choose to adopt a whole-system approach in line with the NEST framework (2021).

Whereas clinicians have been traditionally required to make a distinction between the effects of CM and ASD (e.g. Childhood maltreatment is considered as one of a number of potential ‘differential diagnoses’ that should be considered when assessing for ASD according to NICE guidelines, 2017), the current research suggests a blurring of this perceived boundary. Since the days of the ‘refrigerator mother’ explanations (Kanner, 1949), there has been growing sensitivity around the idea of parent blaming in clinical practice, which enquiries about potential CM can appear to be seeking to do (Gillingham and Bromfield, 2008).

Rather than either blaming parents or understanding that traits resembling ASD are purely due to biological factors, there is an alternative. That is, while adhering to safeguarding guidelines, a way of asking children, parents and families about potential ACEs without pressure, blame or judgement, and helping them to understand the potential associations between the ACEs and traits resembling ASD. As discussed in section 2.3, awareness of ACEs changes practice (e.g. Early Intervention Foundation, 2020; The NEST framework Wales, 2021). Results from the current research have strengthened the need to weave together a psychological formulation containing consideration of ACEs with families in clinical practice.

Results from the current research suggested that it was traits resembling impaired sociability that was most associated with occurrence of ACEs especially in the 7-year-old children. This implies that clinicians should perhaps note where on the triad any traits resembling ASD lie during initial assessments. Traits resembling impaired sociability (which may include turn-taking, eye contact, social engagement without toys, facial expressions, imitation, shared experiences, soothability and so on) should then be especially recognised and considered in light of any earlier ACEs.

* 1. **Further Reflections**

The process of working on this research highlighted to the author the strengths and challenges of drawing from secondary data. On the one hand, the data was readily collected and potentially available. However, the process of properly securing access was more cumbersome than anticipated, highlighting the considerable ethical and security implications of conducting the work. As not all data points of interest were coded or entered, organising, coding and entering the raw data posed additional challenges, especially given the geography (the author is based in Bangor, North Wales and the data in Cardiff, South Wales. This is a 4-5 hour train or car ride each way).

As well as the impact of the Covid-19 pandemic on children’s development, as discussed, the pandemic impacted the current research in terms of practicality (i.e. travel to Cardiff, data entering) and disruption to the author’s work. During January 2021 and summer 2022 there were frequent large disruptions to schooling and workplaces as well as constant pressure to isolate with symptoms of Covid-19. These factors directly affected the author, being the mother of two young children/toddlers and with a husband in the NHS workforce.

Finally, the jump from research to practice is complex and rarely smooth. This research highlighted to the author, an experienced clinician, the challenges and caution required when making any assumptions in translating findings from academic research into clinical practice and into explanations given to colleagues and families about the nature of ACEs and ASD traits.

* 1. **Final Conclusion**

Increasingly, children are referred to mental health and neurodevelopmental services with concerns including those compatible with traits resembling ASD. The concept of ASD has historically been fluid, and there are calls for ASD to be increasingly considered as a difference rather than a disorder and for children to be responded to based on need, rather on the of degree of compatibility with diagnostic categories. Over the course of many decades, studies have shown that early deprivation, childhood maltreatment and/or early adversity are associated with traits resembling ASD. One possible way of explaining this is through a bi-directional relationship that children with ASD traits will have with their adverse environment. Or, it may be, as Rutter et al. (1999) proposed, that early social deprivation hinders brain development and programming for elements of psychological capacities that are relevant to the genesis of autism (Rutter et al., 1999).

It is also the case that there are similarities but important differences between children who meet criteria for ‘ASD’ and those with ‘quasi-autism’ or ‘attachment disorders’. Whatever the true reasons for the associations found, this study has provided evidence that children’s sociability (i.e. proclivity to look others in the eye and ability to ‘get on’ with other children) at 7 years of age is more likely to be considered ‘impaired’ when they have experienced an adverse childhood experience compared to when they haven’t. The study has a number of limitations and future research is needed to further establish this link.

Further exploration in this area could have important clinical implications. Most notably, clinicians would be increasingly made aware of the association between impaired sociability as is defined in ASD instruments and early adversity. This may assist the clinician in the line of inquiry during assessments and in drawing a more accurate formulation of a child’s presenting needs. This also seems to be in line with current reports and priorities from Wales, such as ‘The No Wrong Door’ approach (Children’s Commissioner for Wales, 2020) and the NEST framework (2021), calling for a system-wide approach to understanding early adversities and their potential impact on later development.

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Appendix 1

**Guidance for Preparing Data entry for Wave 6**

**Parent Interview Part 2 (by Siwan Roberts)**

*Things you will need:*

1. Access to SPSS data file saved on shared drive, under Research > DHPVG > Wave 6 > W6 Interview part 2 data entry, and ‘CCDS wave 6 Part 2 Interview datababse\_1.sav’

 \**believe I inadvertently changed file name by adding the “\_1” at the end (so, the version before I started* *working on it is the file with the same name, minus the ‘underscore 1’)*

OR, can access this via screenshare with Siwan (Siwan entering, and other person ‘presenting’ the raw data)

Paper copy (printed) of ‘Wave 6 Parent Interview Part 2 CODE BOOK: Work Section and Child-Rearing Practices’

1. Access to the three filing cabinets in room 9.04, where Wave 6 interview data are stored, filed and labelled (from 1001 – 1260, and 1351).
2. Notebook/paper (or open word document) for writing down queries/issues/questions as you go

*Before starting data entry first time:*

1. Familiarise self with SPSS file, switching between data view and variable view tab to have an overview of the data points you will be entering. You can also see how the CODEBOOK paper document maps onto the file, and how, in some places, there are variables on the SPSS file, not included in the code book.
2. Familiarise self with filing cabinets in Room XXXX and key system. Notice how each sling contains ‘Part 1’ and ‘Part 2’ of the interview, labelled with the family ID. You will need both parts in order to enter the data, but data is mostly drawn from ‘Part 2’.
3. There is a separate excel document with ‘Age of Participants’ (at time of interview), and this document needs to be used to inform the ‘AGE OF INTERVIEWEE’, 3rd column on SPSS document (PIW6PT2PAGE

**Let’s work together (virtually) on inputting one or two cases. If we feel that system works well and is more reliable (in terms of working in pairs in a covid-friendly way), then we could continue with data entry “together” in this way for chunks of time. Otherwise, we may decide that this is a good way to introduce new students to the process, before letting student continue with the data entry independently.**

**Wave 6 Parent Interview Part 2**

**NOTES ON CODING AND ENTERING**

SIWAN ROBERTS AND BETHANY IRELAND

(Notes by Siwan Roberts, agreed in discussion with Bethany Ireland)

Notes based on our experience coding and entering are written in this colour font

|  |  |  |
| --- | --- | --- |
| Variable Label | Value Labels | Variable Name |
| ID Number  |  | FAMCODE |
| Interviewee This information is on Page 2 of ‘Part 1’ booklet |  1 = Mother  2 = Father  3 = Legal Guardian i.e. Grandparent/adoptive 4 = Grandparent-9 = Missing | PIW6PT2INT |
| Age To be completed from excel document (Cerith has this) |  | PIW6PT2PAGE |
| Interviewer |  1 = JS 2 = CSW 3 = RF 4 = JM 5 = MM 6 = BP | PIW6PT2INTR |
| Date of interview |  | PIW6PT2INTDATE |
| **A1.** Education/Qualifications since X was 6 months old?This is when you move to the ‘Part 2’ booklet | 0 = None1 = GCSE’s2 = A-Levels3 = NVQ’s4 = GNVQ’s5 = HNC6 = HND7 = Undergraduate degree8 = Postgraduate degree9 = Other-9 = Missing | PIW6PT2A1We have coded some ‘in process of completing’ as already being at that level (not always). Sometimes hard to know if qualification (e.g. CPD course) should be counted as one, and so “other” category is quite miscellaneous.  |
| **C1.** Are you working at the moment? | 0 = No1 = Yes | PIW6PT2C1 |
| **C1.a.** If yes, code as follows | 1 = Full time2 = Part time (<20hrs/week)3 = No, full time mother4 = Full-time college5 = Part-time college6 = Part-time work and Part-time college7 = Other-8 = Not Applicable-9 = Missing | PIW6PT2C1.aWe’ve had responses such as “Part-time, 22 hours” or 34 hours, but coded as ‘full time’ all the same due to criteria (there is room to specify hours in another column)  |
| **C1.b.** What is your current job title? |  | PIW6PT2C1.b |
| **C1.c.** How many hours do you work? |  | PIW6PT2C1.c |
| **C1.d.** Are you planning on going back to work? | 0 = No1 = Yes-8 = Not Applicable-9 = Missing | PIW6PT2C1.d |
| **C1.e.** When do you plan to go back to work? |  | PIW6PT2C1.e |
| **C1.f.** Will you go back full-time or part-time? | 1= Full time2 = Part time | PIW6PT2C1.f |
| **C2.** Is your partner working at the moment? | 0 = No1 = Yes | PIW6PT2C2 |
| **C2.a.** If yes, code as follows | 1 = Full time2 = Part time (<20hrs/week)3 = No, full time caregiver4 = Full-time college5 = Part-time college6 = Part-time work and Part-time college7 = Other-8 = Not Applicable-9 = Missing | PIW6PT2C2.a |
| **C2.b.** What is his/her current job title? |  | PIW6PT2C2.b |
| **C2.c.** How many hours does he/she work? |  | PIW6PT2C2.c |
| **C2.d.** Is he/she planning on going back to work? | 0 = No1 = Yes-8 = Not Applicable-9 = Missing | PIW6PT2C2.d |
| **C2.e.** When does he/she plan to go back to work? |  | PIW6PT2C2.e |
| **D.1.** Satisfaction with weekly childcare schedule | 1 = Very dissatisfied2 = Dissatisfied3 = Satisfied4 = Very satisfied -9 = Missing | PIW6PT2D.1 |
| **D.2.** Does X every play independently outside without your supervision? Jump to page 49 of the ‘Part 2’ booklet here | 0 = Absent1 = Present | PIW6PT2D.2Sometimes, this has been answered as “in the garden”. However, we have still counted that as “present”. It is hard to know how useful this variable is in terms of drawing any meaningful conclusions from it |
| **D.2.1.1.** Do you use time out | 0 = Absent1 = Present | PIW6PT2D.2.1.1We have counted “Naughty Step” as “Time out” present |
| **D.2.1.2.** Spanking with hand | 0 = Absent1 = Present | PIW6PT2D.2.1.2 |
| **D.2.1.3.** Spanking with Implement | 0 = Absent1 = Present | PIW6PT2D.2.1.3 |
| **D.2.1.4.** Marks or bruises ever | 0 = Absent1 = Present | PIW6PT2D.2.1.4 |
| **D.2.1.5.** Sent to room | 0 = Absent1 = Present | PIW6PT2D.2.1.5 |
| **D.2.1.6.** Locked in room, basement or cupboard | 0 = Absent1 = Present | PIW6PT2D.2.1.6This has only ever been coded as present once |
| **D.2.1.7.** Loss of privileges | 0 = Absent1 = Present | PIW6PT2D.2.1.7 |
| **D.2.1.8.** When you discipline or punish, do you get very angry? | 0 = Absent1 = Parent feels out of control when administering discipline, but punishment is accompanied by a generally nurturant atmosphere.2 = Discipline delivered coldly, or frequently in anger, AND unaccompanied by a generally nurturant atmosphere.-9 = Missing | PIW6PT2D.2.1.8The codes here are different to code in interview book (in terms of how 1, 2 and 3 are defined); we have stuck to these definitions.We also ran into some difficulties in categorising answers that fit BOTH dimensions of the 1 or 2 scores. We decided that what we were interested in, ultimately, is the anger projected towards child and most importantly the presence of the nurturing atmosphere or not. We therefore prioritised that (i.e. nurturing atmosphere) AND frequency over whether parent was reporting being ‘out of control’, or ‘cold’. |
| **D.2.1.9** Verbal Dispraise. Have you told X that s/he is bad or no good? | 0 = Absent1 = Occasional verbal dispraise by parent2 = Verbally dispraising statements by parent are characteristic-9 = Missing | PIW6PT2D.2.1.9From the PAPA definition in the interview booklet, the key distinction is “…between condemnation of a child’s action and condemnation of the child him/herself”. We decided to stay true to that spirit, and so do code “naughty girl/boy” as verbal dispraise, and put less heed as to whether or not swear words were used *per se.* |
| **D.2.1.10.** Verbal Rejection. Has X ever made you so mad you said that you wished s/he had never been born? | 0 = Absent1 = Present-9 = Missing | PIW6PT2D.2.1.10This has never been coded as present  |
| **D.2.1.11.** Selective Negative View. Which child in your family do you find it most difficult to get along with? | 0 = Target child treated in same way as rest of children.1 = Target child consistently treated differently from other children in a negative manner, in some areas.2 = Target child is regarded as being markedly different from other children in family, and subjected to markedly different rules or restrictions.-9 = Missing | PIW6PT2D.2.1.11We weren’t always sure how meaningful this variable was, unfortunately. Of course, there were occasions when it was “N/A” as there were no siblings. At other times, parents had reflected more, and spotted some perhaps subtle differences that only seemed like honest perception and insight into how siblings are inevitable ‘treated’ different to a degree. On other, rarer, occasions, it did seem that the target child (or a sibling) was being treated consistently negatively different to others. We aimed to code meaningfully, but not sure exactly of the reliability/validity of this variables, |
| **D.2.2.1.** Does OP1 use time out? | 0 = Absent1 = Present | PIW6PT2D.2.2.1.I’ve noticed here that “OP1” was ‘biological Dad’ in a case where Mum was single, and Dad was absent. In another case, Mum lived with a new partner, and so the ‘absent Dad’ was coded under ‘Absent parent’ category. Will clarify when coding.  |
| **D.2.2.2.** Does OP1 spank with hand | 0 = Absent1 = Present | PIW6PT2D.2.2.2 |
| **D.2.2.3.** Does OP1 spank with an implement | 0 = Absent1 = Present | PIW6PT2D.2.2.3 |
| **D.2.2.4.** Has OP1 ever left marks or bruises  | 0 = Absent1 = Present | PIW6PT2D.2.2.4 |
| **D.2.2.5.** Does OP1 send to room | 0 = Absent1 = Present | PIW6PT2D.2.2.5 |
| **D.2.2.6.** Does OP1 lock X in a room, basement or cupboard | 0 = Absent1 = Present | PIW6PT2D.2.2.6 |
| **D.2.2.7.** OP1 Loss of privileges | 0 = Absent1 = Present | PIW6PT2D.2.2.7 |
| **D.2.2.8.** When OP1 disciplines or punishes, does s/he get very angry? | 0 = Absent1 = OP1 feels out of control when administering discipline, but punishment is accompanied by a generally nurturant atmosphere.2 = Discipline delivered coldly, or frequently in anger, AND unaccompanied by a generally nurturant atmosphere.-9 = Missing | PIW6PT2D.2.2.8 |
| **D.2.2.9.** OP1 Verbal Dispraise. Have you told X that s/he is bad or no good? | 0 = Absent1 = Occasional verbal dispraise by parent2 = Verbally dispraising statements by parent are characteristic-9 = Missing | PIW6PT2D.2.2.9 |
| **D.2.2.10.** OP1 Verbal rejection. Has X ever made you so mad you said that you wished s/he had never been born? | 0 = Absent1 = Present-9 = Missing | PIW6PT2D.2.2.10 |
| **D.2.2.11.** OP1 Selective negative view  | 0 = Target child treated in same way as rest of children.1 = Target child consistently treated differently from other children in a negative manner, in some areas.2 = Target child is regarded as being markedly different from other children in family, and subjected to markedly different rules or restrictions.-9 = Missing | PIW6PT2D.2.2.11 |
| **D.2.2.12.** OP1: Quality of relationship | 0 = No evidence of relationship problems with absent parent.1 = No relationship and child grieves or is angry over this.2 = Relationship has negative aspects (e.g. child argues with absent parent, or resents that parent's new partner).3 = Relationship with absent parent almost completely negative (e.g. child very unhappy until visit ends, or persistently difficult during visits to or from absent parent).-9 = Missing | PIW6PT2D.2.2.12Unfortunately, this variable, we feel, is quite unreliable. It felt like sometimes this represented the quality of relationship between a present parent and the child. At other times, interviewer had deemed question “N/A” as there was no absent parent. There were occasions when child did have an absent parent, and we could only imagine that the child may have felt some grief or anger, but we had no information on whether they did or not. The coding categories under ‘Variable View’ on SPSS document is also different to the ones listed here. We went with SPSS, and coded this consistent with interviewer’s interpretation. As mentioned this, led to variance in what exactly is captured here. |
| **D.3.1.** Dissatisfaction with other parent’s help | 0 = Satisfied with partner’s help1 = Dissatisfied with some aspects of partner’s help to an extent sufficient to cause at least occasional anger or arguments2 = Almost complete dissatisfaction with partner’s contribution to home-making. Almost no positive help perceived as being provided by partner | PIW6PT2D.3.1 |
| **D.3.2.** Dissatisfaction with communication and decision making with other parent | 0 = Dissatisfaction absent1 = Some dissatisfaction that at least sometimes causes anger and arguments 2 = Almost complete dissatisfaction. Almost nothing about the partner’s communication style or the decision-making process is seen as being satisfactory.  | PIW6PT2D.3.2 |
| **D.3.3.1.** Parental Arguments | 0 = No parental arguments1 = Occasional parental arguments that the children are not exposed to 2 = More frequent arguments that the children are exposed too | PIW6PT2D.3.3.1We weren’t sure about how reliable the answers on degree children were exposed was, and we therefore prioritised frequency of arguments in this coding, whether or not children were considered to have been exposed. |
| **D.3.3.2.** Inter-parental physical aggression | 0 = Absent1 = At least one incident of physical violence | PIW6PT2D.3.3.2We included throwing dishcloth at partner as an incident here. On the whole, it feels like a reliable measure/variable. |
| **D.3.3.3.** Involvement of child in argument/violence | 0 = Child is not involved in arguments.1 = Child is upset by arguments/violence at least sometimes as manifested by protesting about them to parents or becoming withdrawn.2 = Child is actively involved in argument/violence by one or both parents | PIW6PT2D.3.3.3 |
| **D.3.3.4.** Apathy. In general how would you describe your relationship with your partner? | 0 = Apathy absent.1 = Marital relationship generally characterized by indifference or dislike, but with some one-sided affection or cooperation over mutual activities.2 = Marital relationship typified by absence of affection, apathy, indifference, dislike, and avoidance; with negligible cooperation in mutual activities. | PIW6PT2D.3.3.4Questions about how applicable this should be for single or separated parents, and so on, and sometimes felt inconsistent with answers given elsewhere in interview! However, on the whole, it seemed fairly reliable. |