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Social and Community Inclusion Outcomes for Adults with Autism

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ABSTRACT

This thesis aimed to explore the outcomes for adults with autism, in terms of social and community inclusion, social satisfaction, and community participation. Childhood predictors and adulthood correlates of outcomes were also investigated. Four studies were undertaken: a systematic review exploring how adults with autism participate in the community, the impact of community participation on quality of life and mental health, and factors that support and hinder participation; and three empirical studies investigating social and community inclusion, and community participation, outcomes in a community sample of adults with autism, building on an existing longitudinal study (the Australian Child to Adult Development study).

The systematic review was undertaken as community participation was identified as a particularly understudied area for adults with autism. The review identified a range of areas in which adults with autism participate, as well as areas in which participation is different to both typically developing peers and peers with other developmental disabilities. The review highlighted factors that have been identified as being associated with outcome in addition to factors that require further exploration.

The first empirical study aimed to identify the overall outcome (ranging from *Very Good* to *Very Poor)*, community inclusion (living arrangements, highest level of education, and daytime activity), and social inclusion (friendships and social satisfaction) outcomes for individuals with autism in adulthood. Community inclusion outcomes were also compared to the general Australian population. The second study investigated both the childhood predictors and adult correlates of adult outcomes. Specifically, the study considered the impact of childhood factors (degree of intellectual disability, age, socioeconomic disadvantage, autism symptomatology, and behaviour and emotional problems), as well as adulthood factors (functional skills, age, socioeconomic disadvantage, autism symptomatology, behaviour and emotional problems, and

mental health disorder diagnoses) on outcome (overall outcome, living arrangements, daytime activity, and friendships). The third study looked more specifically at community participation for adults with autism (e.g. attending social clubs, going to the park, shopping), investigating how often adults engaged in the community, how much variety they had in activities, and whether they did so with or without additional support. Factors impacting community participation were also explored.

Overall, the work that makes up this thesis highlights that, for many adults with autism, social and community inclusion and participation is challenging. Degree of intellectual disability, autism symptoms, and behaviour and emotional problems across childhood and adulthood were found to be associated with a range of social and community inclusion and participation outcomes. The studies in this thesis demonstrate that there are a number of areas where intervention programmes, including early intervention, and resources are needed to allow adults with autism to choose how they want to participate in the community and support them to achieve this.

PUBLICATIONS DURING ENROLMENT

PUBLICATIONS

Cameron, L. A., Tonge, B. J., Howlin, P., Einfeld, S. L., Stancliffe, R. J., & Gray, K. M. (submitted). Childhood and adulthood predictors of community participation by adults with autism. *Journal for Autism and Developmental Disorders.*

Cameron, L. A., Tonge, B. J., Howlin, P., Einfeld, S. L., Stancliffe, R. J., & Gray, K. M. (submitted). Childhood and adulthood predictors of outcomes for adults with autism. *Journal for Autism and Developmental Disorders.*

Cameron, L. A., Tonge, B. J., Howlin, P., Einfeld, S. L., Stancliffe, R. J., & Gray, K. M. (submitted). Social and community inclusion outcomes for adults with autism with and without intellectual disability in Australia. *Journal for Intellectual Disability Research.*

Cameron, L. A., Borland, R. L., Tonge, B. J, & Gray, K. M. (under review). Community participation for adults with autism: A systematic review. *Journal of Applied Research in Intellectual Disability*.

Cameron, L. A., Phillips, K., Melvin, G. M., Hastings, R. P., and Gray, K. M. (2020). Psychological interventions for depression for children and young people with an intellectual disability and/or autism: systematic review. *British Journal of Psychiatry*, *218*(6), 305-314. doi: 10.1192/bjp.2020.226

Cameron, L. A., Borland, R. & Gray, K. (2019). Community participation in adults with autism: A systematic review. *Journal of Intellectual Disability Research, 63*(7), 665.

Cameron, L. A., Gray, K., & Tonge, B. (2019). Community participation in adults with autism. *Journal of Intellectual Disability Research, 63*(7), 656.

CONFERENCE PRESENTATIONS

Cameron, L. A., Tonge, B., Howlin, P., Einfeld, S., Stancliffe, R., and Gray, K. M. (December 2020). Child to adult outcomes for children with Autism Spectrum Disorder in Australia. Oral presentation at the World Congress of the International Association for Child and Adolescent Psychiatry and Allied Professions (IACAPAP), Singapore.

Cameron, L. A. (June 2020). Community participation for adults with autism. Department of Psychiatry representative, Monash Health Translational Precinct Student Symposium, Monash University, Clayton, Australia.

Cameron, L. A., Gray, K. M., & Tonge, B. J. (August 2019). Community participation in adults with autism. Oral presentation at the World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD), Glasgow, Scotland.

Cameron, L. A., Borland, R. L., & Gray, K. M. (August 2019). Community participation in adults with autism: A systematic review. Poster presentation at the World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD), Glasgow, Scotland.

THESIS INCLUDING PUBLISHED WORKS DECLARATION

I hereby declare that this thesis contains no material which has been accepted for the award of any other degree or diploma at any university or equivalent institution and that, to the best of my knowledge and belief, this thesis contains no material previously published or written by another person, except where due reference is made in the text of the thesis.

This thesis includes one original paper under review for publication in a peer reviewed journal and three submitted publications. The core theme of the thesis is social and community inclusions outcomes for adults with autism. The ideas, development and writing up of all the papers in the thesis were the principal responsibility of myself, the student, working within the Centre for Developmental Psychiatry and Psychology, Department of Psychiatry under the supervision of Professor Kylie Gray and Emeritus Professor Bruce Tonge.

The inclusion of co-authors reflects the fact that the work came from active collaboration between researchers and acknowledges input into team-based research.

In the case of chapters 4, 7, 8, and 9 my contribution to the work involved the following:

Thesis Chapter	Publication Title	Status	Nature and % of student contribution	Co-author name(s) Nature and % of Co-author's contribution*	Co-author(s), Monash student Y/N*
4	Community Participation for Adults with Autism: A Systematic Review	Under review	65%; formulation of research questions, data collection and analysis, writing the manuscript	1) Kylie Gray, data analysis, input into manuscript 20% 2) Ross Borland, input into manuscript 10% 3) Bruce Tonge, input into manuscript 5%	No Yes No
7	Social and Community Inclusion Outcomes for Adults with Autism with and without Intellectual Disability in Australia	Submitted	60%; co-development of research questions, data collection and analysis, writing of the manuscript	1) Kylie Gray, development of research questions, input into manuscript 20% 2) Bruce Tonge, input into manuscript 5% 3) Patricia Howlin, input into manuscript 5% 4) Stewart Einfeld, input into manuscript 5% 5) Roger Stancliffe, input into manuscript 5%	No

8	Childhood and Adulthood Predictors of Social and Community Inclusion Outcomes for Adults with Autism	Submitted	60%; co-development of research questions, data collection and analysis, writing of the manuscript	1) Kylie Gray, development of research questions, input into manuscript 20% 2) Bruce Tonge, input into manuscript 5% 3) Patricia Howlin, input into manuscript 5% 4) Stewart Einfeld, input into manuscript 5% 5) Roger Stancliffe, input into manuscript 5%	No
9	Childhood ad Adulthood Predictors of Community Participation by Adults with Autism	Submitted	60%; co-development of research questions, data collection and analysis, writing of the manuscript	1) Kylie Gray, development of research questions, input into manuscript 20% 2) Bruce Tonge, input into manuscript 5% 3) Patricia Howlin, input into manuscript 5% 4) Stewart Einfeld, input into manuscript 5% 5) Roger Stancliffe, input into manuscript 5%	No

I have renumbered sections of submitted or published papers in order to generate a consistent presentation within the thesis.

Student signature: **Date:**   10/08/2021

The undersigned hereby certify that the above declaration correctly reflects the nature and extent of the student's and co-authors' contributions to this work. In instances where I am not the responsible author I have consulted with the responsible author to agree on the respective contributions of the authors.

Main Supervisor signature: **Date:**   10/08/2021

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CONTENTS

LIST OF TABLES

LIST OF FIGURES

CHAPTER 1: AUTISM SPECTRUM DISORDER AND ADULTHOOD

This chapter reviews the existing literature on autism in adulthood. The chapter begins by reviewing the current state of the autism prevalence literature, both internationally and in Australia, and how this research applies to adults. Next, an overview of the literature exploring outcomes for individuals in adulthood is provided, particularly noting how the research has changed its focus in evaluating outcomes in adulthood over time. A summary and direction for next steps is provided.

1.1 AUTISM SPECTRUM DISORDER

Autism Spectrum Disorder (hereafter referred to as autism) is a pervasive neurodevelopmental disorder characterised by difficulties in social communication and interaction, as well as restricted and repetitive behaviours and/or interests (American Psychiatric Association, 2013). Current prevalence rates indicate that autism is present in approximately 1% of children in the United States (Centers for Disease Control and Prevention, 2016), with worldwide estimates between 0.9% and 1.5% (Fombonne, 2020). Research suggests this is similar in adults however only two studies, conducted in the United Kingdom, have explored prevalence in adults (Brugha et al., 2011; Brugha et al., 2016). These figures are comparable in Australia, with 205,200 Australians currently diagnosed with autism, an overall prevalence of 0.8% (Australian Bureau of Statistics, 2018). However, the measurement of autism used by the Australian Bureau of Statistics (ABS) is important to consider, with the Survey of Disability, Ageing, and Caring relying on self- or informant-reported diagnosis.

1.1.1 Prevalence of Autism

The prevalence of autism in children has grown considerably since it was first recognised by Leo Kanner in 1943, with early epidemiological studies suggesting a prevalence rate of less than 0.05% (Lotter, 1966). Studies conducted in the intervening years demonstrate a steady increase in the number of children being diagnosed with autism (Wing & Potter, 2002). Regular meta-analyses conducted by Eric Fombonne highlight this increase, with estimates of 10 in 10,000 in 2003, 13 in 10,000 in 2005 and 20.6 in 10,000 in 2009 (Fombonne, 2003, 2005, 2009). These increases have been observed in Australian population data over recent years, with a 25.1% increase in prevalence from 164,000 people with autism in 2015 to 205,200 people with autism in 2018 (Australian Bureau of Statistics, 2018).

The observed increase in prevalence is likely the result of a number of factors, including changes in diagnostic criteria, diagnostic practices, and better understanding and knowledge of the presentation of autism, leading to earlier identification and diagnosis (Arvidsson, Gillberg, Lichteinstein, & Lundstrom, 2018; Fombonne, 2020; Lai & Baron-Cohen, 2015; Sonido, Arnold, Higgins, & Hwang, 2020; Wing & Potter, 2002). Improved awareness and changes from more restrictive diagnostic criteria has also provided an avenue for more individuals to be diagnosed in adulthood, who may have missed diagnoses earlier in life due to presentation of more mild symptoms (Lai & Baron-Cohen, 2015).

Despite the evidence that diagnosis of autism in children is increasing, prevalence research in adults is lacking. Brugha and colleagues (Brugha et al., 2011; Brugha et al., 2016) have undertaken the only prevalence studies to date in adults, finding an overall prevalence of 9.8 to 11 per 1000 in the English adult population. This study supports the notion that autism is a stable, lifelong diagnosis, with prevalence rates in adults similar to that seen in children. However, as discussed by Lai and Baron-Cohen (2015), it is likely that many adults continue to go unrecognised and undiagnosed, possibly due to a lifetime of developing coping

strategies that have hidden the presentation of symptoms and traits of autism. There is, therefore, a significant need for further research to comprehensively identify how many adults are in the population living with autism, whether diagnosed or undiagnosed.

It is clear that autism is becoming more prominent in our society in both children and adults. The children that have been diagnosed with autism over the past few decades are now approaching, or have entered, adulthood and there is a growing number of individuals who are being diagnosed as adults (Lai & Baron-Cohen, 2015). As a result, it is becoming increasingly important to gain a greater understanding of what autism looks like in adulthood, what outcomes can be expected in terms of independence and quality of life, and how adults can be best supported. Despite this, the literature for research on adults with autism is scarce compared to the research focused on children. A review found that, of 2,857 empirical research studies looking at autism, only 21% ($n = 605$) had a focus on adulthood (Jang et al., 2014), pointing to a prominent gap in the literature and in our knowledge of autism in adulthood.

1.1.2 Autism in Adulthood

While the literature is beginning to reflect the lifelong nature of autism, there is still a long way to go in our understanding of what autism looks like in adulthood, particularly mid adulthood and older age. Most of the few studies examining adults with autism focus on young adulthood (Sonido et al., 2020) and even fewer studies have undertaken longitudinal research to gain an understanding of the full life course for individuals with autism[1].

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[1] There is considerable discussion in the autism community and within the autism literature about use of language, with some individuals preferring person-first language (i.e. person with autism) and others preferring identity-first language (i.e. autistic person). Person-first language has been used throughout this thesis in accordance with the editorial policies in international journals based on consultations with people with autism (Journal of Applied Research in Intellectual Disability, and Journal of Autism and Developmental Disorders) who endorse the use of either terminology. The Journal of Applied Research in Intellectual Disability also notes that individuals with intellectual disability prefer person-first language, and do not endorse the use of abbreviations. Therefore, 'person with intellectual disability' has been used throughout this thesis.

It is evident that autism is a lifelong disorder, with difficulties in social interaction, communication, and stereotyped and repetitive behaviours persisting in adulthood. While some symptoms and behaviours associated with autism may see an improvement in adulthood, individuals rarely see significant enough improvements to no longer meet diagnostic criteria, with the majority of those diagnosed with autism as children continuing to meet diagnostic criteria as adults (Magiati, Wei Tay, & Howlin, 2014; Seltzer, Shattuck, Abbeduto, & Greenerg, 2004). These difficulties continue to impact the individuals ability to live independently, gain meaningful employment and develop friendships and romantic relationships (Howlin & Magiati, 2017; Tobin, Drager, & Richardson, 2014).

In addition, adults with autism often experience impairments in cognitive and adaptive skills, with high rates of co-occurring intellectual disability (Walton & Ingersoll, 2013), and high rates of behaviour and emotional problems and psychiatric comorbidities (Lugo-Marin et al., 2019; Tonge & Einfeld, 2003), further impacting on overall quality of life and other social and community inclusion outcomes. An understanding of these factors in adulthood, and the role they play in influencing outcomes, is critical to furthering knowledge on difficulties experienced by adults with autism and how they can be best supported.

1.1.2.1 *Cognitive and adaptive skills*

While prevalence rates are extremely varied in the literature, it is estimated that as many as 38% to 70% of people with autism have a co-occurring intellectual disability (Centers for Disease Control and Prevention, 2016; Walton & Ingersoll, 2013), with up to 40% of individuals with autism in the severe to profound intellectual disability range (Fombonne, 2003). More recent data suggests that as few as 30% of children with Autism Spectrum Disorder also have intellectual disability (Baio et al., 2018). However, as highlighted by Thurm et al. (2019) varying methodologies may result in underreporting of rates of co-

occurring intellectual disability, with minimally verbal individuals and those with more severe intellectual disability are often excluded from the research.

The presence of intellectual disability and the impact of co-occurring intellectual disability is critical to understand, as it has been one of the most consistent factors in influencing adult outcomes in the literature (Taylor & Mailick, 2014). Co-occurring intellectual disability is likely to impact on support needs and opportunities for adults with autism. When examining life outcomes for adults with autism, it is therefore necessary to consider how the presence of intellectual disability plays a role in addition to a diagnosis of autism.

Despite this, much of the autism related research has a focus on participants in the average IQ range, with minimal studies including adults of all intellectual abilities (Sonido et al., 2020; Zimmerman, Ownsworth, O'Donovan, Roberts, & Gullo, 2018). While these studies continue to add to our understanding of the life course of autism, it is important to remember that excluding individuals with co-occurring intellectual disability limits the generalisability of their findings to a specific group of individuals with autism. It is apparent that the presence of intellectual disability has an impact above and beyond an autism diagnosis on outcomes in adulthood, with those diagnosed with an intellectual disability often experiencing poorer overall outcomes, as well as lower levels of independent living, employment and education (Chamak & Bonniau, 2016; Gray et al., 2014). Even in individuals without a co-occurring intellectual disability, adaptive skills are often significantly lower than their peers (Kraper, Kenworthy, Popal, Martin, & Wallace, 2017), impacting ability to live independently, gain meaningful employment and seek relationships.

1.1.2.2   *Behaviour and emotional problems*

It is well established that individuals with intellectual and developmental disabilities, including autism, often experience significant behaviour and emotional problems and higher

rates of psychiatric disorders (Emerson & Hatton, 2007; Simonoff et al., 2008; Tonge & Einfeld, 2003). Behaviour and emotional problems in adulthood are often predictors of greater difficulty in living independently or engaging in the community (Gray et al., 2014). It is therefore necessary to consider outcomes for individuals with autism in the context of presence of behaviour and emotional problems, as well as considering the impact of these problems on overall quality of life.

The literature has historically focused on the behaviour and emotional problems of children and adolescents with intellectual disability and autism, with high rates of behaviour and emotional problems reported in these populations however, these problems persist from childhood and adolescence into adulthood (Gray et al., 2012; Tonge & Einfeld, 2003). Using the Developmental Behavior Checklist, a well-established measure of behaviour and emotional problems in individuals with intellectual and other developmental disabilities (Einfeld & Tonge, 2002; Gray, Tonge, Einfeld, Gruber, & Klein, 2018), it has been demonstrated that while behaviour and emotional problems may decline as individuals get older, the rates in adulthood are still high.

A systematic review undertaken by Lugo-Marin et al. (2019) highlighted the remarkably high prevalence of psychiatric disorders in adults with autism, with depression and anxiety being amongst the most common mental health disorders experienced. Anywhere between 28% to 86% of adults with autism have been identified as having at least one mental health comorbidity (Howlin & Magiati, 2017), with a further recent study reporting that 80% of young adults with autism had experienced mental health problems in their lifetime (Crane, Adams, Harper, Welch, & Pellicano, 2018). Moss, Mandy, and Howlin (2017) evaluated mental health outcomes in adults aged 33 to 68 years, finding that, while 63% had a *good* or *very good* mental health outcome, 34% had a *poor* or *very poor* outcome. Diagnosis of anxiety and/or depression are common in this cohort, with adults with autism three to four

times more likely to experience depression than the general population (Hudson, Hall, & Harkness, 2018).

The high prevalence of mental health diagnoses and behaviour and emotional problems reported in adults with autism highlights the challenges adults continue to face. Services and supports are often difficult to find (Crane et al., 2018), adding to negative experiences and exacerbating symptoms. Importantly, mental health issues and concerns have been reported to be a factor in contributing to the overall social outcome and quality of life for adults (Kamio, Inada, & Koyama, 2012; Mason et al., 2018; McCauley, Elias, & Lord, 2020) and should therefore be considered when examining potential influencing factors on outcome and life satisfaction.

The psychological difficulties experienced by adults with autism often come as a result of the attitudes and behaviours of the community and individuals. For example, the negative life experiences, ranging from unemployment to victimisation, often experienced by adults with autism, have been linked to adverse mental health outcomes in the literature (Griffiths et al., 2019). As stated by Griffiths et al. (2019), adults with autism are more vulnerable to these negative life experiences when compared to typically developing adults. This vulnerability includes financial hardship, negative work experiences and unemployment, and physical, verbal, emotional, and sexual victimisation, and reducing these vulnerabilities should be a core aim of support services (Griffiths et al., 2019). The impact of these community and environmental factors for adults with autism is substantial, and is important to consider in research in addition to personal factors, such as co-occurring intellectual disability and autism symptom severity, when exploring outcomes for adults with autism.

1.1.2.3   *Quality of life*

Quality of life is defined as "an individual's perception of their position in life in the context of culture and value systems in which they live and in relation to goals, expectations, standards and concerns" (World Health Organisation, 2018). It incorporates a number of elements such as physical and psychological health, personal beliefs, social relationships, and relationships to their environment (World Health Organisation, 2018). Recent meta-analyses have demonstrated that individuals with autism experience significantly lower quality of life than their peers across the lifespan (Tobin et al., 2014; van Heijst & Geurts, 2015). These low scores are seen particularly in the social domain quality of life (Tobin et al., 2014; van Heijst & Geurts, 2015), as would be expected in individuals with autism. Tobin et al. (2014) contend that these experiences are likely due to difficulties in social participation and inclusion, with informal social supports suggested to be an important contributor to improved quality of life.

Despite the general agreement that quality of life is poorer for adults with autism than their peers, there is some inconsistency in the literature, with some studies suggesting that quality of life is not worse for adults with autism. Moss et al. (2017) evaluated quality of life using the Abbreviated World Health Organisation Quality of Life (WHOQoL-BREF; World Health Organisation, 2018) in adults with autism, finding that most participants scored within one standard deviation of the mean WHOQoL-BREF scores, suggesting that quality of life in this sample was comparable to the general population. This was especially true for self-reported information. Although only a subset of this sample was able to complete the self-report measure, between 91% and 100% of participants scored within one standard deviation of the mean (Moss et al., 2017), suggesting that adults who self-reported experienced a good quality of life. When considering informant report, however, these figures dropped slightly, with 78% to 98% of participants reported to be within one standard deviation of the mean (Moss et

al., 2017). Differences seen in informant versus self-reported quality of life has been relatively consistent in the literature (Moss et al., 2017; van Heijst & Geurts, 2015). This is important in considering the results of studies examining quality of life in adults with autism, as studies using informant reports may be underestimating the quality of life experienced by the adult themselves. While this highlights the importance of gaining self-report data, this is not always possible in adults with autism, often due to communication problems of those with co-occurring intellectual disability.

Quality of life is an important element in understanding the experiences and outcomes for those with autism, as it incorporates subjective experiences of the individuals, rather than solely applying society's expectations of what constitutes a good outcome, often in terms of independence and employment. To gain a broader understanding of the life experience for adults with autism it is necessary to consider elements of quality of life, including life satisfaction, social and community inclusion, and mental health in addition to more objective measures of outcome, such as independent living, employment and educational attainment.

1.2   DEFINING AND EXPLORING OUTCOMES IN ADULTHOOD

Understanding what constitutes a good outcome in adulthood has changed over time, with Henninger and Taylor (2012) highlighting that "success in adulthood no longer means avoiding institutionalisation, but achieving practical independence in relationships, employment and living arrangements" (p110). Georgiades and Kasari (2018) argue that a successful outcome should be based on the individual's history, rather than being based on set criteria such as no longer meeting criteria for a diagnosis of autism, as optimal outcomes have often been defined in the past. Further, Howlin (2021) highlights the importance of listening more closely to the voices of those with autism and their families in understanding what a *good* outcome means to them.

Studies of adult outcome have evolved from simply making a subjective rating of outcome, to using more structured formulas to determine an outcome rating, to assessing outcome based on individual factors, particularly what the adult feels is a good outcome for them. The first follow up study of the original clients recognised by Leo Kanner as having infantile autism was published in 1971 (Kanner, 1971). All participants were aged between 29 and 39 at follow up. In this case study, Kanner reported that only two of the original 11 had successful outcomes. These two participants were both employed and living relatively independent lives, although both still lived with their parents (or carers since a young age, in one case). Although there was little information reported on their social lives, Kanner indicated that both of these participants appeared to engage socially and also had regular interactions and engagements with the local community. One participant did not achieve regular employment, however, continuing to live on a farm with the family he had grown up with and was able to participate in daily chores and errands effectively. While Kanner did not categorise this participant as having a particularly good outcome, he did suggest it was not as poor as others. In the remainder of the cases, while two participants were unable to be followed up, the remaining six had significantly worse outcomes, all continuing to live in state hospitals, with extremely limited involvement in the community or with others. Although presented as a case study report, and therefore unable to be evaluated effectively with statistical methods, the trends found by Kanner in the outcomes of the first adults diagnosed with autism have been supported by subsequent systematic research.

A number of review articles have highlighted this change in methodology over time, with a focus on normative outcomes transitioning to studies considering more subjective assessments of outcome and quality of life (Howlin & Magiati, 2017). As highlighted by Howlin and Magiati (2017), what is often considered a *good* outcome for adults is not always the most relevant or most practical for adults with autism. More recently, studies have taken a

range of factors into consideration, including determining what could be considered a *good* outcome for adults with autism both with and without co-occurring intellectual disability (Lord, McCauley, Pepa, Huerta, & Pickles, 2020; Pickles, McCauley, Pepa, Huerta, & Lord, 2020). These studies demonstrate the importance of tailoring determination of *good* outcomes and goals to the individual.

1.2.1 Overall Outcome Ratings

Early studies systematically examining the social outcomes for those diagnosed with autism as children suggested that the majority of these children have poor outcomes later in life (Howlin, Goode, Hutton, & Rutter, 2004; Lotter, 1974; Rutter, Greenfeld, & Lockyer, 1967). As one of the first systematic follow up studies in this field, Rutter et al. (1967) highlighted the *poor* to *very poor* outcomes achieved by the majority of children diagnosed with autism. In their study of 63 children originally diagnosed with infantile psychosis and followed up at the mean age of 15 years and seven months, Rutter and colleagues developed outcome categories, ranging from *very poor* to *good*, in which they rated each participant. These categories were based on the individual's ability to function independently in society, with those achieving a *good* outcome considered to be living a near-normal social life, those with a *fair* outcome making social and educational progress despite significant abnormalities in relationships and behaviour, those with a *poor* outcome being severely handicapped and unable to lead an independent life, although some behaviours demonstrated a potential for progress, and those with a *very poor* outcome completely unable to lead any kind of independent life (Rutter et al., 1967). This study found that nearly half of all participants (48%) achieved *very poor* outcomes, with only 25% and 14% achieving *fair* and *good* outcomes respectively (Rutter et al., 1967). As the first study to systematically allocate outcomes to individuals, these ratings become important in demonstrating the continued difficulty for those with autism throughout life, however, it is important to note that the

participants in this study were still in their adolescence, and the outcomes can therefore not be generalised to adulthood. Further, the outcome ratings allocated to each participant appear to be subjective and based on the authors impression, rather than by following any specific criteria.

Expanding on the findings from Rutter et al. (1967), Lotter (1974) evaluated social outcomes for a sample of 29 children diagnosed with autism in childhood. At the time of follow up, participants were aged 16 to 18 years of age. Using the same outcome categories and criteria as Rutter et al. (1967), the study by Lotter (1974) found very similar results. Forty-eight percent of participants were considered to have a *very poor* outcome, 14% a *poor* outcome, 24% a *fair* outcome, and only 14% achieving a *good* outcome. While this study adds further support to the original findings by Rutter et al. (1967), this study also does not include adults and makes use of subjective ratings.

Howlin et al. (2004) conducted the first follow-up study to utilise a specific coding and rating strategy to assign outcome categories to participants. In their sample of 68 participants (mean age 29.33 years), overall outcome was scored based on ratings in three areas: occupation, living arrangements, and friendships. Each participant was given a rating under each category from one to five based on predefined criteria, resulting in an overall outcome score being calculated based on the sum of the individual category scores. As a result, the outcome ratings assigned to each participant are more objective than seen previously. In this study, outcome categories were defined as follows: a *very good* outcome involved achieving a high level of independence, while having some friends and a job; a *good* outcome included those who were working but required some support in terms of daily living, while having some friends or acquaintances; a *fair* outcome involved some degree of independence but requiring support and supervision, and having no close friends; a *poor* outcome included those living in residential accommodation, requiring a high level of support, and having no friends, and; a

very poor outcome involved high level hospital care and no autonomy. Using this criteria, Howlin et al. (2004) found that nearly 60% of participants achieved a *poor* or *very poor* outcome, with only 22% achieving a *good* or *very good* outcome.

Multiple studies have been conducted since the Howlin study, utilising the same or similar criteria to gauge the overall outcome for various populations of adults with autism. Regardless of the sample, results have been generally consistent with previous literature: most adults achieving a *poor* outcome, with few achieving what is considered a *good* outcome using these criteria. For example, in their study of 120 individuals followed from childhood to adulthood (aged 17 to 40 years at adult follow-up), Billstedt et al. (2005) reported that no adults had achieved what was considered a *good* outcome, with the overwhelming majority of participants (78%) achieving a *poor* or *very poor* outcome. A greater proportion of adults were reported by Eaves and Ho (2008), in their sample of adults aged 19 to 31 years, to have a *good* or *very good* outcome (21%), however, most participants were considered to have a *poor* outcome (56%). More recent studies, however, have begun to report better overall outcomes. Both Sevaslidou, Chatzidimitriou, & Abatzoglou (2019) and Pickles et al. (2020) reported over 40% of participants achieving a *good* outcome in adulthood. Importantly, these studies involved 100% and 50.6% of participants respectively without an intellectual disability, which may have contributed to the rate of people reported as having a better outcome.

A review and meta-analysis evaluating the studies using the overall outcome rating to assess outcome in adulthood (15 studies, N = 828 individuals) found that nearly half (47.7%) of adults with autism achieved a *poor* outcome (Steinhausen, Mohr Jensen, & Lauritsen, 2016). Thirty-one percent (31%) achieved *fair* outcomes in adulthood, with just under 20% achieving a *good* outcome (Steinhausen et al., 2016). These rates are supported by a more recent systematic review and meta-analysis undertaken by Mason et al. (2021). Despite

including nine papers published since the Steinhausen review (total of 18 studies (n = 6 studies from Steinhausen review did not meet criteria for this review), N = 1199 individuals), rates reported by Mason and colleagues (2021) were comparable, with 49.3% achieving a *poor* outcome, 26.6% achieving a *fair* outcome, and 20% achieving a *good* outcome.

1.2.2 Longitudinal Studies

Much of the research of adult outcomes in autism has utilised a cross-sectional study design. While these studies provide useful information about adult outcomes, longitudinal studies are needed to gain an understanding of what factors predict certain outcomes, and therefore, where services can intervene. There are a small number of well-known longitudinal samples following individuals with autism into adulthood in the literature, with a brief discussion of these provided below. While these samples consist of different methodologies, age ranges, and autism and intellectual disability diagnoses, the difficulties experienced by individuals with autism in adulthood are consistent.

Ongoing work by Lord and colleagues has followed a group of individuals originally recruited from autism referral programs as young children in North Carolina and Chicago (mean age 2.5 years, SD = 0.43 years), and a group of individuals recruited in later childhood from Michigan in the United States (mean age 13.3 years, SD = 2.49) (Lord et al., 2020). All children involved in this longitudinal study were seen for face-to-face assessments at regular intervals, from age 2 to age 27 (Lord et al., 2020; Pickles et al., 2020). At the most recent follow-up, participants were young adults (mean age 26.15 years, SD = 1.47 for the North Carolina and Chicago participants; mean age 25.00 years, SD = 1.84 for the Michigan participants) (Pickles et al., 2020). Within the study are a number of individuals who were referred for autism assessments as children but have never received a diagnosis of Autism Spectrum Disorder, despite showing many similarities with the group that has received a diagnosis (McCauley, Pickles, Huerta, and Lord, 2020). Their sample also includes

individuals with IQ scores above and below 70 (with and without intellectual disability (Lord et al., 2020; McCauley et al., 2020; Pickles et al., 2020). When considering adult outcomes, McCauley et al. (2020) highlighted that outcomes differed between those with and without intellectual disability, and that different conceptualisations of outcomes for those with and without intellectual disability is important to consider.

Howlin and colleagues have followed a clinical sample of individuals with autism in the United Kingdom from childhood (mean age 7.24 years (SD = 3.10 years), range 3.1 – 15.66 years) through young adulthood (mean age 29.33 years (SD = 7.97), range 21.16 – 48.58; Howlin et al., 2004) and mid-adulthood (mean age 44 years 2 months, SD = 9 years 4 months), range 29 – 64 years; Howlin, Moss, Savage, & Rutter, 2013). Participants were recruited for this study between 1950 and 1979. Participants in this sample generally had a higher IQ, with those in young adulthood having an IQ of 50 or above, and 70 or above in the mid-adulthood follow up. Although some improvements were seen over time, participants in this UK clinical sample largely had *poor* outcomes, as defined by limitations in employment, friendships, and independent living. While the earlier study found that those with a lower IQ (between 50 and 69) had significantly poorer outcomes in all areas than those with an IQ of 70 and above, the later follow up, in which all participants had an IQ of 70 or above, still demonstrated consistently poor outcomes. While the authors report that IQ score was significantly related to outcome in both studies, it is clear that presence of co-occurring intellectual disability is not solely responsible for poor outcomes experienced in adulthood for a number of individuals with autism.

This was further demonstrated by Farley and colleagues, who followed an epidemiological sample of children with autism in Utah, United States, recruited between 1984 and 1988 in an attempt to identify all cases of autism in Utah between 1960 and 1984. The initial follow-up reported on for this sample (Farley et al., 2009) involved only those participants without a co-

15

occurring intellectual disability (full scale IQ of 70 or above; *n* = 41). Participants were aged between 22.3 and 46.4 years (mean age 32.5, SD = 5.7 years). Overall social outcomes for this group in adulthood were encouraging, with only 17% of participants achieving a *poor* outcome. This outcome has been largely attributed to the strong community from which participants were recruited. Ninety-three percent of participants were members of the Church of Jesus Christ of Latter Day Saints, a community that is known for their support of members of the community. A secondary follow-up of participants (Farley et al., 2017), this time including participants of a wide degree of intellectual disability and autism diagnosis (*n* = 162), however, showed different results. This sample included participants with IQ scores from 40 to 140 (M = 71.2, SD = 27.4), with over 75% of the participants with an IQ of 70 or below. Participants were aged between 22.2 and 51.4 years (mean age 35.4 years). Nearly half of the sample were considered to have *poor* or *very poor* outcomes, demonstrating a high level of dependence on others. This significantly decreased when only those without a co-occurring intellectual disability were considered, with only 3% now rated as having a *poor* outcome, and over half demonstrating *very good* or *good* outcomes.

A community-based population study undertaken by (Billstedt, Gillberg, & Gillberg, 2005; Billstedt, Gillberg, & Gillberg, 2011) followed 120 individuals in Sweden who had been diagnosed with autistic disorder or atypical autism in childhood. Diagnosis had been made using gold standard criteria available at the time by experts in the field of autism. Diagnoses of autistic disorder were made using DSM-III -R criteria (American Psychiatric Association, 1987). Atypical autism was diagnosed where individuals met six or more of the 18 criteria, but not the full criteria for an autism diagnosis. At follow up, participants were aged between 17 and 40 years (mean age 25.5 years), with the majority of participants categorised as having a moderate or severe intellectual disability. Further, most participants now met criteria for autistic disorder under DSM-IV (American Psychiatric Association, 1994), with 85% of

the original autistic disorder sample, and 86% of the original atypical autism sample, receiving a clinical diagnosis of autistic disorder. Similarly, to the previous studies, the majority of participants achieved *very poor* (57%) or *poor* (21%) outcomes in adulthood. No participants in this study achieved a *good* outcome (defined by the authors as being employed/in higher education and either living independently or having two or more friends/a steady relationship) (Billstedt et al., 2005). Further, few participants were independent, with most continuing to live with family or in group homes, only a third were engaged in regular recreational activities, and few were in employment (Billstedt et al., 2011). The authors note, however, that the sample was likely not representative of all adults with autism, particularly as the sample was predominantly made up of individuals with moderate to severe intellectual disability and was therefore less representative of individuals without intellectual disability (Billstedt et al., 2005).

A review of longitudinal studies of childhood predictors of outcomes in adults, including employment, social relationships, independent living, and overall outcome (Kirby, Baranek, & Fox, 2016) identified 8 unique studies (published across 12 articles) published between 2000 and 2014 from Europe, the UK, Canada, and the USA. No Australian studies were identified. This review identified personal characteristics (age, gender, race), individual functioning (IQ, communication/social skills, autism diagnosis/severity, independence), family context (household income, parent education, two-parent household, family support), and services (career counselling, school services) as the main outcome predictors across the range of studies (Kirby et al., 2016). The authors highlight individual functioning characteristics (including cognitive functioning, communication, and diagnosis and severity of autism symptomatology) as having the strongest evidence base for predicting outcomes in adulthood (including employment, social relationships, independent living, and overall outcomes), despite methodological differences across studies.

When considering longitudinal studies, it is important to remember that the samples are generally representative of the conceptualisation of autism at the time of recruitment, and the samples do not necessarily reflect the individuals who are diagnosed with autism today. Further, the availability of interventions and support at the time these individuals were children was much less prominent than today, meaning children and adults diagnosed with autism today are likely to have greater access to resources to support them in their development and daily lives. However, despite these limitations, longitudinal studies are critical in furthering understanding of the trajectory of change for individuals with autism from childhood to adulthood, as well as understanding the factors in childhood that can influence outcome in adulthood. Understanding these factors is particularly important in order to identify where resources and support are best directed to support individuals to achieve the best outcome and quality of life.

1.3 SUMMARY AND NEXT STEPS

The research has well established that adults with autism have poor outcomes in adulthood, however, it is important not to focus solely on these composite ratings for understanding the experiences of adults with autism. Even for individuals who may appear to have an objectively good outcome, adults with autism often continue to be dependent on their parents and face social difficulties and anxieties (Chamak & Bonniau, 2016). The overall outcome ratings devised by Rutter, Lotter and Howlin have been used in numerous studies providing further evidence to demonstrate this trend (Eaves & Ho, 2008; Gillespie-Lynch et al., 2012), with adults consistently reported to have predominantly *poor* outcomes. This has been demonstrated by numerous studies, and further supported by meta-analyses (Mason et al., 2020; Steinhausen et al., 2016). While it is important to recognise the continued difficulties this population experiences as they get older, the research now needs to evaluate the factors that contribute to these outcomes.

Existing longitudinal cohorts have provided a base of knowledge of factors that are likely to impact overall outcome in adulthood, particularly personal characteristics such as IQ, communication skills, and severity of autism symptoms. However, inconsistencies in methodology, participant characteristics, and predictors measured, mean there is still gaps in our knowledge - more research is needed to explore outcomes for adults with co-occurring intellectual disability, in addition to continuing to build understanding of what constitutes a *good* outcome for adults with autism and what factors can predict or influence outcome. Rates of behaviour and emotional problems, including presence of comorbid mental health problems, have been consistently reported to be high for adults with autism, however few studies have considered the impact of behaviour and emotional problems on adult outcomes, a considerable gap in the literature. Further research exploring childhood predictors and concurrent adulthood factors impacting outcome, including personal characteristics such as IQ, communication skills, autism symptom severity, and presence of behaviour and emotional problems, as well as external characteristics such as family socioeconomic status and experience of socioeconomic disadvantage, will enable services to pinpoint the areas that warrant further attention and support in order to help adults with autism to achieve positive outcomes.

REFERENCES

American Psychiatric Association. (1987). *Diagnostic and Statistical Manual for Mental Disorders* (3rd ed.). Washington, DC: American Psychiatric Association.

American Psychiatric Association. (1994). *Diagnostic and Statistical Manual for Mental Disorders* (4th ed.). Washington, DC: American Psychiatric Association.

American Psychiatric Association. (2013). *Diagnostic and Statistical Manual for Mental Disorders* (5th ed.). Washington, DC: American Psychiatric Association.

Arvidsson, O., Gillberg, C., Lichteinstein, P., & Lundstrom, S. (2018). Secular changes in the symptom level of clinically diagnosed autism. *The Journal of Child Psychology and Psychiatry, 59*(7), 744-751. doi:10.1111/jcpp.12864

Australian Bureau of Statistics. (2018). Disability, Ageing and Carers, Australia: Summary of Findings. Retrieved from https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release#autism-in-australia

Baio, J., Wiggins, L., Christensen, D. L., Maenner, M. J., Daniels, J., Warren, Z., Kurzius-Spencer, M., Zahaorodny, W., Rosenberg, C. R., White, T., Durkin, M. S., Imm, P., Nikolaou, L., Yeargin-Allsopp, M., Lee, L., Harrington, R., Lopez, M., Fitzgerald, R. T., Hewitt, A. … Dowling, N. F. (2018). The prevalence of Autism Spectrum Disorder among children aged 8 years – Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014. *Morbidity and Mortality Weekly Report. Surveillance Summaries (Washington, D.C.:2002), 67*(6), 1 – 23. doi: 10.15585/mmwr.ss6706a1

Billstedt, E., Gillberg, C., & Gillberg, C. (2005). Autism after adolescence: Population-based 13- to 22-year follow-up study of 120 individuals with autism diagnosed in childhood. *Journal of Autism and Developmental Disorders, 35*(3), 351-360. doi:10.1007/s10803-005-3302-5

Billstedt, E., Gillberg, I. C., & Gillberg, C. (2011). Aspects of quality of life in adults diagnosed with autism in childhood. *Autism, 15*, 7-20. doi:10.1177/1362361309346066

Brugha, T. S., McManus, S., Bankart, J., Scott, F., Purdon, S., Smith, J., . . . Meltzer, H. (2011). Epidemiology of Autism Spectrum Disorders in adults in the community in England. *Archives of General Psychiatry, 68*(5), 459-466. doi: 10.1001/archgenpsychiatry.2011.38

Brugha, T. S., Spiers, N., Bankart, J., Cooper, S., McManus, S., Scott, F., . . . Tyrer, F. (2016). Epidemiology of autism in adults across age groups and ability levels. *The British Journal of Psychiatry, 2019*, 498-503. doi:10.1192/bjp.bp.115.174649

Centers for Disease Control and Prevention. (2016). *Prevalence and characteristics of autism spectrum disorder among children aged 8 years - Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2012*. Atlanta, GA. doi: 10.15585/mmwr.ss6503a1

Chamak, B., & Bonniau, B. (2016). Trajectories, long-term outcomes and family experiences of 76 adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 46*, 1084-1095. doi:10.1007/s10803-015-2656-6

Crane, L., Adams, F., Harper, G., Welch, J., & Pellicano, E. (2018). 'Something needs to change': Mental health experiences of young autistic adults in England. *Autism, 23*(2), 477-493. doi:10.1177/1362361318757048

Eaves, L. C., & Ho, H. H. (2008). Young adult outcome of autism spectrum disorders. *Journal of Autism and Developmental Disorders, 38*, 739-747. doi: 10.1007/s10803-007-0441-x

Einfeld, S., & Tonge, B. J. (2002). *Manual for the Developmental Behaviour Checklist Second Edition*. Melbourne: Monash University.

Emerson, E., & Hatton, C. (2007). Mental health of children and adolescents with intellectual

    disabilities in Britain. *British Journal of Psychiatry, 191*, 493-499.

    doi:10.1192/bjp.bp.107.038729

Farley, M. A., Cottle, K. J., Bilder, D., Viskochil, J., Coon, H., & McMahon, W. M. (2017).

    Mid-life social outcomes for a population-based sample of adults with ASD. *Autism*

    Research, 11, 142-152. doi:10.1002/aur.1897

Farley, M. A., McMahon, W. M., Fombonne, E., Jenson, W. R., Miller, J., Gardner, M., . . .

    Coon, H. (2009). Twenty-year outcome for individuals with autism and average or

    near-average cognitive abilities. *Autism Research, 2*, 109-118. doi:10.1002/aur.69

Fombonne, E. (2003). Epidemiological surveys of autism and other pervasive developmental

    disorders: An update. *Journal of Autism and Developmental Disorders, 33*(4), 365-

    382. doi: 10.1023/a:1025054610557

Fombonne, E. (2005). The changing epidemiology of autism. *Journal of Applied Research in*

    Intellectual Disabilities, 18, 281-294. doi:10.1111/j.1468-3148.2005.00266.x

Fombonne, E. (2009). Epidemiology of pervasive developmental disorders. *Pediatric*

    Research, 65(6), 591-598.

    doi:10.1203/PDR.0b013e31819e72030.1203/PDR.0b013e31819e7203

Fombonne, E. (2020). Epidemiological controversies in autism. *Swiss Archives of Neurology,*

    Psychiatry and Psychotherapy, 171, w03084. doi:10.4414/sanp.2020.03084

Georgiades, S., & Kasari, C. (2018). Reframing optimal outcomes in autism. *JAMA*

    Pediatrics, 172(8), 716-717. doi:10.1001/jamapediatrics.2018.1016

Gillespie-Lynch, K., Sepeta, L., Wang, Y., Marshall, S., Gomez, L., Sigman, M., & Hutman,

    T. (2012). Early childhood predictors of the social competence of adults with autism.

    Journal of Autism and Developmental Disorders, 42, 161-174. doi:10.1007/s10803-

    011-1222-0

Gray, K. M., Keating, C. M., Taffe, J., Brereton, A. V., Einfeld, S., & Tonge, B. J. (2012). Trajectory of behavior and emotional problems in autism. *American Journal of Intellectual and Developmental Disabilities, 117*(2), 121-133. doi:10.1352/1944-7588-117-2.121

Gray, K. M., Keating, C. M., Taffe, J. R., Brereton, A. V., Einfeld, S. L., Reardon, T. C., & Tonge, B. J. (2014). Adult outcomes in autism: Community inclusion and living skills. *Journal of Autism and Developmental Disorders, 44*, 3006-3015. doi:10.1007/s10803-014-2159-x

Gray, K. M., Tonge, B. J., Einfeld, S., Gruber, C., & Klein, A. (2018). *Developmental Behavior Checklist 2 (DBC2) (Manual)*. Torrance, CA: Western Psychological Services.

Griffiths, S., Allison, C., Kenny, R., Holt, R., Smith, P., & Baron-Cohen, S. (2019). The Vulnerability Experiences Quotient (VEQ): A study of vulnerability, mental health and life satisfaction in autistic adults. *Autism Research, 12*(10), 1516-1528. doi: 10.1002/aur.2162

Henninger, N. A., & Taylor, J. L. (2012). Outcomes in adults with autism spectrum disorders: A historical perspective. *Autism, 17*, 103-116. doi:10.1177/1362361312441266

Howlin, P., Goode, S., Hutton, J., & Rutter, M. (2004). Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry, 45*(2), 212-229. doi:10.1111/j.1469-7610.2004.00215.x

Howlin, P. (2021). Adults with autism: Changes in understanding since DSM-111. *Journal of Autism and Developmental Disorders*. doi:10.1007/s10803-020-04847-z

Howlin, P., & Magiati, I. (2017). Autism spectrum disorder: Outcomes in adulthood. *Current Opinion in Psychiatry, 30*, 69-76. doi:10.1097/YCO.0000000000000308

Howlin, P., Moss, P., Savage, S., & Rutter, M. (2013). Social outcomes in mid- to later

adulthood among individuals diagnosed with autism and average nonverbal IQ as

children. *Journal of the American Academy of Child & Adolescent Psychiatry, 52*(6),

572-581. doi:10.1016/j.jaac.2013.02.017

Hudson, C. C., Hall, L., & Harkness, K. L. (2018). Prevalence of depressive disorders in

individuals with autism spectrum disorder: A meta-analysis. *Journal of Abnormal*

Child Psychology, 47, 165-175. doi:10.1007/s10802-018-0402-1

Jang, J., Matson, J. L., Adams, H. L., Konst, M. J., Cervantes, P. E., & Goldin, R. L. (2014).

What are the ages of persons studied in autism research: A 20 year review. *Research*

in Autism Spectrum Disorders, 8, 1756-1760. doi:10.1016/j.rasd.2014.08.008

Kamio, Y., Inada, N., & Koyama, T. (2012). A nationwide survey on quality of life and

associated factors of adults with high-functioning autism spectrum disorders. *Autism,*

17, 15-26. doi:10.1177/1362361312436848

Kanner, L. (1971). Follow-up study of eleven autistic children originally reported in 1943.

Journal of Autism and Childhood Schizophrenia, 1(2), 119-145.

doi:10.1007/BF01537953

Kirby, A. V., Baranek, G. T., & Fox, L. (2016). Longitudinal predictors of outcomes for

adults with autism spectrum disorder: Systematic review. *Occupation, Participation*

and Health, 36(2), 55-64. doi:10.1177/1539449216650182

Kraper, C. K., Kenworthy, L., Popal, H., Martin, A., & Wallace, G. L. (2017). The gap

between adaptive behavior and intelligence in autism persists into young adulthood

and is linked to psychiatric co-morbidities. *Journal of Autism and Developmental*

Disorders, 47(10), 3007-3017. doi:10.1007/s10803-017-3213-2

Lai, M., & Baron-Cohen, S. (2015). Identifying the lost generation of adults with autism spectrum conditions. *Lancet Psychiatry, 2*, 1013-1027. doi: 10.1016/S2215-0366(15)00277-1

Lord, C., McCauley, J. B., Pepa, L. A., Huerta, M., & Pickles, A. (2020). Work, living, and the pursuit of happiness: Vocational and psyschosocial outcomes for young adults with autism. *Autism, 24*(7), 1691-1703. doi:10.1177/1362361320919246

Lotter, V. (1966). Epidemiology of autistic conditions in young children. *Social Psychiatry, 1*(3), 124-137. doi: 10.1007/BF00584048

Lotter, V. (1974). Social adjustment and placement of autistic children in Middlesex: A follow-up study. *Journal of Autism and Childhood Schizophrenia, 4*, 11-32. doi: 10.1007/BF02104997

Lugo-Marin, J., Magan-Maganto, M., Rivero-Santana, A., Cuellar-Pompa, L., Alviani, M., Jenaro-Rio, C., . . . Canal-Bedia, R. (2019). Prevalence of psychiatric disorders in adults with autism spectrum disorder: A systematic review and meta-analysis. *Research in Autism Spectrum Disorders, 59*, 22-33. doi:10.1016/j.rasd.2018.12.004

Magiati, I., Wei Tay, X., & Howlin, P. (2014). Cognitive, language, social and behavioural outcomes in adults with autism spectrum disorders: A systematic review of longitudinal follow-up studies. *Clinical Psychology Review, 34*, 73-86. doi:10.1016/j.cpr.2013.11.002

Mason, D., Capp, S. J., Stewart, G. R., Kempton, M. J., Glaser, K., Howlin, P., & Happe, F. (2021). A meta-analysis of outcomes studies of autistic adults: Quantifying effect size, quality, and meta-regression, *51*, 3165-3179. *Journal of Autism and Developmental Disorders*. doi:10.1007/s10803-020-04763-2

Mason, D., McConachie, H., Garland, D., Petrou, A., Rodgers, J., & Parr, J. R. (2018). Predictors of quality of life for autistic adults. *Autism Research, 11*(8), 1138-1147. doi:10.1002/aur.1965

McCauley, J. B., Elias, R., & Lord, C. (2020). Trajectories of co-occurring psychopathology symptoms in autism from late childhood to adulthood. *Development and Psychopathology, 32*(4), 1287-1302. doi:10.1017/S0954579420000826

McCauley, J. B., Pickles, A., Huerta, M., & Lord, C. (2020). Defining positive outcomes in more and less cognitively able autistic adults. *Autism Research, 13*, 1548-1580. doi:10.1002/aur.2359

Moss, P., Mandy, W., & Howlin, P. (2017). Child and adult factors related to quality of life in adults with autism. *Journal of Autism and Developmental Disorders, 47*, 1830-1837. doi:10.1007/s10803-017-3105-5

Pickles, A., McCauley, J. B., Pepa, L. A., Huerta, M., & Lord, C. (2020). The adult outcome of children referred for autism: Typology and prediction from childhood. *The Journal of Child Psychology and Psychiatry, 61*(7), 760-767. doi:10.1111/jcpp.13180

Rutter, M., Greenfeld, D., & Lockyer, L. (1967). A five to fifteen year follow-up study of infantile psychosis. *British Journal of Psychiatry, 113*, 1183-1199. doi: 10.1192/bjp.113.504.1183

Seltzer, M. M., Shattuck, P. T., Abbeduto, L., & Greenerg, J. S. (2004). Trajectory and development in adolescents and adults with autism. *Mental Retardation and Developmental Disabilities, 10*, 234-247. doi: 10.1002/mrdd.20038

Sevaslidou, I., Chatzidimitriou, C., & Abatzoglou, G. (2019). The long-term outcomes of a cohort of adolescents and adults from Greece with autism spectrum disorder. *Annals of General Psychiatry, 18*(26), 1-6. doi: 10.1186/s12991-019-0250-6

Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008).
Psychiatric disorders in children with autism spectrum disorders: Prevalence,
comorbidity, and associated factors in a population-derived sample. *Journal of the
American Academy of Child & Adolescent Psychiatry, 47*, 921-929.
doi:10.1097/CHI.0b013e318179964f

Sonido, M., Arnold, S., Higgins, J., & Hwang, Y. (2020). Autism in later life: What is known
and what is needed? *Current Developmental Disorders Reports, 7*, 69-77.
doi:10.1007/s40474-020-00192-z

Steinhausen, H.-C., Mohr Jensen, C., & Lauritsen, M. B. (2016). A systematic review and
meta-analysis of the long-term overall outcomes of autism spectrum disorders on
adolescence and adulthood. *Acta Psychiatrica Scandinavica, 133*, 445-452.
doi:10.1111/acps.12559

Taylor, J. L., & Mailick, M. R. (2014). A longitudinal examination of 10-year change in
vocational and educational activities for adults with autism spectrum disorders.
Developmental Psychology, 50(3), 699-708. doi:10.1037/a0034297

Thurm, A., Farmer, C., Salzman, E., Lord, C., & Bishop, S. (2019). State of the field:
Differentiating intellectual disability from Autism Spectrum Disorder. *Frontiers in
Psychiatry, 10*, 256. doi: 10.3389/fpsyt.2019.00526

Tobin, M. C., Drager, K. D. R., & Richardson, L. F. (2014). A systematic review of social
participation for adults with autism spectrum disorders: Support, social functioning,
and quality of life. *Research in Autism Spectrum Disorders, 8*, 214-229.
doi:10.1016/j.rasd.2013.12.002

Tonge, B. J., & Einfeld, S. (2003). Psychopathology and intellectual disability: the Australian
Child to Adult longitudinal study. In L. M. Glidden (Ed.), *International Review of*

Research in Mental Retardation, Volume 26 (pp. 61-91). San Diego, CA: Academic Press.

van Heijst, B. F. C., & Geurts, H. M. (2015). Quality of life in autism across the lifespan: A meta-analysis. *Autism, 19*(2), 158-167. doi:10.1177/1362361313517053

Walton, K. M., & Ingersoll, B. R. (2013). Improving social skills in adolescents and adults with autism and severe to profound intellectual disability: A review of the literature. *Journal of Autism and Developmental Disorders, 43*(3), 594-615. doi:10.1007/s10803-012-1601-1

Wing, L., & Potter, D. (2002). The epidemiology of autistic spectrum disorders: Is the prevalence rising? *Mental Retardation and Developmental Disabilities, 8*, 151-161. doi: 10.1002/mrdd.10029

World Health Organisation. (2018). WHOQOL: Measuring Quality of Life. Retrieved from http://www.who.int/healthinfo/survey/whoqol-qualityoflife/en/

Zimmerman, D., Ownsworth, T., O'Donovan, A., Roberts, J., & Gullo, M. J. (2018). High-functioning autism spectrum disorder in adulthood: A systematic review of factors related to psychosocial outcomes. *Journal of Intellectual and Developmental Disability, 43*, 2-19. doi:10.3109/13668250.2016.1262010

CHAPTER 2: COMMUNITY INCLUSION IN ADULTHOOD

This chapter provides a review of the literature, looking more specifically at community inclusion outcomes and predictors of these outcomes. Throughout this thesis, community inclusion refers to the integration of adults with autism into core elements of community living, in particular, independent living, education, and employment. The ability to participate in the community independently is generally a marker of adulthood, not only for adults with autism, but also for the general population. While there is some disagreement amongst studies, it is clear that adults with autism experience significantly poorer community inclusion outcomes than both their typically developing peers and individuals with other developmental disabilities, across the areas of independent living, education, and employment (Howlin & Magiati, 2017).

The social model of disability posits that individuals are not disabled by impairments, but by the barriers that exist in society (Oliver, 2013). This is especially important when considering community inclusion for adults with autism. While we know that independent living, education, and employment is often limited for adults with autism, the barriers to successful inclusion in these areas is critical to understand. Burchardt (2004) describes a range of barriers in the community that are experienced by people with a range of disabilities – including economic, social, and physical barriers. The presence of these environmental barriers is likely to impact on the ability for an adult to live independently, undertake education, or succeed in employment, without additional supports.

2.1 LIVING ARRANGEMENTS

Independent living is an important part of adulthood, however, the research demonstrates that adults with autism are less likely to live independently than their typically developing peers and adults with other developmental disabilities (K. A. Anderson, Shattuck, Cooper, Roux, &

Wagner, 2014; Levy & Perry, 2011). Despite the considerable variability in the exact rates of living arrangements, it has been consistently demonstrated that very few adults live on their own, and the majority will continue to be dependent on their families or disability services well into adulthood (Lord, McCauley, Pepa, Huerta, & Pickles, 2020).

Low rates of independent living, and high rates of living with family and in supported accommodation into adulthood is consistently reported across the literature. Lord et al. (2020) recently reported in their study that, regardless of IQ, 60% of participants had always lived with their parents. While this sample was comprised of young adults all in their late teens to early twenties, similar rates of living arrangements have been reported in older samples. For example, Dudley, Klinger, Meyer, Powell, and Klinger (2019) reported that more than half of their sample (53%) aged 20 to 58 years lived with family, 37% lived in supported group accommodation, and only 10% lived independently.

Few studies have reported high rates of adults living independently, with most reporting between 4% and 26% of participants living on their own (Billstedt, Gillberg, & Gillberg, 2011; Eaves & Ho, 2008; Farley et al., 2009; Gray et al., 2014; Howlin, Goode, Hutton, & Rutter, 2004; Howlin, Moss, Savage, & Rutter, 2013). In these studies, the lower rates of independent living are more prominent in samples that include individuals with co-occurring intellectual disability (Billstedt et al., 2011; Eaves & Ho, 2008; Gray et al., 2014), and the higher rates are seen in samples with IQ scores greater than 70 (Farley et al., 2009; Howlin et al., 2013). Despite the apparent differences in independent living between adults with and without intellectual disability, independent living is still quite low in those without intellectual disability, suggesting that intellectual functioning is not the main factor influencing living arrangements.

Reported rates of living in supported group disability accommodation in adulthood varies across the literature, often due to cultural aspects of availability of supported living services at the time of the study. While some studies report high rates of adults, particularly with co-occurring intellectual disability and extreme behavioural issues, living in residential accommodation and long stay hospitals (for example, Howlin et al., 2004) this may be reflective of the choice of services and suitable accommodations and living arrangements available at the time. Despite this, more recent studies still demonstrate high rates of supported living, even amongst adults without co-occurring intellectual disability, with 24-50% of adults living in supported group homes (Billstedt et al., 2011; Helles, Gillberg, Gillberg, & Billstedt, 2017; Howlin et al., 2013). Similar rates have been found for adults with a wide range of co-occurring intellectual disability, with one study reporting that 28% of participants were living in supported care (Gray et al., 2014).

Overwhelmingly, adults with autism continue to live with their parents and families. Living with family has been reported to be anywhere from 38% to 92% (Billstedt et al., 2011; Eaves & Ho, 2008; Farley et al., 2017; Gray et al., 2014; Howlin et al., 2004; Kamio, Inada, & Koyama, 2012; Saldana et al., 2009). While these studies all involve participants of varying intellectual functioning, lower rates of living with family have been reported in some studies with participants with an IQ greater than 70 (14-17%; Helles et al., 2017; Howlin et al., 2013). The continued high rate of living with families becomes increasingly important to understand as adults, and therefore their parents, get older, with concern about what will happen to their children when they are no longer able to look after them consistently reported amongst parents (Steinhausen, Mohr Jensen, & Lauritsen, 2016). Not only do a large proportion of adults continue to live with their parents, but many have never lived away from them and do not have the means or skills, or access to appropriate services and supports,

necessary to support themselves without their parents (K. A. Anderson et al., 2014; Dudley et al., 2019; Lord et al., 2020).

It is evident that adults with autism rarely live independently and are often reliant on supports from family or community services. However, it is also clear that these services are not readily available to adults who need them, particularly those who are living independently or continuing to live with family. It is therefore increasingly important to understand what personal (for example, daily living skills, co-occurring intellectual disabilities, autism symptoms) and environmental (for example, access to services, housing, and employment) factors are impacting living arrangements and what areas can be better supported to allow adults to live more independently and with greater choice in where and how they live.

2.2 EDUCATION

Despite the fact that educational attainment is an important contributor to improved quality of life and employment for individuals with and without disability (Emerson et al., 2020; National Center for Special Education Research, 2011), the research demonstrates that adults with autism are less likely than their typically developing peers to be involved in post-secondary education. Levy and Perry (2011) highlight in their review that 50-60% of individuals with autism do not achieve any formal qualifications upon leaving school, further perpetuating the low rates of engagement in post-secondary education, with rates reported from 8% in some cases (Howlin et al., 2013) to 30-40% in others (Eaves & Ho, 2008; Farley et al., 2009; Kamio et al., 2012). Eaves & Ho (2008) report that of the 30% ($n = 14$) of participants that attended post-secondary education, only one attended university. More advanced education degrees were evident in the Farley et al. (2009) study, with seven participants earning a bachelor's degree, although participants in this study did not have intellectual disability.

While these studies did not compare educational attainment to other populations, there is evidence to highlight that adults with autism do not achieve the same level of education as the general population. Drawing on the Australian Bureau of Statistics data, few adults with autism in Australia achieve post-secondary education. The highest level of education achieved by adults with autism is mostly in secondary school, either Year 10 or below (32.4%) or Year 11 or 12 (43.2%) (Australian Bureau of Statistics, 2017). Only 26% of adults with autism achieved a post-secondary qualification, considerably lower than individuals with other disabilities (45.5%) or no disability (59.3%) (Australian Bureau of Statistics, 2017). These figures, however, do not paint a clear picture of the experience of education for adults with autism in Australia, particularly surrounding post-secondary education retention and drop-out rates, or indeed the rates of individuals who actually desire to attend post-secondary education

In addition to the evidence that simply achieving a post-secondary qualification contribute to better overall outcome (National Center for Special Education Research, 2011), attending college or university can also be an important avenue for increasing socialisation and community participation, further improving overall wellbeing (Koegel, Ashbaugh, Koegel, & Detar, 2013). Supporting adults to attend post-secondary education if they desire should therefore be an important consideration for community interventions and support programs. The research does suggest that, for adults with autism, additional barriers and hurdles are encountered that make the experience more difficult, for example, difficulties with social communication, daily living skills, mental health concerns, and the expectations of academic performance (C. Anderson & Butt, 2017; Elias & White, 2018). Without adequate supports in place, young adults may be less inclined to attend, or complete, post-secondary education. Further research is needed to determine what supports would be helpful for adults with a wide range of functional skills and co-occurring intellectual disability, as currently most of

the research exploring education outcomes for adults focuses on individuals without co-occurring intellectual disability.

2.3 EMPLOYMENT AND DAYTIME ACTIVITY

Adults with autism are considerably less likely to be engaged in the labour force than both their typically developing peers, and those with other disabilities. In Australia, only 40.8% of those diagnosed with autism are engaged with the labour force, compared with 53.4% of those with other disabilities, and 83.2% of people without disability (Australian Bureau of Statistics, 2017). Further, the unemployment rate for those with autism is as high as 31.6%, compared to rates of 10% and 5.3% in people with other disabilities, or no disabilities, respectively (Australian Bureau of Statistics, 2017). This comparison with the general Australian population, however, is limited by the self- or informant-report nature of the measurement of autism in the Australian Census and Labour Force Survey. It is not clear whether the individuals included in these figures have co-occurring intellectual or other disabilities, or have received a formal diagnosis of autism. Further, the employment figure provided by the Australian Bureau of Statistics includes persons aged 15 to 65 years, and does not take into account the type of employment engaged in (i.e. whether mainstream or disability-specific).

Despite the limitations of the Australian Bureau of Statistics data, low rates of employment for adults with autism are consistently reported in the literature. Review articles have repeatedly found that employment rates are as low as 25% (Levy & Perry, 2011), and underemployment is also prominent, with adults working few hours, in low paying jobs, and often at a skill level far lower than their capabilities (Eaves & Ho, 2008; Roux et al., 2013; Shattuck et al., 2012). Only 17% of participants in a UK study of adults aged 29 to 64 years without co-occurring intellectual disability were working in skilled jobs, 11% working in

partly skilled or unskilled jobs, 15% working in sheltered employment, and 55% were unemployed (Howlin et al., 2013). An Australian study reported that only 18% of adults, aged 17 to 35 years, including adults with co-occurring intellectual disability, were engaged in paid employment (Gray et al., 2014). Underemployment for adults with autism in Australia has also been reported, with a study of adults aged 18 to 65 years without co-occurring intellectual disability finding that 46% of employed adults were overeducated for their job, and 29% were working fewer than 15 hours per week (Baldwin, Costley, & Warren, 2014). A Danish study of young adults (18 to 26 years), however, reported that 41% of participants who were employed worked at least 30 hours per week, a third worked between 15 and 29 hours per week, and 16% worked less than 15 hours per week (Knuppel, Telleus, Jakobsen, & Lauritsen, 2019). Further, this study reported that 80% of parents of the adult participants considered the occupation their child participated in to be at their educational level. It is likely that culture differences and availability of programmes in different countries contributes to the different employment outcomes and opportunities available to adults.

Studies examining employment trends and trajectories throughout adulthood not only find consistently low employment rates, but also highlight that quality of engagement continues to decline over time. Following a sub-sample of participants who had left high school before data collection commenced in an existing longitudinal cohort (age 18 to 52 years; 80.7% co-occurring intellectual disability), Taylor and Mailick (2014) found that independence and hours worked declined over time. This difficulty in maintaining employment was further highlighted by Taylor, Henninger, and Mailick (2015), in a sample of adults with autism without co-occurring intellectual disability from the same longitudinal study. This study found that only 25% of the sample were consistently engaged in competitive employment over the 10-year period, and 42.5% were unemployed for at least one of the seven time points

in a 14-year period (Taylor et al., 2015). This work highlights that, not only do adults with autism have difficulty finding employment, it is often also difficult to maintain employment.

The employment experiences of adults with autism are important to consider for a range of reasons, including the negative impact of unemployment on the individual's quality of life and wellbeing (Hedley et al., 2017) and the ability for individuals to earn an income and not only support themselves, but reduce their reliance on family members and other financial supports. A range of support services and employment programmes exist to provide adults with autism an avenue for pursuing employment, however, these are often insufficient and do not have the capacity to support adults with autism to engage in the level of employment they desire (Hedley et al., 2017; Nicholas et al., 2018). Hedley et al. (2017) suggest that involvement in employment programmes with ongoing support have benefits for the individual's social, communication, and behavioural outcomes, in addition to better employment outcomes such as increased hours and wages. Therefore, better understanding of the current employment experiences of adults with autism, and the factors that are related to unemployment and underemployment, are critical to ensuring services and programmes are developed in a way that best targets the needs and desires for adults with autism when looking for employment. Additionally, further understanding of what it is that adults with autism actually desire when looking for employment or daytime activities is a field that is yet to be comprehensively explored. While some studies have reported that adults with autism and their families have a desire to gain employment, they would ideally like employment to play to the individual's strengths and interests (C. Anderson, Butt, & Sarsony, 2021). Further, employment may not be a goal for all adults. Gaining an understanding of the desires for daytime activity directly from adults with autism is essential in ensuring that programs and services meet their needs.

Particularly concerning is the considerable number of adults with autism who are not engaged in any daytime activity (Cedurland, Hagberg, Billstedt, Gillberg, & Gillberg, 2008; Farley et al., 2009; Gray et al., 2014; Knuppel et al., 2019). Taylor and Seltzer (2011) reported a significant difference between adults with and without co-occurring intellectual disability in terms of lack of daytime activity, with individuals without a co-occurring intellectual disability more likely to have no daytime activity. The number of participants included in the sample without intellectual disability, however, was small ($n = 17$ of 66). While these results should be interpreted cautiously, they do point to a trend in the literature of rates of disengagement from any daytime activity for adults with autism that is not restricted to those with intellectual disability. In their recent longitudinal follow up study of children who were referred for possible autism, now adults, Lord et al. (2020) reported that 20% of participants with autism and lower IQ (IQ < 70) had no planned daytime activities, as did 10% of participants with autism and higher IQ (IQ ≥ 70). This suggests that it is not just individuals with co-occurring intellectual disability who are not engaged in any daytime activity, although further research should explore the lack of activity for adults with autism and how they can be supported to engage in activities that are meaningful for them. Importantly, it is necessary to gain further insight and understanding from adults themselves about what activities they find meaningful and what supports they need to be able to engage in these activities.

2.4 PREDICTORS AND CORRELATES OF COMMUNITY INCLUSION

A number of factors have been identified in the literature as predictors of living arrangements, education, and employment in adulthood. Degree of intellectual disability, autism symptom severity, functional and daily living skills, age, and family income, have all been implicated. Understanding the factors related to community inclusion outcomes allows us to identify where interventions can be targeted and what additional supports are needed to

allow adults with autism to live independently. Further, identification of those most likely to require ongoing support from supported living arrangements enables policy and funding frameworks to be better informed about the individuals requiring these ongoing services.

2.4.1 Degree of Intellectual Disability and Adaptive Functioning

IQ and degree of intellectual disability have consistently been found to be predictive of community inclusion outcomes in adulthood. Those with more severe impairments are more likely to be living in supported residential accommodation or group homes than living independently or with family, less likely to be engaged in post-secondary education, and less likely to be engaged in paid employment (Billstedt et al., 2011; Gray et al., 2014; Helles et al., 2017; Howlin et al., 2013).

Significant differences have been reported for independent living arrangements for those with and without co-occurring intellectual disability, with adults with co-occurring intellectual disability more likely to remain dependant on others (Howlin et al., 2004). Even amongst adults with intellectual disability, individuals with more severe intellectual disability or lower IQ have been found to be significantly more likely to be living in supported living or groups homes than those with average IQ or no intellectual disability (Billstedt et al., 2011; Gray et al., 2014). A recent study conducted by Lord et al. (2020), however, reported no significant relationship between IQ and living situation. Further, low rates of independent living have been reported for adults without co-occurring intellectual disability (Howlin et al., 2013), highlighting the complexities in understanding the impact of IQ and intellectual disability on independent living.

The relationship between intellectual disability and daytime activity is more clear. Degree of intellectual disability in both childhood (Gray et al., 2014) and adulthood (Taylor & Seltzer, 2011) have been reported to be related to daytime activity for young adults with autism. In

particular, adults who were determined to have average intellectual functioning, borderline, or mild intellectual disability in childhood were more likely to be in paid employment as adults than participants with moderate or severe intellectual disability (Gray et al., 2014). Similarly, a significant relationship was reported by Taylor and Seltzer (2011) between presence of intellectual disability and daytime activity, with adults with a co-occurring intellectual disability more likely to be engaged in disability day programs than employment or education. Even amongst adults of average IQ, Lord et al. (2020) reported that adults with a higher verbal IQ were more likely to be employed.

Co-occurring intellectual disability has been demonstrated to be a significant factor in the ability of a person with autism to attend college or university. Taylor and Seltzer (2011) found, in a sample of young adults aged 19 to 25 years, 13.6% of participants were engaged in post-secondary education. Forty seven percent of those who did not have a co-occurring intellectual disability were engaged in post-secondary education, while only 2% of those with a co-occurring intellectual disability were. In addition to whether or not an individual is engaged in employment or education, Knuppel et al. (2019) highlight that the type of activity is often different for individuals with co-occurring intellectual disability. In their study, they report that individuals with a co-occurring intellectual disability were significantly more likely to be involved in customised or disability specific education or employment than a mainstream activity.

In addition to cognitive ability, greater daily living skills and adaptive functioning have been found to be associated with an increased likelihood of independent living in adulthood (K. A. Anderson et al., 2014; Dudley et al., 2019). In their nationwide study conducted in Sweden, Knuppel et al. (2019) found that adults in mainstream education and employment had better adaptive skills than those in disability specific services or no regular activity. There was,

however, no difference in adaptive skills between those in disability specific and no regular activities.

Despite the clear impact of co-occurring intellectual disability and lower IQ on outcome in adulthood, reviews have consistently identified that, even amongst adults without co-occurring intellectual disability, outcomes are limited (Howlin & Magiati, 2017; N = 43 studies). It is therefore crucial for research to consider the range of factors that may impact outcome above and beyond presence of intellectual disability. In particular, further exploration of the relationship between adaptive and functional skills and community inclusion is important. Adaptive and functional skills are able to be taught and therefore can be considered as targets for interventions aimed at improving community inclusion.

2.4.2 Autism Diagnosis and Symptomatology

The literature has consistently demonstrated that adults with autism fare worse in terms of community inclusion outcomes than adults with other disabilities and developmental disorders, including intellectual disability. Adults with autism have been reported to have lower rates of independent living, employment, and education opportunities (K. A. Anderson et al., 2014; Hewitt et al., 2017). These studies suggest that there are specific difficulties associated with having a diagnosis of autism that make these outcomes more difficult to achieve. Further, for those with a diagnosis of autism, severity of autism symptom has been implicated in impacting outcomes in adulthood.

There is some evidence that autism symptom severity, both in childhood and in adulthood, has a relationship with independent living in adulthood. In a sample of participants diagnosed with Asperger's Syndrome, and of average IQ, Helles et al. (2017) found a significant relationship between autism symptom severity in adolescence and living arrangement in

adulthood, with greater symptom severity reflecting those less likely to live independently in adulthood.

The research into post-secondary education in particular has found significant impacts of autism diagnosis and autism symptom severity. For young adults all of average IQ, Howlin (2003) reported that formal educational attainment was the only difference found between adults diagnosed with autism and adults diagnosed with Asperger syndrome. One study conducted in Sweden, however, reported that autism symptoms were not predictive of engagement in post-secondary education, with adults in their study attending post-secondary education at the same rate as the national average (Helles et al., 2017). Importantly, this study included a sub-group of participants who no longer met criteria for a diagnosis of autism.

2.4.3 Behaviour and Emotional Problems

The impact of behaviour and emotional problems, including psychopathology and psychiatric comorbidities, on community inclusion in adulthood is important to consider. Presence of mental health diagnoses and psychiatric conditions have been demonstrated to negatively impact overall quality of life in adults 55 years or older (Mason et al., 2019). Further, one study suggests that more severe behaviour and emotional problems in childhood were associated with less time spent engaging in daytime activities as an adult (Gray et al., 2014), while another reported that presence of maladaptive behaviours and psychiatric comorbidities were greater in adults with no participation in a regular daytime activity when compared to those who had a regular activity (Knuppel et al., 2019). While there is considerable research exploring mental health outcomes for adults with autism, few studies have investigated how mental health and behavioural and emotional problems may impact on community inclusion outcomes. This is an important area for future research to consider, as addressing behaviour and emotional problems may be a critical step in supporting independent living and engagement in meaningful daytime activities.

2.4.4 Age and Sex

Significant differences between age groups in terms of adult living arrangements have been identified in one study (Dudley et al., 2019). This study found that adults living in supported accommodation were significantly older than individuals living independently or with family (Dudley et al., 2019). No other studies have examined this relationship. To date, few studies have involved participants greater than 40 years old, with less still involving participants over the age of 50. With the autism population continuing to age, it is becoming increasingly important to understand how older adults with autism are living, particularly as the research highlights such large numbers continuing to live at home with ageing parents. The question of what will happen to ageing adults who are reliant on family and parent support as their parents pass away is a matter of critical importance.

There is limited evidence of any relationship between gender and community inclusion outcomes for adults with autism, largely due to the higher rate of diagnosis in males, and therefore fewer females recruited to research studies (Lord & DaWalt, 2020). Despite this, there is some evidence of gender differences in outcomes. In terms of employment, some studies have reported that women were more likely to have declining engagement in employment overtime, with no women in this longitudinal study being employed consistently over the course of the study (Taylor et al., 2015; Taylor & Mailick, 2014). One Australian study has specifically recruited females, and reports that females were significantly more likely than males to be enrolled in an education course, significantly more likely to have a preference for part-time work, and significantly more likely to live independently (Baldwin & Costley, 2016). This study, however, should be considered with caution, as participants were only included if they had no co-occurring intellectual disability, with the sample unlikely to be representative of all adults, or even all females, with autism. Further understanding of the

experiences of women, and the impact gender has on outcomes in adulthood, is an important area for future research.

2.4.5 Family Income and Socioeconomic Status

There have been inconsistent findings in relation to the association between family income and adult living arrangements. While one large study found that adults with a higher family income were more likely to live independently (K. A. Anderson et al., 2014), another study found no relationship between socio-economic status and living arrangements (Gray et al., 2014). A significant association between higher family income and better employment outcomes has also been reported (Roux et al., 2013). The impact of family socio-economic status, however, has rarely been examined in relation to adult outcome in the literature.

2.5 SUMMARY

It is evident that adults with autism experience challenges with community inclusion, particularly independent living, education, and participation in meaningful daytime activities. While a range of factors have been recognised across the literature as influencing these outcomes, both in childhood as well as in adulthood, there is still a way to go with understanding the complexity of these relationships and how adults can be best supported to live within their community how they choose to.

REFERENCES

Anderson, C., & Butt, C. (2017). Young adults on the autism spectrum at college: Successes and stumbling blocks. *Journal of Autism and Developmental Disorders, 47*, 3029-3039. doi:10.1007/s10803-017-3218-x

Anderson, C., Butt, C., & Sarsony, C. (2021). Young adults on the autism spectrum and early employment-related experiences: Aspirations and obstacles. *Journal of Autism and Developmental Disorders, 51*, 88-105. doi:/10.1007/s10803-020-04513-4

Anderson, K. A., Shattuck, P. T., Cooper, B. P., Roux, A. M., & Wagner, M. (2014). Prevalence and correlates of postsecondary residential status among young adults with an autism spectrum disorder. *Autism, 18*(5), 562-570. doi:10.1177/1362361313481860

Australian Bureau of Statistics. (2017). Autism in Australia. Retrieved from http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/4430.0Main%20Features752015

Baldwin, S., & Costley, D. (2016). The experiences and needs of female adults with high-functioning autism spectrum disorder. *Autism, 20*(4), 486-495. doi:10.1177/1362361315590805

Baldwin, S., Costley, D., & Warren, A. (2014). Employment activities and experiences of adults with high-functioning autism and Asperger's disorder. *Journal of Autism and Developmental Disorders, 44*, 2440-2449. doi:10.1007/s10803-014-2112-z

Billstedt, E., Gillberg, I. C., & Gillberg, C. (2011). Aspects of quality of life in adults diagnosed with autism in childhood. *Autism, 15*, 7-20. doi:10.1177/1362361309346066

Burchardt, T. (2004). Capabilities and disability: The capabilities framework and the social model of disability. Disability & Society, 19(7), 735-751. doi: 10.1080/0968759042000284213

Cedurland, M., Hagberg, B., Billstedt, E., Gillberg, I. C., & Gillberg, C. (2008). Asperger Syndrome and autism: A comparative longitudinal follow-up study more than 5 years after original diagnosis. *Journal of Autism and Developmental Disorders, 38*, 72-85. doi:10.1007/s10803-007-0364-6

Dudley, K. M., Klinger, M. R., Meyer, A., Powell, P., & Klinger, L. G. (2019). Understanding service usage and needs for adults with ASD: The importance of living situation. *Journal of Autism and Developmental Disorders, 49*, 556-568. doi:10.1007/s10803-018-3729-0

Eaves, L. C., & Ho, H. H. (2008). Young adult outcome of autism spectrum disorders. *Journal of Autism and Developmental Disorders, 38*, 739-747. doi:10.1007/s10803-007-0441-x

Elias, R., & White, S. W. (2018). Autism goes to college: Understanding the needs of a student population on the rise. *Journal of Autism and Developmental Disorders, 48*, 732-746. doi:10.1007/s10803-017-3075-7

Emerson, E., Fortune, N., Aitken, Z., Hatton, C., Stancliffe, R. J., & Llewellyn, G. (2020). The wellbeing of working-age adults with and without disability in the UK: Associations with age, gender, ethnicity, partnership status, educational attainment and employment status. *Disability and Health Journal, 13*(3), 100889. doi:10.1016/j.dhjo.2020.100889

Farley, M. A., Cottle, K. J., Bilder, D., Viskochil, J., Coon, H., & McMahon, W. M. (2017). Mid-life social outcomes for a population-based sample of adults with ASD. *Autism Research, 11*, 142-152. doi:10.1002/aur.1897

Farley, M. A., McMahon, W. M., Fombonne, E., Jenson, W. R., Miller, J., Gardner, M., . . . Coon, H. (2009). Twenty-year outcome for individuals with autism and average or near-average cognitive abilities. *Autism Research, 2*, 109-118. doi:10.1002/aur.69

Gray, K. M., Keating, C. M., Taffe, J. R., Brereton, A. V., Einfeld, S. L., Reardon, T. C., & Tonge, B. J. (2014). Adult outcomes in autism: Community inclusion and living skills. *Journal of Autism and Developmental Disorders, 44*, 3006-3015. doi:10.1007/s10803-014-2159-x

Hedley, D., Uljarevic, M., Cameron, L., Halder, S., Richdale, A., & Dissanayake, C. (2017). Employment programmes and interventions targeting adults with autism spectrum disorder: A systematic review of the literature. *Autism, 21*(8), 929-941. doi:10.1177/1362361316661855

Helles, A., Gillberg, I. C., Gillberg, C., & Billstedt, E. (2017). Asperger syndrome in males over two decades: Quality of life in relation to diagnostic stability and psychiatric comorbidity. *Autism, 21*(4), 458-469. doi:10.1177/1362361316650090

Hewitt, A. S., Stancliffe, R. J., Hall-Lande, J., Nord, D., Pettingell, S. L., Hamre, K., & Hallas-Muchow, L. (2017). Characteristics of adults with autism spectrum disorder who use residential services and supports through adult developmental disability services in the United States. *Research in Autism Spectrum Disorders, 34*, 1-9. doi:10.1016/j.rasd.2016.11.007

Howlin, P. (2003). Outcome in high-functioning adults with autism with and without early language delays: Implications for the differentiation between autism and Asperger syndrome. *Journal of Autism and Developmental Disorders, 33*, 3-13. doi:10.1023/A:1022270118899

Howlin, P., Goode, S., Hutton, J., & Rutter, M. (2004). Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry, 45*(2), 212-229. doi:10.1111/j.1469-7610.2004.00215.x

Howlin, P., & Magiati, I. (2017). Autism spectrum disorder: Outcomes in adulthood. *Current Opinion in Psychiatry, 30*, 69-76. doi:10.1097/YCO.0000000000000308

Howlin, P., Moss, P., Savage, S., & Rutter, M. (2013). Social outcomes in mid- to later

   adulthood among individuals diagnosed with autism and average nonverbal IQ as

   children. *Journal of the American Academy of Child & Adolescent Psychiatry, 52*(6),

   572-581. doi:10.1016/j.jaac.2013.02.017

Kamio, Y., Inada, N., & Koyama, T. (2012). A nationwide survey on quality of life and

   associated factors of adults with high-functioning autism spectrum disorders. *Autism,*

   17, 15-26. doi:10.1177/1362361312436848

Knuppel, A., Telleus, G. K., Jakobsen, H., & Lauritsen, M. B. (2019). Characteristics of

   young adults with autism spectrum disorder performing different daytime activities.

   Journal of Autism and Developmental Disorders, 49, 542-555. doi:10.1007/s10803-

   018-3730-7

Koegel, L. K., Ashbaugh, K., Koegel, R. L., & Detar, W. J. (2013). Increasing socialization

   in adults with Asperger's syndrom. *Psychology in the Schools, 50*(9), 899-909.

   doi:10.1002/pits.21715

Levy, A., & Perry, A. (2011). Outcomes in adolescents and adults with autism: A review of

   the literature. *Research in Autism Spectrum Disorders, 5*, 1271-1282.

   doi:10.1016/j.rasd.2011.01.023

Lord, C., & DaWalt, L. S. (2020). Working towards a better understanding of the life

   experiences of women on the autism spectrum. *Autism, 24*(5), 1027-1030.

   doi:10.1177/1362361320913754

Lord, C., McCauley, J. B., Pepa, L. A., Huerta, M., & Pickles, A. (2020). Work, living, and

   the pursuit of happiness: Vocational and psyschosocial outcomes for young adults

   with autism. *Autism, 24*(7), 1691-1703. doi:10.1177/1362361320919246

Mason, D., Mackintosh, J., McConachie, H., Rodgers, J., Finch, T., & Parr, J. R. (2019).

    Quality of life for older autistic people: The impact of mental health difficulties.

    Research in Autism Spectrum Disorders, 63, 13-22. doi:10.1016/j.rasd.2019.02.007

National Center for Special Education Research. (2011). *The Post-High School Outcomes of*

    Young Adults with Disabilities up to 8 Years After High School: A Report from the

    National Longitudinal Transition Study-2 (NLTS2) (NCSER 2011-3005*)*. Insitute of

    Education Sciences, U.S. Department of Education.

Nicholas, D. B., Zwaigenbaum, L., Zwicker, J., Clarke, M. E., Lamsal, R., Stoddart, K. P., . .

    . Lowe, K. (2018). Evaluation of employment-support services for adults with autism

    spectrum disorder. *Autism, 22*(6), 693-708. doi:10.1177/1362361317702507

Oliver, M. (2013). The social model of disability: Thirty years on. Disability & Society, 28(7)

    1024-1026. doi: 10.1080/09687599.2013.818773

Roux, A. M., T., S. P., Cooper, B. P., Anderson, K. A., Wagner, M., & Narendorf, S. C.

    (2013). Postsecondary employment experiences among young adults with an autism

    spectrum disorder. *Journal of the American Academy of Child & Adolescent*

    Psychiatry, 52(9), 931-939. doi:10.1016/j.jaac.2013.05.019

Saldana, D., Alvarez, R. M., Lobaton, S., Lopez, A. M., Moreno, M., & Rojano, M. (2009).

    Objective and subjective quality of life in adults with autism spectrum disorders in

    southern Spain. *Autism, 13*(3), 303-316. doi:10.1177/1362361309103792

Shattuck, P. T., Narendorf, S. C., Cooper, B. P., Sterzing, P. R., Wagner, M., & Taylor, J. L.

    (2012). Postsecondary education and employment among youth with an autism

    spectrum disorder. *Pediatrics, 129*, 1042-1049. doi:10.1542/peds.2011-2864

Steinhausen, H. C., Mohr Jensen, C., & Lauritsen, M. B. (2016). A systematic review and

    meta-analysis of the long-term overall outcomes of autism spectrum disorders on

adolescence and adulthood. *Acta Psychiatrica Scandinavica, 133*, 445-452.

doi:10.1111/acps.12559

Taylor, J. L., Henninger, N. A., & Mailick, M. R. (2015). Longitudinal patterns of

employment and postsecondary education for adults with autism and average-range

IQ. *Autism, 19*(7), 785-793. doi:10.1177/1362361315585643

Taylor, J. L., & Mailick, M. R. (2014). A longitudinal examination of 10-year change in

vocational and educational activities for adults with autism spectrum disorders.

Developmental Psychology, 50(3), 699-708. doi:10.1037/a0034297

Taylor, J. L., & Seltzer, M. M. (2011). Employment and post-secondary educational activities

for young adults with Autism Spectrum Disorders during the transition to adulthood.

Journal of Autism and Developmental Disorders, 41, 566-574. doi:10.1007/s10803-

010-1070-3

CHAPTER 3: SOCIAL INCLUSION IN ADULTHOOD

This chapter provides a review of the literature exploring social inclusion for adults with autism. Throughout this thesis, social inclusion refers to the integration of adults with autism in social settings, particularly relating to friendships and social experiences such as meeting up with friends. With deficits in social interaction and reciprocal relationships at the core of Autism Spectrum Disorder (American Psychiatric Association, 2013), difficulties in building and keeping social relationships and friendships are common amongst individuals with autism. The research suggests this difficulty continues into adulthood, with many adults with autism having few friendships or romantic relationships (Orsmond, Krauss, & Seltzer, 2004), even more so than adults with other developmental disabilities (DaWalt, Usher, Greenerg, & Mailick, 2019). While there is considerable research highlighting the importance of friendships and social relationships for emotional, physical, and psychological health in typically developing adults (Umberson, Crosnoe, & Reczek, 2010), very little is known about social relationships and their impact for adults with autism.

The impact of the 'double empathy problem' is important to consider when discussing friendships and social participation for adults with autism. This concept refers to the barrier created for adults with autism by being misunderstood and misperceived by people without autism (Mitchell, Sheppard, & Cassidy, 2021). Specifically, the literature highlights that the communication differences between individuals with and without autism impact understanding of each other. As a result, social communication between people with and without autism is likely to be more difficult than communication between individuals with autism (Crompton et al., 2021; Mitchell et al., 2021). These differences in perception, understanding, and communication are likely to lead to difficulties in building relationships, particularly between adults with autism and typically developing adults.

3.1   FRIENDSHIPS

Adults with autism often have difficulty making and maintaining meaningful and reciprocal friendships, with rates of young adults having at least one reciprocal friendship ranging from 8% to 33%, and as many as 46 - 56% having no friendships or acquaintances at all (Billstedt, Gillberg, & Gillberg, 2011; Eaves & Ho, 2008; Howlin, Goode, Hutton, & Rutter, 2004). These difficulties continue into later adulthood, with 63% of older adulthoods continuing to have no friendships or peer relationships (Howlin, Moss, Savage, & Rutter, 2013). It is important to note that these studies have all relied on caregiver report and have not taken the experience of the individual with autism into consideration. This is likely to have a considerable influence on the reporting of meaningful and reciprocal friendships, as parents and caregivers may be interpreting the relationships of the adult with autism based on their personal expectations and experience of what friendship is. For example, one study has suggested that 11% of adults with autism wanted friendships but did not know how to form them (Billstedt et al., 2011), however, this is based on parent report and observation, which is likely to be influenced by their own feelings on whether their children should want friendships, regardless of what the person themselves feel.

Consideration of the views of adults with autism themselves is important. A qualitative study undertaken by Sosnowy, Silverman, Shattuck, and Garfield (2018) further highlighted that adults with autism desire and seek friendships but often encounter difficulties due to social differences. These difficulties are likely to be further impacted by the perceptions of others, as described by the notion of the double empathy problem earlier in this chapter (Mitchell et al., 2021). In contrast to parent-report studies, when utilising a self-report interview, Helles, Gillberg, Gillberg, and Billstedt (2017) found 48% of adults with autism having two or more friends, 34% only having one close friend or acquaintance, and 18% having no friendships at all. This sample comprised a number of people who no longer met criteria for autism,

however, even when considering only the adults who continued to meet criteria for autism as adults, 78% of the sample had at least one friendship, and only 23% had no peer relationships (Helles et al., 2017). Mazurek (2014), found similar results using a self-report interview, with 60.2% of their participants, aged 18 to 62 years, identifying themselves as having a close or best friend. Importantly, neither of these studies included participants with intellectual disability, or at least required participants to be able to respond to questionnaires independently. As a result, these findings may not be generalisable to all adults with autism, however, the insight from adults themselves about their experiences of friendships is critical. It is important for future research to consider both the objective ratings of caregivers as well as the first-hand experiences of adults with autism, to gain a greater understanding of the nature and impact of social relationships in this population.

Both severity of autism symptomatology and IQ have been demonstrated to be significantly associated with having close friendships in adulthood (Helles et al., 2017; Howlin et al., 2004), however, few studies have examined this relationship. Helles et al. (2017) reported that autism severity measured at Time 1 of their longitudinal study was significantly associated with friendship ratings in adulthood. Further. Howlin et al. (2004) found a significant relationship between intellectual functioning and friendships in adulthood. A significant difference was found in this sample between those with an IQ greater than 70 in childhood, having more close friendships, and those with an IQ lower than 70, with only one individual in this group having a close friend (Howlin et al., 2004). Unsurprisingly, impairment in social skills has also been demonstrated to influence ability to form friendships, with greater impairment in this area leading to fewer friendships (Orsmond et al., 2004).

As the research on friendships in adults with autism is scarce, there has been little investigation into the potential benefits of positive friendships on overall wellbeing and

outcome. The research that has been undertaken in children with autism suggests that these children are at risk of experiencing loneliness, often leading to more negative emotional states, such as depression and anxiety (Mazurek, 2014). As the only study to investigate the protective nature of friendships in adults, Mazurek (2014) found that those with close friendships reported significantly less loneliness than those without friends. The effects of having positive relationships and friendships on overall wellbeing in adults with autism is an important area for future research to explore.

3.2   SOCIAL PARTICIPATION

Along with difficulties in maintaining friendships and relationships for adults with autism, social participation is significantly restricted. Social participation refers to the social contacts and engagement the individual has with others. For example, whether an individual meets up with friends or communicates with friends over the phone (double check definitions from studies below). A systematic review highlighted that the social participation for adults is often limited to involvement in social skills or support groups rather than involvement in social activities with friends, often leading to increased feelings of loneliness (Tobin, Drager, & Richardson, 2014; N = 13 studies, n = 454 participants). The research on social participation for adults with autism is limited, however, it is clear that social participation in adolescence is limited and impacted by difficulties with social communication and cognitive skills (Shattuck, Orsmond, Wagner, & Cooper, 2011). It is therefore likely that social participation continues to be limited into adulthood as social opportunities offered through school are no longer available.

The National Longitudinal Transition Study 2, undertaken in the United States, includes two items measuring social participation over the past 12 months, assessing the frequency and reciprocal nature of an individual's social participation (Liptak, Kennedy, & Dosa, 2011;

Myers, Davis, Stobbe, & Bjornson, 2015). At Wave 3 of the study, with participant's an average of 19.2 years old, more than half of participants (55%) had not met up with friends over the past 12 months, and 64% had not received phone calls from friends in this period (Liptak et al., 2011). A multiple linear regression analysis suggested that communication ability, social assertion, and speech at Wave 1 were related to the level of social participation at Wave 3 (Liptak et al., 2011).

Wave 5 of the study occurred when participants were in their early 20's (age 21 to 25 years), with social participation again measured in terms of frequency and social reciprocity over the previous 12 months (Myers et al., 2015; Orsmond, Shattuck, Cooper, Sterzing, & Anderson, 2013). While the social participation rates appear to have improved since Wave 3 (i.e. 38.6% of adults at Wave 5 having never seen friends in previous 12 months, compared with 55% at Wave 3) (Liptak et al., 2011; Orsmond et al., 2013), young adults with autism were significantly more likely to never see friends, never receive phone calls from friends, and never receive invitations to social events, than young adults with an intellectual disability, learning disability, or emotional disturbance (Orsmond et al., 2013). Factors such as continuing to live with parents, poor social skills, and low cognitive ability were demonstrated to contribute to social isolation in young adulthood (Myers et al., 2015; Orsmond et al., 2013).

3.3   LONELINESS AND SOCIAL SATISFACTION

While it is apparent that adults with autism often have restricted social participation, the limited research suggests that adults with autism are lonelier than typically developing adults, although continue to desire friendships and social relationships (Mazurek, 2014). Despite this, the experience and impact of loneliness in this population is overlooked in the literature.

In a study examining the experiences of support groups for adults with Aspergers Syndrome aged 24 to 75 years, Jantz (2011) reported that participants scored higher on the UCLA Loneliness Scale (Russell, 1996) than other populations (Jantz, 2011), however, no statistical analyses were undertaken to determine whether this difference was significant. This study did, however, report a significant relationship between loneliness score and number of close friends and social engagements (Jantz, 2011). Further, Jantz (2011) reported that a higher score on the Autism-Spectrum Quotient (Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001), measuring behaviours related to autism, was associated with higher loneliness scores. While this study did involve groups of people who were waiting, were in, or had left support groups, no significant difference was found on any loneliness or autism behaviour measures (Jantz, 2011), suggesting that involvement in social groups does not necessarily mediate feelings of loneliness.

Mazurek (2014) found loneliness to be significantly correlated with emotional functioning in a sample of adults diagnosed with autism. In particular, they demonstrated loneliness to be associated with greater depression and anxiety, and lower life satisfaction and self-esteem (Mazurek, 2014). This study did not report on whether participants had an intellectual disability, although relied on self-report data, suggesting most participants had the cognitive capability to respond to questions independently. As a result, a large proportion of adults with autism may have been missed in this study.

More recently, Lin and Huang (2017) compared the experiences of adults with autism to their neuro-typical peers in Taiwan and found that those with autism experienced significantly greater loneliness. This study also demonstrated a significant relationship between loneliness and both the psychological health and social relationship domains of quality of life. Regression analyses suggested the impact of loneliness to continue to be significant, even when taking other factors, such as autism symptom severity, into account (Lin & Huang,

2017). However, similarly to Mazurek (2014), adults with intellectual disability were excluded from this study. Some factors have been identified as being associated with greater experiences of loneliness in adults with autism, including gender (being female), fewer support persons, less satisfaction with social support, greater autism symptomatology, unemployment, and depression and anxiety (Ee et al., 2019) however, further research is needed to explore the impact of these factors.

Despite the evidence that adults with autism are more often lonely than typically developing adults (Mazurek, 2014), some qualitative literature highlights that some adults with autism are satisfied with being alone or seeing friends only occasionally (Ee et al., 2019). As would be expected for all adults, individual experiences of loneliness vary. It is therefore important to identify the barriers encountered by each individual in achieving their desired goal, whether that be to increase their socialisation or not. For example, Ee et al. (2019) highlight some barriers to being able to increase socialisation and therefore decrease loneliness include feeling misunderstood, experiencing difficulty with social skills, the exhaustive nature of social interactions and keeping up with conversation and social etiquette, and experiences of bullying.

Few studies involved participants with autism and a co-occurring intellectual disability. A recent systematic review found loneliness to be prevalent in nearly 45% of people with an intellectual disability (Alexandra, Angela, & Ali, 2018; N = 6 studies, n = 11,685 participants), therefore including people with an intellectual disability in these studies may have led to a greater understanding of the experience of loneliness for the wider autism population. Nevertheless, the limited research available highlights loneliness as an important factor in influencing the outcome and quality of life for adults with autism and this relationship warrants additional research to explore the prevalence and effect of loneliness further.

3.4 SUMMARY

It is clear that adults with autism experience difficulty with developing and maintain friendships and engaging in social activities, despite a desire to do so. This may be, in part, due to the lack of appropriate resources and programs to support adults with autism to participate in social activities and events. This, coupled with the common misperceptions of people with autism, is likely to impact the ability for adults with autism to maintain friendships and participate in social activities. Increased availability and accessibility of services and programs is critical to ensure adults with autism are given the opportunity to be included in social activities and is necessary to address the gap between desire to participate and actual participation.

Further, the experience of loneliness and social dissatisfaction is prominent. However, the research in this area is limited, particularly in relation to exploring the wider effects of isolation and lack of meaningful friendships on overall mental health and wellbeing for adults with autism. Future research is needed to continue to develop understanding of the experience of friendships and social participation for adults, as well as finding ways to support adults to develop friendships and increase social participation in a way that is meaningful to the individual.

REFERENCES

Alexandra, P., Angela, H., & Ali, A. (2018). Loneliness in people with intellectual and
developmental disorders across the lifespan: A systematic review of prevalence and
interventions. *Journal of Applied Research in Intellectual Disabilities, 31*(5), 643-
658. doi:10.1111/jar.12432

American Psychiatric Association. (2013). *Diagnostic and Statistical Manual for Mental
Disorders* (5th ed.). Washington, DC: American Psychiatric Association.

Baron-Cohen, S., Wheelwright, S., Skinner, R., Martin, J., & Clubley, E. (2001). The
Autism-Spectrum Quotient (AQ): Evidence from Asperger syndrome/high-
functioning autism, males and females, scientists and mathematicians. *Journal of
Autism and Developmental Disorders, 31*, 5-17. doi:10.1023/A:1005653411471

Billstedt, E., Gillberg, I. C., & Gillberg, C. (2011). Aspects of quality of life in adults
diagnosed with autism in childhood. *Autism, 15*, 7-20.
doi:10.1177/1362361309346066

Crompton, C. J., DeBrander, K., Heasman, B., Milton, D., and Sasson, N. J. (2021). Double
empathy: Why autistic people are often misunderstood. *Frontiers for Young Minds, 9,*
554875. doi: 10.3389/frym.2021.554875

DaWalt, L. S., Usher, L. V., Greenerg, J. S., & Mailick, M. R. (2019). Friendships and social
participation as markers of quality of life of adolescents and adults with fragile X
syndrome and autism. *Autism, 23*(2), 383-393. doi:10.1177/1362361317709202

Eaves, L. C., & Ho, H. H. (2008). Young adult outcome of autism spectrum disorders.
Journal of Autism and Developmental Disorders, 38, 739-747. doi:10.1007/s10803-
007-0441-x

Ee, D., Hwang, Y., Reppermund, S., Srasuebkul, P., Troller, J. N., Foley, K., & Arnold, S.

    (2019). Loneliness in adults on the autism spectrum. *Autism in Adulthood, 1*(3).

    doi:10.1089/aut.2018.0038

Helles, A., Gillberg, I. C., Gillberg, C., & Billstedt, E. (2017). Asperger syndrome in males

    over two decades: Quality of life in relation to diagnostic stability and psychiatric

    comorbidity. *Autism, 21*(4), 458-469. doi:10.1177/1362361316650090

Howlin, P., Goode, S., Hutton, J., & Rutter, M. (2004). Adult outcome for children with

    autism. *Journal of Child Psychology and Psychiatry, 45*(2), 212-229.

    doi:10.1111/j.1469-7610.2004.00215.x

Howlin, P., Moss, P., Savage, S., & Rutter, M. (2013). Social outcomes in mid- to later

    adulthood among individuals diagnosed with autism and average nonverbal IQ as

    children. *Journal of the American Academy of Child & Adolescent Psychiatry, 52*(6),

    572-581. doi:10.1016/j.jaac.2013.02.017

Jantz, K. M. (2011). Support groups for adults with Asperger syndrome. *Focus on Autism*

    and Other Developmental Disabilities, 26(2), 119-128.

    doi:10.1177/1088357611406903

Lin, L., & Huang, P. (2017). Quality of life and its related factors for adults with autism

    spectrum disorder. *Disability and Rehabilitation, 41*(8), 896-903.

    doi:10.1080/09638288.2017.1414887

Liptak, G. S., Kennedy, J. A., & Dosa, N. P. (2011). Social participation in a nationally

    representative sample of older youth and young adults with autism. *Journal of*

    Developmental & Behavioral Pediatrics, 32, 277-283.

    doi:10.1097/DBP.0b013e31820b49fc

Mazurek, M. O. (2014). Loneliness, friendship, and well-being in adults with autism

    spectrum disorder. *Autism, 18*(3), 223-232. doi:10.1177/1362361312474121

Myers, E., Davis, B. E., Stobbe, G., & Bjornson, K. (2015). Community and social

participation among individuals with autism spectrum disorder transitioning to

adulthood. *Journal of Autism and Developmental Disorders, 45*, 2373-2381.

doi:10.1007/s10803-015-2403-z

Mitchell, P., Sheppard, E., & Cassidy, S. (2021). Autism and the double empathy problem:

Implications for development and mental health. *British Journal of Developmental

Psychology, 39*, 1-18. doi: 10.1111/bjdp.12350

Orsmond, G. I., Krauss, M. W., & Seltzer, M. M. (2004). Peer relationships and social and

recreational activities among adolescents and adults with autism. *Journal of Autism

and Developmental Disorders, 34*(3), 245-256. doi:

10.1023/B:JADD.0000029547.96610.df

Orsmond, G. I., Shattuck, P. T., Cooper, B. P., Sterzing, P. R., & Anderson, K. A. (2013).

Social participation among young adults with an autism spectrum disorder. *Journal of

Autism and Developmental Disorders, 43*, 2710-2719. doi:10.1007/s10803-013-1833-

8

Russell, D. (1996). UCLA Loneliness Scale (Version 3): Reliability, validity, and factor

structure. *Journal of Personality Assessment, 66*, 20-40. doi:

10.1207/s15327752jpa6601_2

Shattuck, P. T., Orsmond, G. I., Wagner, M., & Cooper, B. P. (2011). Participation in social

activities among adolescents with an autism spectrum disorder. *PLOS One, 6*(11), 1-9.

doi:10.1371/journal.pone.0027176

Sosnowy, C., Silverman, C., Shattuck, P. T., & Garfield, T. (2018). Setbacks and successes:

How young adults on the autism spectrum seek friendship. *Autism in Adulthood, 1*,

44-51. doi:10.1089/aut.2018.0009

Tobin, M. C., Drager, K. D. R., & Richardson, L. F. (2014). A systematic review of social

    participation for adults with autism spectrum disorders: Support, social functioning,

    and quality of life. *Research in Autism Spectrum Disorders, 8*, 214-229.

    doi:10.1016/j.rasd.2013.12.002

Umberson, D., Crosnoe, R., & Reczek, C. (2010). Social relationships and health behavior

    across the life course. *Annual Review of Sociology, 36*, 139-157.

    doi:10.1146/annurev-soc-070308-120011

CHAPTER 4: "COMMUNITY PARTICIPATION FOR ADULTS WITH AUTISM: A SYSTEMATIC REVIEW"

4.1 PAPER COMMENTARY

This chapter presents a paper submitted for publication in the Journal of Applied Research in Intellectual Disabilities. Responses to reviewer comments have been submitted to the journal. This paper has been formatted to the specific requirements of the journal. Headings and page numbers have been renumbered and reformatted for consistency within the thesis.

Further to exploring community and social inclusion outcomes for adults with autism, the role of community participation on the day-to-day life for adults is an important element of outcome, and one that is particularly understudied in the adult outcome literature. Community participation refers to the ways in which adults with autism engage in community life, whether this be in online communities, organised group activities, or community events. However, the variation in measurement and description of community participation limits the ability to understand the current state of the literature. As a result, a systematic review was undertaken to comprehensively understand this concept and the role it plays for adults with autism. The review identified a range of areas in which adults with autism participate, as well as areas in which participation is different to both typically developing peers and peers with other developmental disabilities. Finally, the review highlighted factors that have been identified as being associated with community participation in addition to factors that require further exploration. Suggestions for future research to consider are discussed.

Cameron, L. A., Borland, R. L., Tonge, B. J., and Gray, K. M. (under review). Community participation for adults with autism: A systematic review. *Journal of Applied Research in Intellectual Disabilities.*

4.2 ABSTRACT

Background. This systematic review aimed to explore how adults with autism participate in the community, the impact of community participation on quality of life and mental health, and factors that support and hinder participation.

Method. A systematic review was conducted including studies published from inception to 17 January 2021.

Results. Sixty-three reports were included, reporting on 58 studies. Solitary activities, organised group activities, community activities, religious groups, and online social participation were identified. The relationship between community participation and quality of life was examined. Barriers and facilitators to increased community participation were identified. Most studies had a moderate to high risk of bias.

Conclusion. Adults with autism participate in a range of independent and community activities. The impact of community participation on quality of life and mental health warrants further exploration. Future studies should find effective ways of supporting adults with autism to participate in the community.

4.3 INTRODUCTION

Many individuals with Autism Spectrum Disorder, hereafter referred to as autism, experience poor social outcomes in adulthood; many do not live independently, struggle to find meaningful employment, and find it difficult to maintain social relationships (Gray et al., 2014b; Howlin, Goode, Hutton, & Rutter, 2004; Mason et al., 2021; Steinhausen, Mohr Jensen, & Lauritsen, 2016). While a focus of the literature has been on reporting overall outcomes in adulthood, less attention has been paid to understanding how adults with autism participate in the community, the benefits of participation, and the barriers and facilitators that may influence participation.

Engagement in informal groups, such as local social clubs or common interest groups, as well as participation in a range of recreation and leisure activities, are considered important factors in contributing to health and functioning for all people (World Health Organisation, 2001). Regular involvement in community, recreation, and leisure activities has positive impacts on quality of life in the general population, as well as for people with a range of physical, intellectual, and developmental disabilities (Andrews, Falkmer, & Girdler, 2015).

Systematic reviews highlight that individuals with autism are less likely to participate in community activities than both their typically developing peers, as well as those with other disabilities (Askari et al., 2015; Tint, Maughan, & Weiss, 2017). Children with autism generally participate less in community, recreation, and leisure activities than their typically developing peers (Askari et al., 2015), with evidence suggesting that participation declines through adolescence into adulthood (Myers, Davis, Stobbe, & Bjornson, 2015). However, there is evidence that individuals with autism may participate in more solo leisure and recreation activities than their typically developing peers, such as watching television, playing video games, or engaging in a hobby (Orsmond, Krauss, & Seltzer, 2004).

While there is some evidence describing a restricted pattern of community engagement and its impact on overall outcomes in children and youth with autism, there is comparatively less known about community participation in adulthood. more community activities in the previous 12 months (Myers at al., 2015). The measurement of community participation in this case, however, only required one instance of participation in a 12-month period. Similarly, Gray and colleagues (2014b) reported that 47% of adults (mean age 24.8 years) had participated in recreation or cultural group activities, and 38% had participated in community or special interest groups, in the previous three months. Orsmond et al. (2004) reported that a third of participants (35.3%) engaged in group recreational activities at least weekly, however, as adolescents and adults were reported together, it is not clear how regularly adults

were participating in these activities. Inconsistencies in both definition and timeline of community participation are evident across the literature, highlighted by these three studies. Additionally, there is little understanding of the impact of increased community participation on social and wellbeing outcomes for adults with autism.

While reviews of community participation in childhood and adolescence have been conducted and demonstrated that participation is often limited at this age (Askari et al., 2015; Tint et al., 2017), it is evident that community participation is different in adulthood, yet no similar reviews currently exist to support this. The current research of community participation for adults with autism involves inconsistent definitions of community participation, with the benefits of community participation on overall wellbeing not clear. Further, the reasons why adults with autism might not be participating in the community have not been well established. These are important elements to understand in order to support adults to engage in the community. As a result, this systematic review will consider the breadth of research, including quantitative and qualitative studies, to ensure that a complete view of community participation for adults with autism is captured.

The aims of this systematic review were to: (1) synthesise the available information on how, and how frequently adults with autism participate in the community, (2) identify the benefits of community participation on wellbeing, and (3) identify barriers and facilitators to engagement in the community. For the purposes of this review, *community participation* will include involvement in community, recreation, and leisure activities, whether undertaken in a group setting or alone. *Community participation* will not include employment and education related activities, due to recent reviews examining these areas (see Hedley et al., 2017; Scott et al., 2019).

4.4 Method

This systematic review followed the Preferred Reporting Items for Systematic Review and Meta-Analysis guidelines (Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009). This review was registered with PROSPERO, registration number CRD42018113064.

4.4.1 Inclusion and Exclusion Criteria

Studies that discussed community participation in any capacity were considered for inclusion. Inclusion criteria were: (a) participants at least 16 years old, (b) participants had an autism diagnosis, whether self-reported or confirmed by the study authors, (c) studies reported on involvement in community activities (such as sport, shopping, group events, religion), recreation, or leisure activities, (d) studies were randomised controlled trials, cohort, case-control, cross sectional, observational, longitudinal, qualitative studies, or grey literature. Studies were excluded if: (a) participants were under 16 years old or the study did not report on those 16 years or older separately, (b) participants were diagnosed with intellectual disability or developmental delay only (i.e. not autism), and (c) the study focused solely on employment or education.

4.4.2 Search Strategy

PsycInfo, Medline, and Scopus databases were searched using the identified search terms (see Table 4.1) for all articles published to 17 January 2021. Search terms were identified based on similar reviews conducted in children with autism (Askari et al., 2015) and adults with intellectual disability (Verdonschot, de Witte, Reichrath, Buntinx, & Curfs, 2009), and further refined through test searches. Search terms were combined with 'and' between domains, and 'or' within domains, with conventions adapted based on each database. Searches were limited to articles written in English. Reference lists of included reports and relevant reviews were hand searched for additional records, with no further records identified.

Table 4.1. Search terms

Community Participation	Population (diagnosis)	Population (age range)
"participation", "leisure", "recreation", "activit*", "sport*", "hobb*", "community involvement", "community inclusion", "community participation", "social participation", "social inclusion"	"autis*", "autism", "PDD", "pervasive developmental disorder", "Asperger",	"adult*"

Following the database search, duplicate records were removed, and all retrieved records were uploaded to Covidence (www.covidence.org), an online tool for managing systematic reviews. Title and abstract screening were undertaken by the first author (LAC) to exclude reports that were clearly not relevant to the current systematic review. Two reviewers (LAC and RLB) independently screened the full text of the remaining reports. Conflicts between decisions to include or exclude reports were resolved by discussion. A third reviewer (KMG) was involved where the first two reviewers were unable to come to an agreement. Figure 4.1 details the study selection process.
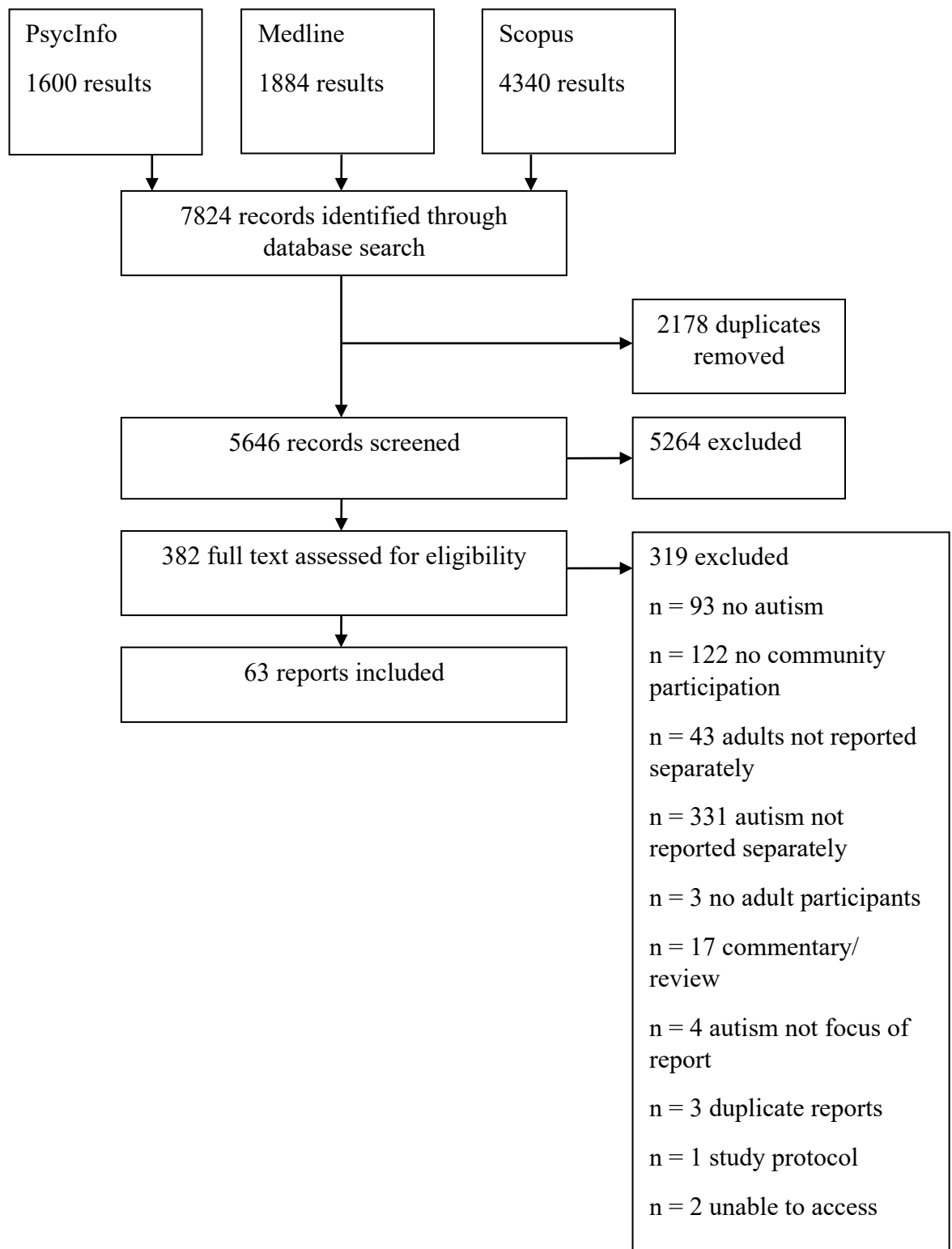
Figure 4.1 PRISMA flow diagram

4.4.3 Data Extraction

Data was extracted from each report by one author (LAC) and coded for (a) study information (type of study, country of publication, year of publication), (b) participant information (age, sex, autism diagnosis, degree of intellectual disability), (c) type of community participation (solitary, organised activities, community activities, religious participation, and/or online social activities), (d) frequency of participation (where reported), (e) impact of community participation (where reported; impact on quality of life, life satisfaction, and mental health), and (f) barriers and facilitators to community engagement (where identified; person-centred and environmental).

4.4.4 Data Synthesis

As the current review included both quantitative and qualitive studies, a data-based convergent synthesis design was undertaken (Hong et al., 2017). While data from quantitative and qualitative reports were extracted and summarised in the results tables separately, overarching themes emerging from the literature were discussed by incorporating both quantitative and qualitative data. This was achieved by grouping the findings into themes, and summarising the evidence from both the quantitative and qualitative literature within each theme.

4.4.5 Risk of Bias

Risk of bias assessment was conducted via consensus discussion between three authors (LAC, RLB, KMG) utilising pre-developed proformas based on the Cochrane risk of bias tool (Monash Centre for Health Research and Implementation, 2014) and the Newcastle-Ottawa Scale, a widely used tool for assessing the quality of nonrandomised studies (Wells et al., 2019). Each report was assessed as being of low, moderate, or high risk of bias.

4.5 RESULTS

A total of 7,824 records were retrieved in the search. After removal of duplicates, 5,646 records remained for abstract and title screening. A further 5,264 were excluded, leaving 382 for full text review. Sixty-three reports met inclusion criteria, with 58 unique studies identified. Details of each study can be found in Tables 4.2 and 4.3, including the study number, which is referenced throughout this review.

4.5.1 Study Characteristics

Studies were published between 1999 and 2020, with 57% of studies (n = 34) published in the last five years (2016 to 2020). Studies were 55 (85%) published, peer reviewed journal articles, and eight (12%) unpublished theses (nos. 17, 30, 32, 35, 40, 42, 48, 50). The studies were largely observational (n = 34; 52%), with eight including longitudinal data. Nineteen studies (29%) used qualitative methods. Ten studies (15%) were experimental designs. Most studies were undertaken in the United States of America (n = 34), with the remainder taking place in Australia (n = 9), Taiwan (n = 7), the United Kingdom (n = 4), Canada (n = 3), Spain (n = 2), India (n = 2), Sweden, Saudi Arabia, Germany, Israel, Nigeria, and the Netherlands (all n = 1) (note: some studies took place across two countries).

A total of 22,998 adults with autism were included in the review. Fourteen (24%) studies had more than 100 participants, and 26 $44%) had fewer than 20 participants. One study (no. 23) reported results based on a weighted population sample, accounting for 17,818 (77%) of the participants in this review. One study (no. 5) did not report the sample size of the autism sub-group included in their results, and is therefore not included in the cumulative total.

4.5.2 Risk of Bias

Six reports were considered to have a low risk of bias (9%). Thirty-seven reports (59%) had a moderate risk of bias. Seven of these (nos. 14, 15, 19, 24, 25, 27, 54) were assessed as

moderate risk of bias, rather than low risk of bias, only due to their lack of inclusion of participants with co-occurring intellectual disability.

Twenty reports (32%) had a high risk of bias. A high risk of bias was most often due to: no inclusion, or poor reporting, of participants with intellectual disability; no information provided on how autism diagnoses were determined; biased sampling methods; little to no demographic information provided; and in some cases, significant issues with interpretation of results and the impact of confounding variables.

4.5.3 Participant Characteristics

4.5.3.1 Age

Participants included in the review ranged in age from 16 to 90 years. Thirteen studies (22%) included participants aged 50 years or older, and participants in 26 studies (44%) were all younger than 30 years. Two studies (nos. 5, 8) only reported on the mean age for the overall sample and did not provide information for the participants with autism.

4.5.3.2 Gender

Most participants were male (77%), with eight studies exclusively male. Three participants identified as non-binary (nos. 1, 30, 49), two as transgender (no. 17), 11 as intersex (no. 17), and 10 reported their gender as 'other' (nos. 24, 27). Four studies (nos. 5, 8, 34, 50) did not report the gender breakdown of their samples, and one (no. 25) did not report the gender breakdown of the participants older than 16 years.

4.5.3.3 Autism diagnosis

Seven studies (12%) included diagnosis by the researchers, undertaking clinical diagnostic assessments using current diagnostic criteria (nos. 3, 12ab, 13, 14, 26, 28, 41). Eight studies (13%) undertook a review of a database or participant files to confirm diagnosis. This included review of government systems used to indicate those receiving government support

services (nos. 5, 8, 18, 19), review of diagnostic assessment records provided directly by service coordinators (nos. 22ab), review of physician and educational records (no. 47), and other files not described (nos. 52, 56). Nine studies (15%) relied on parent-report of their child receiving a diagnosis of autism by a professional (nos. 4, 10, 11, 23, 25, 36, 37, 40, 49). Twenty studies (35%) included participants with a self-reported autism diagnosis (nos. 1, 2, 7abc, 9, 16, 17, 21, 24, 27, 29, 30, 31, 32, 33, 35, 42, 43, 46, 48, 57). Five studies (10%) used other methods to identify participants with autism, such as recruiting from a school specifically for those with autism and from autism support groups and services (nos. 34, 38, 44, 45, 50). Five studies (8%) reported that participants had been diagnosed by a professional but did not report how this was determined (nos. 6, 15, 53ab, 54, 57). Four studies (7%) did not report how they acquired information about autism diagnoses (nos. 20, 39, 51, 55).

4.5.3.4 Intellectual disability

Inclusion of, and reporting on, participants with co-occurring intellectual disability, was inconsistent. Only 15 studies (26%) included participants with intellectual disability (nos. 3, 4, 6, 10, 11, 12ab, 13, 16, 22ab, 28, 40, 44, 51, 56, 58). Twenty-four studies (41%) did not include participants with intellectual disability (nos. 1, 2, 7abc, 14, 15, 19, 21, 24, 25, 26, 27, 29, 32, 37, 39, 41, 42, 43, 46, 48, 50, 53, 55, 57).Nineteen studies (33%) did not report presence or absence of co-occurring intellectual disability (nos. 5, 8, 9, 17, 18, 20, 23, 30, 31, 33, 34, 35, 36, 37, 45, 47, 49, 52, 53ab).

Table 4.2. Observational studies

	Article	Study Characteristics			Participant Characteristics			Key Findings	Risk of Bias[†]
		Country	Study Design	Sample Size	Gender	Autism & ID	Age		

Quantitative Studies

	Article	Country	Study Design	Sample Size	Gender	Autism & ID	Age	Key Findings	Risk of Bias[†]
1	Bailey et al., 2019	USA	Cross sectional	N = 42	67% male	Autism ID not reported	M = 21.76 (5.02)	Most time doing hobbies alone, some time hanging out with friends and participating in organised groups, least time in sports Hanging out with friends only type of participation significantly associated with subjective well-being	M
2	Baldwin & Costley, 2016	Australia	Cross sectional	N = 82	0% male	ASD No ID	18 – 64 years M = 32.7 (12.3)	33% would like to be (but were not currently) involved in a social group or club 27% preferred to be alone	M
3	Billstedt et al., 2011	Sweden	Longitudinal	N = 108	71% male	DSM-III Autistic Disorder or atypical autism 90% with ID	17 – 40 years M = 25.5 (6.4)	33% involved in regular recreational activities organised by others (horseback riding, bowling, and swimming) 44% enjoyed listening to music	M
4	Bishop-Fitzpatrick et al., 2017	USA	Longitudinal	N = 67	75% male	ASD 27.6% with ID	24 – 55 years M = 31.5 (6.7)	Average 3 recreational activities per week 95% watching TV/play video games 86.7% work on hobbies Recreational activities buffered impact of stress on QoL (higher levels of participation, negative effect of stress on QoL lessened) more than social activities	M
5	Carter et al., 2015	USA	Cross sectional	N = 12,706 ASD group sample size not reported	Overall: 58% male ASD: Not reported	ASD ID not reported	Overall: M = 42.3 (14.8) ASD group ages not reported	40.3% attended a religious service in the previous month 34.6% attended 3 or more times 89.1% had been shopping in past month 88.2% had been to a restaurant 75.8% went out for entertainment Participate less than adults with Down Syndrome, similar levels to those with behavioural challenges and other psychiatric disabilities	H
6	Chan et al., 2020	USA	Cross sectional	N = 124	81.1% male	ASD 56.6% ID	21 – 54 years M = 34.8	Higher daily living skills significantly related to increased attendance at religious services; more religious organisations in the local area was positively related to attending religious services, number of close-by bus	H

stops negatively related
Attending social skills groups or taking lessons (e.g. art, dance) not predicted by population density nor access to resources

7	a) Chen et al., 2015 b) Chen et al., 2016 c) Chen et al., 2017	Australian & Taiwan	Cross sectional	N = 30 Australian group: n = 14 Taiwan group: n = 16	Australian: 29% male Taiwan: 75% male	ASD: autism, Asperger Syndrome No ID	Australian group: 16 – 43 years M = 24.8 (9) Taiwan group: 19 – 45 years M = 27.8 (6.3)	Most time spent in solitary/parallel leisure activities (42.4%) Higher levels of interest and enjoyment in social activities and solitary/parallel leisure activities More severe ASD experience greater interest and enjoyment in solitary/parallel leisure than those with less severe ASD Majority of time spent at home (67.2%)	M
8	Chi et al., 2014	Taiwan	Cross sectional	N = 158,174 Autism: n = 800	Not reported	Autism ID not reported	Overall male: M = 56.27 (18.09) Overall female: M = 59.35 (18.33) Autism only not reported	Participation in society more impaired than for those with hearing impairment and mental retardation, but less impairment than schizophrenia, stroke, dementia, bipolar, visual impairment, depression, and spinal cord injury WHODAS score (i.e. level of impairment in functioning) increases as autism severity increases	M
9	Daley et al., 2014	India	Cross sectional	N = 54	82% male	Autism ID not reported	18 – 44 years M = 25.1 (6.2)	70.4% watched television for at least 30 minutes per day 37% use computer or iPad Many adults have very little to do during the day, nearly half of the sample do not have a daytime activity	L
10	Da Walt et al., 2017	USA & Canada	Longitudinal	ASD cohort; N = 226 Teen group: n = 106 Adult group: n = 120 Fragile X cohort; N = 81 Teen group: n = 37	ASD; Teen: 74% male Adult: 73% male Fragile X; Teen 78% male Adult: 89% male	Autistic Disorder No ID	ASD cohort; Teen group: M = 16.46 (2.26) Adult group: M = 32.20 (8.65) Fragile X cohort; Teen group: M = 18.66 (1.93) Adult group: M = 29.71 (5.67)	ASD less likely to engage in a hobby or spend time with friends than Fragile X, adults less likely to participate in sports or recreational activities Living away from parent: more social time with co-workers, recreation activities, going for walks, less engagement with religious service, hobbies (analyses across both diagnostic groups) Behavioural problems did not impact community involvement	M

							Adult group: n = 44		
11	Farley et al., 2018	USA	Longitudinal	N = 162	76% male	Autism 77% with ID (IQ 70 or below)	22.2 – 51.4 years M = 35.5 (6.1)	61% involved in organised groups 44% in one club/group 14% in two clubs/groups 3% in three or more 45% attended church (most of which belong to the Church of Jesus Christ of Latter-Day Saints) Other organised groups: martial arts, Special Olympics, self-advocacy organisations Social opportunities, particularly initiated by peers rather than parents or carers, desired to enhance the adult's QoL	M
12a	Felce et al., 2011	UK	Cross sectional	N = 427 ASD group: n = 158 No ASD group: n = 269	Overall: 58.5% male ASD: 54.4% male	ASD ID	15 – 86 years M = 45.5	Index of Community Involvement: Variety score, M = 7 Frequency score, M = 18 No significant difference between ASD and non-ASD	L
12b	Totsika et al., 2010	UK	Cross sectional	N = 819 ASD group: n = 281 Group aged 50 and over: n = 282 (n = 87 ASD) Group aged under 50: n = 537 (n = 194 ASD)	Overall: 52.7% male	ASD ID	Group aged 50 or over: M = 59.1 Group aged under 50: M = 35.9	Aged 50 and older, with ASD involved in a significantly lower variety of community activities (M = 6.8, SD = 2.7) than without ASD (M = 7.6, SD = 2.4). With ASD participated in community activities M = 19 (SD = 8.6) times in previous month (not significantly different to without ASD). With ASD significantly less time in activities (M = 38.8% of time) compared to without ASD (M = 58.7% of time). No significant difference in community engagement when matched on adaptive skills	L
13	Gray et al., 2014b	Australia	Longitudinal	N = 89	80.9% male	ASD 76% with ID	17.1 – 35.2 years	Community social involvement significantly greater than adults with mild-profound ID	L

							M = 24.8 (4.7)	Participation in recreational/cultural group activities, community/special interest groups significantly higher than general population Less participation in movies, theatres concerts (statistically significant) and attendance at church, café, restaurants and bars (not significant) than the general population Level of community involvement not associated with living skills	
14	Howlin et al., 2000	UK	Longitudinal	N = 39 Autism group: n = 19 Language delay group: n = 20	100% male	ASD No ID	Autism group: 21.3 – 26.7 years M = 23.9 (1.79) Language delay group: 21.10 – 28.2 years M = 24110 (1.56)	27.8% engaged in a range of activities outside the home on own initiative 11.1% infrequent activities on own initiative 5.3% few spontaneous outside adult interests 55.3% leisure activities arranged by others More reliant on others to organise leisure activities than comparison Language Delay group Less than half with adequate independence/daily living skills to allow them to participate independently (Vineland Daily Living domain)	M
15	Jennes-Coussens et al., 2006	Canada	Cross sectional	Asperger group: n = 12 Control group: n = 13	100% male	Asperger Syndrome No ID	Asperger group: M = 20.3 (1.3) Control group: M = 20.5 (1.3)	With Asperger Syndrome spent significantly more time in leisure than those without Asperger Syndrome (likely reflective of employment differences) With Asperger Syndrome spent time watching television/movies, surfing the internet, playing video games, reading Over half spent most of their time in solitary activities QoL rated lower in Asperger Syndrome than control group Significant difference only in social domain	M
16	Jozkowski & Cermak, 2019	USA	Experimental	ASD group: n = 18 NT group: n = 18	ASD: 89% male NT: 17% male	ASD 28% with ID	ASD group: Male, M = 22.3 years Female, M = 20.4 years NT group: Male, M = 18.6 years Female, M = 19.9 years	Exergames (boxing/tennis videogames) more enjoyable than traditional video games Playing with a partner increased enjoyment Those with ASD owned more videogame systems, played more frequently, played alone more often than NT peers Those with ASD engaged less in physical activity for recreation/leisure than NT peers 83% with ASD play videogames, usually alone, average 2.5 hours per day (compared with NT peers, 56% play videogames, usually with a friend, average of 0.75 hours per day; all significant differences)	H
17	Kidney, 2016	USA	Cross sectional	N = 324 ASD group: n = 151 Non-	ASD: 40.4% male Non-ASD:	Asperger's Syndrome or Autistic Disorder ID not	18 – 74 years M = 37.44 (12.75) ASD group: M = 36.96	82% accessed forums, blogs, Wikipedia, other webpages 82% used social networking sites Significant positive relationship between involvement in online autistic community and autistic identity	H

				ASD group: n = 173	38.2% male	reported	(12.32) Non-ASD group: M = 37.92 (13.10)		
18	Lin et al., 2012	Taiwan	Cross sectional	N = 81	85.2% male	Autistic Disorder Asperger Syndrome PDD-NOS ID diagnosis not clear	18 – 48 years M = 22.8 (5.1)	55.6% used a computer most days 38.3% used a phone most days Difficulties engaging in outdoor and leisure activities Leisure/work domain of Instrumental Activities of Daily Living: M = 9.3 (SD = 3.3)	M
19	Lin et al., 2020	Taiwan	Cross sectional	N = 5374 Autism: n = 670 ID: n = 4455 CCI: n = 110 Combination of any two diagnoses: n = 139	88.1% male	Autism No ID	M = 23.19 (7.73)	Domain 6 (Participation in Society) on the WHODAS: M = 32.41 (23.06) No significant difference in Domain 6 score based on urbanisation (i.e. where the participant lived) With autism scored significantly lower (i.e. experienced less impairment in participation in society) than ID, CCI, and combination	M
20	Mashat et al., 2016	Saudi Arabia	Cross sectional	N = 13	77% male	ASD ID diagnosis unclear	15 – 28 years* M = 20.6 (5.02)	Use of social media and social networks differed considerably Some reported using social media to post content they are interested in (comedy videos, photos of their own drawings or artwork, videos of self talking about their life), rather than for social reasons	H
21	McCollum et al., 2016	USA	Cross sectional	N = 24	71% male	Autism or Asperger Syndrome No ID	18 – 25 years M = 20 (2.1)	100% watched TV, listened to music, ate at a restaurant in past 6 months 58% went to a place of worship No difference between those who worked competitively or in a sheltered workshop in terms of engagement in leisure or social activities Majority of activities engaged in were solitary (Internet, watching television, completing chores, time with family) Higher family income associated with more participation in leisure activities	M
22	a) Mehling & Tasse,	USA	Cross sectional	N = 1772 ASD	ASD: 75.4%	ASD Range of ID	ASD group: M = 33.58 (0.59)	No significant difference between participants with autism and participants with other developmental disabilities on levels of social participation	M

	2014 b) Mehling & Tasse, 2015			group: n = 886 Other DD: n = 886	male Other DD: 75.2% male	reported	Other DD group: 43.35 (0.70)	Access to services and supports contributed significantly to social participation outcomes	
23	Myers et al., 2015	USA	Longitudinal	N = 17,818 (weighted population)	83% male	ASD ID not reported	21 – 26	46% paricipated in one or more community activities in previous 12 months (significant decrease from adolescence (63%)) Higher family income, utilisation of case management services associated with improved community participation	M
24	Pearlman-Avnion et al., 2017	Israel	Cross sectional	N = 31	58% male	ASD No ID	17 – 62 years M = 27.79 (11.30)	Individuals in a relationship reported higher level of social belonging/community inclusion than those not in a relationship	M
25	Ratcliff et al., 2018	USA	Cross sectional	N = 35,280 ASD group: n = 823	Overall: 50.9% male ASD: 82% male	ASD No ID	6 – 17 years‡ Overall: M = 12.1 (3.4) ASD group: M = 12 (3.3)	Results for the 16-17 year olds: With ASD participated significantly less than controls in physical activities, social activities, skill activities, jobs/chores No difference in solitary recreational activities	M
26	Schmidt et al., 2015	Germany	Cross sectional	N = 87 ASD group: n = 43 Non-ASD group: n = 44	ASD: 37% male Non-ASD: 43% male	ASD No ID	ASD group: M = 31 (10) Non-ASD group M = 30 (5)	WHODAS 2.0, Participation in Society subscale: Significantly greater impairment in participating in society (M = 46.6, SD = 26.9) than nonclinical sample (M = 15.7, SD = 19.7) No significant difference between ASD and nonclinical participants for satisfaction with leisure time Participation in society only significant predictor of life satisfaction (explaining 49% of the overall variance); less difficulties reported with participation, more satisfied with their life	H
27	Stacey et al., 2018	Australia	Cross sectional	N = 249 ASD group: n = 145 NT group: n = 104	ASD: 40% male NT: 22% male	ASD No ID	25 – 85 years ASD group: M = 42.7 (12.4) NT group: M = 43.5 (13.6)	Significant difference between ASD and NT groups in frequency of: visiting family/friends, attending sporting/cultural events No significant difference in using electronic chat rooms/forums, physical activities, attending museums, libraries or national parks, surfing the Internet, arts/crafts/hobbies at home, watching TV/listening to music With ASD significantly less satisfied with leisure than NT participants Younger age, less depressive symptoms significantly associated with higher leisure satisfaction SES not associated with higher leisure satisfaction	M

28	Taylor et al., 2017	USA	Longitudinal	N = 36	83% male	ASD 27.8% with ID Mean IQ = 85.33 (25.65)	At baseline: 17 – 22 years M = 18.71 (1.30)	Average amount of participation in unstructured social activities (time with friends/family) did not change over time (high school to after high school) Structured social activities (church, organised groups, sports) significantly declined after high school More structured activities in high school related to increases in unstructured social participation after high school Internalising problems in high school related to few unstructured social activities after high school Fewer internalising problems, greater increases in both types of activities Social activities did not significantly predict change in internalising symptoms	L
29	Wang et al., 2014	Taiwan	Cross sectional	Autism group: n = 11 TD group: n = 11	Autism: 73% male TD: 73% male	Autism or Asperger Syndrome No ID	18 – 25 years Autism group: M = 21.5 (2.4) TD group: M = 21.6 (2.2)	With autism participated significantly less than TD peers on 9 out of 61 possible activities: 'hanging out', dating, driving/riding scooter, entertaining friends, leading a group, going to karaoke With autism participated significantly more than TD peers in: watching television, using public transport Participants with autism participated the most in: listening to music, reading, surfing the internet, using public transport, watching television Participants with autism participated the least in: dating, going to karaoke, having a committed relationship, driving/riding a scooter Barriers to participation: sensation issues, attention difficulties, lacking appropriate resources, not having enough time, not thinking of it	H
30	Ward, 2016	USA	Cross sectional	N = 110	60.9% male	57.3% Asperger Syndrome 25.5% ASD 17.3% autism ID not reported	18 – 57 years M = 29	Social media used by 86% Most used social media sites: Facebook (50.9%), Twitter (18.2%), none (14.5%) Most used social media site used for M = 2.68 hours per day (overall social media use, M = 5 hours per day) Significant difference in happiness scores for social media users compared to non-users (big difference in group sizes) No significant difference on life satisfaction for social media users and non-users	H

Qualitative Studies

31	Buchanan et al., 2017	USA	Qualitative	N = 7	86% male	ASD ID not reported	18 – 42 years	Parents used a variety of strategies to encourage children to participate in physical activity Parents sought out external agencies/organisations to provide support Barriers to participation: loss of interest in activity, lack of physical ability (coordination, motor skills, overweight), anxiety	M
32	Finke et al.,	USA	Qualitative	N = 10	90%	Asperger	18 – 24 years	Reasons for videogame play as leisure: friendship (playing with friends,	H

#	Author, Year	Country	Design	N	Sex	Diagnosis	Age	Findings	
	2018				male	Syndrome or Autistic Disorder No ID	M = 21	meeting new people); emotion (stress relief, having fun); functioning and skill (improved focus, motor skills); escape/being creative (seeing different worlds, escaping the real world) Most participants perceived playing videogames as having a positive impact on their lives	
33	Galler, 2013	USA	Qualitative	N = 15	73% male	ASD ID not reported (varying degrees of ability noted)	19 – 33 years M = 24.7 (4.7)	Participants engaged in activities that were structured and organised by others (e.g. through residential setting, day program): basketball, bowling, volunteering, going out for lunch, swimming, martial arts, Special Olympics Participants highlighted the importance of having support from family and staff in allowing them to engage in various activities, as well as the support and comfort they felt various activities offered them Some participants discussed the importance of religion in their lives in giving them a sense of connectedness and belonging	M
34	Haertl et al., 2013	USA	Qualitative	N = 24	Not reported	ASD ID not reported	27 – 55 years	Desire to participate in social activities, but many found this difficult, instead participated in solitary leisure activities Barriers: difficulties with social skills, difficulties forming friendships/relationships Solo leisure activities: biking, baking, reading, computers Some participants identified sports as a way to develop social relationships	H
35	Jones, 2016	USA	Qualitative	N = 8	100% male	Autism ID not reported	18 – 24 years	Social experiences reported: social media or other apps for communication, organised groups Some reported no interest in social or community activities Barriers: communication/social difficulties, preferred being alone	M
36	Joshi, 2020	India	Qualitative	N = 1	100% male	Autism ID not reported	24 years	Leisure activities: chess, Sudoku, watching videos on YouTube Dislikes watching television	H
37	Kersten et al., 2020	Australia	Qualitative	N = 17 N = 15 parents	88% male	Autism or Asperger's Syndrome No ID	17 – 26 years M = 19.6	Online gaming and social media important for filling need for belonging and social contact; possibly decreases motivation for face-to-face participation Structured community activities important for providing opportunities to increase community participation/leading to further opportunities to learn independence in the community	M
38	Koffer Miller et al., 2018	USA	Qualitative	N = 36	64% male	Autism ID not reported	21 – 29 years (58%) 30 – 39 years (28%)	Programs provided opportunities to engage with other adults with autism, to engage in their community Desire for opportunities for community participation that are not specifically for people with autism or other disabilities	M

							40+ years (14%)	Programs did not always provide sufficient support to participants to allow them to meet their goals
39	Liu et al., 2014	USA	Qualitative	N = 20 ASD group: n = 12 ID group: n = 8	70% male	ASD No ID	13 – 21 years‡ M = 16.9 (2.4)	13 participants participated worship services, Sunday school, retreats, camps 6 participants described a sense of belonging	M
40	Marquette, 2007	USA	Qualitative	N = 15 parents	Not reported	ASD Some participants with ID	18 – 32 years	5 participants were able to drive and independently access the community for personal or leisure activities Leisure activities: solo activities (watching television, computer, reading), attending movie theatres/plays/musicals, physical activities (riding a bike, roller skating), shopping, volunteering Community participation often involved integrating special interests into routine or community experiences	H
41	Mazurek et al., 2015	USA	Qualitative	N = 58	86.2% male	ASD No ID	17 – 25 years M = 20.5 (2.0)	Reasons for playing video games: fun/entertainment, relief from anxiety/stress, escape from reality Social relatedness reported by 20% of participants, (video games a shared activity with friends/family) Some reported compulsive or addictive reasons for game play	M
42	McEvoy, 2016	USA	Qualitative	N = 5	100% male	ASD No ID	19 – 24 years	Reasons for playing MMORPGs: socialisation with friends, improving competence/ability in the game, immersion in the game through attachment to a character, relieving boredom or stress	H
43	Muller et al., 2008	USA	Qualitative	N = 18	72% male	Asperger Syndrome or ASD No ID	18 – 62 years M = 37.2 (14.6)	Desire to use time to contribute, by volunteering, and helping others with ASD by organising support and advocacy groups Importance of sharing interests and activities with others by joining various groups (chess, jogging, hiking etc.) Some activities create a shared focus with others but require minimal interaction, (listening to books on tape, watching television/movies together) Enjoyment of structured social activities (church, public speaking group, choirs, bands, dance classes): predictable, sense of community Importance of alone time as a coping strategy, as well as enjoying time by themselves	M
44	Muller & Cannon,	USA	Qualitative	N = 23 (parents	78% male	ASD ID	19 – 27 years	44% of parents perceived that their children were *very satisfied* with their social and community life	M

	2016					as proxies reporting on behalf of their children)			75% of young adults belonged to one or more organised community groups (mostly sports groups for people with disabilities) Social clubs, religious groups, community outings for people with disabilities were commonly reported activities Few young adults were involved in community groups that integrated individuals with and without disabilities Some parents reported their children enjoyed the social nature of these groups, others suggested their children enjoyed going out and doing activities irrespective of the social element Others reported their children were content with minimal social interaction Barriers: lack of opportunities to be involved in social groups, difficulty gauging child's satisfaction with activities, the need for parents to spend considerable time facilitating activities	
45	Nichols et al., 2019	USA	Qualitative	N = 8	100% male	Autism ID not reported	22 – 28 years	Facilitators: parent factors (parental attitudes, physical activity habits, financial resources, and time), behaviours associated with autism (for example, routine), access and opportunities (e.g., Special Olympics program, local community exercise facilities, community programs) Barriers: parent factors (parent attitudes toward physical activity, concerns about participation), behaviours associated with autism (e.g., lack of interest, preoccupations with other objects/tasks, motor skills, aggression, hypersensitivity, cognitive abilities, unpredictable behaviours), access and opportunities (e.g., location)	H
46	Turcotte et al., 2015	Canada	Qualitative	N = 3 N = 5 parents	66% male	ASD No ID	19 – 34 years M = 26.7 (7.5)	Barriers: limited access to resources, needs unmet by available resources, difficulty finding suitable activities, leisure participation mostly solitary and sedentary, limited opportunity for leisure and community activities Particular difficulty with independently identifying, planning and organising activities	M

†Risk of bias (H = High, M = Moderate, L = Low); ‡Results reported only for those participants 16 years or older; ASD = Autism Spectrum Disorder; DD = developmental disability; CCI = Concomitant Communicative Impairment; HRQOL = health related quality of life; ID = ID; MMORPGs = massively multi-player online role-playing games; NT = neurotypical; PDD-NOS = Pervasive Developmental Disorder – Not Otherwise Specified; TD = typically developing; QoL = quality of life; WHODAS = World Health Organisation Disability Assessment Schedule

Table 4.3. Intervention studies

	Article	Study Characteristics			Participant Characteristics			Intervention	Key Findings	Risk of Bias†
		Country	Study Design	Sample Size	Gender	Autism & ID	Age			
47	Akabogu et al., 2019	Nigeria	Randomised controlled trial	N = 86 (treatment: n = 43, control: n = 43)	37% male (treatment, 33% male, control, 42% male)	ASD ID not reported	Treatment: M = 23.36 (SD = 1.10) Control: M = 24.01 (SD = 2.80)	Language Education Intervention 28 group sessions: 2 hours, 2x per week, 14 weeks Focus is to improve cognitive abilities, adaptive skills, and rational thoughts to increase social participation	At post-intervention, a significant increase in social participation for those in the treatment group when compared to the control group Long term follow up demonstrated an additional significant increase in social participation for those in the treatment group compared to control	M
48	Ashbaugh, 2017	USA	Case series	N = 3	33% male	ASD No ID	P1: 24 years P2: 21 years, 4 months P3: 19 years, 2 months	Structured social planning 10 weeks, 1 hour per week Focus on supporting participants to choose social activities, develop necessary skills	2 participants increased the number and hours of weekly social and community-based activities, and 1 participant maintained a consistent amount All participants increased the scope of their activities 2 participants increased the number of independent social and community-based activities they participated in, and 1 participant maintained a consistent amount All participants reported increases in their satisfaction with the number of social activities they attend Participants reported consistent levels of wellbeing throughout the intervention, and improved academic performance	M
49	Ashburner et al., 2018	Australia	Qualitative evaluation	N = 11	73% male	ASD ID not reported	17 – 21 M = 19 (1.61)	Community social programme (Studio G: mentor/mentee design with the aim to support participants to engage in a range of multimedia experiences, such as graphic design, photography,	Regular engagement in this organised group promoted increased social participation, development of friendships, skill development, and opportunities for other social/community activities (such as café outings with the group)	H

								animation etc.)		
50	Bourdeau, 2019	USA	Quasi-experimental	N = 38	Not reported	ASD No ID	18 – 40 years	Adult Social Groups (monthly meetings for adults with autism to attend group activities in the community, for example, bowling, mini-golf, paddle boarding, going out for dinner)	Scores on the SRS-2 overall score, SRS-2 communication subscale, and the SELSA all significantly decreased (i.e. improved) from the pre-test measurement to post-test	H
51	Burckley et al., 2015	USA	Case study	N = 1	100% female	PDD-NOS ID (FSIQ = 54)	18 years	Visual cues and video prompting on an iPad to teach shopping and community skills	Participant's ability to complete steps of the shopping task independently increased following intervention, but varied widely from 10-100% of steps completed

The participant still required instructor support to hold and navigate the iPad during the task following intervention | H |
| 52 | Cashin et al., 2019 | Australia | Qualitative evaluation | N = 6 | 100% male | ASD ID not reported | 19 – 24 years | Social gaming group (weekly meetings for adults with ASD to share their interest in gaming: 2-4 player games, tournaments, recording commentaries and filming other people playing, uploading material to YouTube and sharing information about games) | Participants discussed 1) making friends and social contact (confidence in talking to others about a shared interest, social interaction moving beyond the group itself to social media contact), and 2) getting out of the house (attendance at the group being the only time they leave their home and communicate with people outside of their families) | H |
| 53a | Garcia-Villamisar et al., 2010 | Spain | Randomised controlled trial | Treatment group: N = 37

Control group: N = 34 | Treatment group: 59% male

Control group: 56% male | ASD ID not reported | Treatment group: M = 31.49 (4.83), 17 – 39

Control group: M = 30.06 (3.44), 24 – 38 | 12 month Leisure Programme 2 hours x 5 days per week Participated in a range of leisure activities Treatment group participated in a range of leisure activities Wait list control | Scores on the Stress scale decreased significantly in the Leisure Group compared to the waitlist control QoL significantly improved for the Leisure Group when compared to the control | M |
| 53b | Garcia-Villamisar | Spain | Randomised controlled | Treatment group: N = | Treatment group: | ASD ID not | Treatment group: M = | 12 month Leisure Programme | Increase in Vineland composite score in Leisure Group | M |

#	Author	Country	Design	N	% male	Diagnosis	Age	Intervention	Results	Quality
	et al., 2011		trial	20 Control group: N = 20	27.5% male Control group: 65% male	reported	32.05 (3.14), 27 – 38 Control group: M = 31.75 (3.65), 24 – 38	2 hours x 5 days per week. Treatment group participated in a range of leisure activities. Wait list control	Some improvements seen in emotion processing and recognition, and some aspects of executive functioning, although mixed results	
54	Kern Koegel et al., 2013	USA	Multiple baseline case series	N = 3	100% male	Asperger Syndrome No ID	P1: 23 years, 11 months P2: 21 years, 6 months P3: 21 years, 7 months	Structured social planning intervention. 33 weeks, 1 hour per week	Increase in the number of social activities attended by each participant from the start of the intervention, and this as maintained at follow up Quality of life (including social, academic, and employment domains) and socialisation improved	M
55	Macleod, 1999	UK	Qualitative evaluation	N = 8	63% male	Asperger Syndrome No ID	19 – 38	Community support scheme (pilot scheme)	Case studies suggest that some participants had been able to access greater opportunities for community participation, for example, joining group and engaging in leisure and recreational activities with others	H
56	Nepo, 2017	USA	Multiple baseline case series	N = 6	50% male	ASD ID	34 – 45 years M = 39 (4.385)	Most-to-least prompting procedure using an iPad. Aim to improve independent leisure skills (playing on an iPad app)	Following intervention, caregivers reported engagement in more leisure activities on the iPad, that the use of the iPad was beneficial, and the iPad promoted various leisure activities Following the most-to-least prompting teaching procedure, participants were able to independently complete M = 87.86% of tasks required to engage in an iPad app, and maintained this during generalisation trials Duration of leisure engagement with the iPad increased from M = 0 minutes to M = 2.5 minutes per trial following intervention Leisure skills taught were isolated to using the specific apps in this study, and not necessarily generalizable to other leisure activities	L
57	Palmen et al., 2011	The Netherlands	Non-randomised controlled	N = 12 (treatment: n = 7,	Treatment, 71% male Control,	ASD No ID	16 – 31 years M = 20.75	6 month Leisure Programme (leisure management and leisure engagement)	Larger decrease seen in need for leisure support in experimental group than control group, although not statistically significant	H

									†
	trial	control: n = 5)	100% male		(4.45)		15 group sessions, 2.5 hours Once a week (first 4 sessions), once evert 6 weeks (last 2 sessions) No-intervention control group	Significant increase seen in engagement in solitary leisure activities for the experimental group, but no significant changes in other community activities (for example, attendance at organised clubs) Significant increase in leisure satisfaction following intervention	
58	Parsons et al., 2009	USA	Multiple baseline case study	N = 1	100% female	ASD Severe to profound ID	32 years	SWAT Support intervention (Say, Wait and Watch, Act out, Touch to guide) Aim to teach simple community skill (grocery shopping)	Following intervention, participant able to independently complete each of the two tasks taught (push shopping cart, place item in shopping cart). Independence maintained at 5 week follow up	M

†Risk of bias (H = High, M = Moderate, L = Low); ASD = Autism Spectrum Disorder; FSIQ = full scale intelligence quotient; ID = ID; PDD-NOS = Pervasive Developmental Disorder – Not Otherwise Specified; QoL = quality of life; SELSA = Social Emotional Loneliness Scale for Adults; SRS-2 = Social Responsiveness Scale, 2nd Edition

4.5.4 Types of Community Participation

Five broad categories of community participation were identified - solitary activities, organised activities, community activities, religious activities, and online social participation.

4.5.4.1 Solitary activities

Solitary activities, such as watching television, engaging in hobbies, listening to music, and reading were reported in 19 studies (33%). Whilst not explicitly community activities, the participation of adults with autism in solitary activities is important to consider as, for many adults, these activities take up most of their time. One study (nos. 7abc) suggested that adults with autism spent the largest portion of their time engaging in solitary leisure activities (42.4% of time). While some qualitative studies (no. 2, 35) reported that participants preferred to be alone, another (no. 34) reported that participants often found social activities difficult and therefore chose solitary leisure activities. Watching television or playing videogames were identified as regular activities, with 70.4% to 100% of participants frequently spending time in these activities (nos. 4, 9, 15, 21, 27, 29). Other solitary activities included spending time on hobbies, using a computer or iPad for games or surfing the internet, reading, watching videos on YouTube, and listening to music (nos. 1, 3, 4, 9, 10, 15, 18, 21, 27, 29, 34, 36, 40).

Four studies compared engagement in solitary activities for adults with autism to other populations, with differing results. One study (no. 10) identified that, while adults with autism engaged in hobbies on average 54 times per year (i.e. at least weekly), they participated less frequently than same aged peers with Fragile X syndrome. When compared to typically developing peers, two studies found no significant difference in solitary engagement in leisure/recreation activities in young adults aged 16 to 17 years (no. 25) and adults aged 25 to 70 years (no. 27). Another suggested that young adults, aged 16 to 25 years,

with autism participated in solitary activities significantly more than typically developing peers (no. 29). None of these studies included participants with co-occurring intellectual disability and only one (no. 10) had a low risk of bias.

4.5.4.2 Organised activities

Participation in regular organised activities, such as interest groups or social groups, was reported in 17 studies (29%). One study (no. 11) reported that 61% of participants were involved in regular organised groups, with some involved in two or more, including church related social groups, martial arts classes, Special Olympics, and self-advocacy groups. A lower rate of participation was reported in another study (no. 3), where only 33% were involved in regular organised recreational activities, such as horseback riding, or swimming. These two samples were similar in terms of age, gender, and intellectual disability. Involvement in volunteer groups (no. 15), structured community support and activity groups (nos. 1, 48, 52, 55), and organised sport (no. 1) were also identified. One study (no. 2) noted that 36% of participants (all females without co-occurring intellectual disability) reported a desire to be involved in a social group yet were not currently involved.

Three studies evaluated the benefits of involvement in structured special interest social groups via qualitative interviews with participants (nos. 49, 52, 55). These included programs designed to support engagement in multimedia experiences (e.g. photography, animation) (no. 49), social gaming (playing games and tournaments with other participants) (no. 52), and more general leisure and recreation activities (no. 55). These studies suggested that organised groups provided structure for the development of friendships, and social skills, and an opportunity for involvement in the community. Self-reported benefits of attending social gaming groups were reported in another study (no. 52), including sharing a common interest with others as well as making friends, social contact, and having an activity to do outside of

the house. Each of these three studies, however, had a high risk of bias, and did not include any participants with an intellectual disability.

A decline in participation in organised, structured activities from adolescence to adulthood was reported in two studies (nos. 10, 28). Frequency of involvement in structured, organised activities, such as attending organised groups or playing team sports, declined significantly from the final year of high school to one year out of school while unstructured activities, such as spending time with friends, did not change (no. 28). A similar decline in participation was evident in another study (no. 8), with participation in recreational activities reported on average 33.10 times per year in adulthood, a decrease, albeit not significant, from the 45.46 times per year reported in adolescence.

Only four studies compared involvement in organised activities to other populations. Adults with autism in one study were significantly more likely than the general population to participate in organised recreational, cultural, community and special interest groups, with 47% having participated in these in the past three months, compared to only 16% of the general population (no. 13). However, adults with autism spent significantly less time engaged in recreational activities than adults with Fragile X syndrome (no. 8) and typically developing peers in the later years of high school (aged 16-17 years) (no. 25, 28). Two of these studies included participants with co-occurring intellectual disability and had a low risk of bias (nos. 13, 28).

4.5.4.3 Activities in the community

Attending activities in the community (for example going to a café, park, movie theatre, zoo) was reported in 9 studies (16%). In a longitudinal study, 46% of young adults had participated in one or more community activities in the previous 12 months, although frequency of engagement was not reported (no. 23). Adults with autism and intellectual

disability living in group homes in the UK participated in community activities an average of 18 to 19 times in a one-month period, across an average of seven different activities (nos. 12ab).

Going out for a meal and going shopping were amongst the most frequently engaged in activities, with as many as 81-100% of participants reporting involvement in these activities over a one-to-six-month period. (no. 5, 9, 13, 21). Community activities such as the movies, theatre, museums, and parks were attended by 32-64% of adults, yet attendance at sporting events was more limited, with approximately 25% of participants having attended in the previous one-to-three months (nos. 13, 27). Only one of these studies included participants with co-occurring intellectual disability (no. 13).

Five studies compared the community participation of people with autism with other populations. When compared to adults with intellectual disability, varying results were found. While one study reported no significant difference between participants with autism and participants with intellectual disability without autism in terms of variety (no. 12a) and frequency (nos. 12ab) of community activities, another reported that adults with autism participated in a significantly wider range of activities than a community sample of adults with intellectual disability (no. 13). Further, for participants older than 50 years, adults with autism participated in significantly less variety, and spent significantly less time in activities, than those with intellectual disability without autism (no. 12b). In addition, no significant difference was found in community and social participation between adults with autism and adults with other developmental disabilities (no. 22b). Similar discrepancies were reported when comparing adults with autism to a typically developing population. While one study reported no significant difference in community activity involvement between adults with autism and typically developing peers (no. 27), others reported that adults with autism participated significantly less frequently (no. 13) and in fewer social activities (no. 29) than a

general population comparison sample. Similarly, one study (no. 16) reported that adults with autism participated significantly less in physical activity for recreation or leisure than typically developing peers.

Only one study reported on the support required for adults with autism to engage in activities in the community (no. 14). The authors reported that in a sample of adults without intellectual disability, 55.6% required leisure activities to be arranged by others, while only 27.8% were able to initiate their own participation in leisure activities.

4.5.4.4 Religious activities

Eight studies (14%) reported on adults with autism engaging in various religious activities. Of the studies that explored participation in church or religious activities, attendance rates were high. One study (no. 11) reported that 45% of their sample, the majority of which were members of the Church of Latter-Day Saints in Utah, attended church regularly. This rate was consistent across studies, all conducted in the USA, with 41– 44% of participants attending church or religious services once or more per week (nos. 5, 28), although study 5 failed to report the sample size of the autism sub-group. A qualitative study (no. 39) highlighted the various religious activities adults with autism participated in, including services, Sunday school, youth groups, choirs, and other social gatherings. One study found that attendance at church was the most common structured social activity participants attended (no. 28). Similarly, one study (no. 21) reported that 58% of people had attended a place of worship in the past 6 months, and another (no. 10) noted that participants attended on average 19.42 times per year. However, in an Australian sample, only 14% of participants had attended church or religious services in the previous three-month period, which was lower than the rate in the general Australian population (no. 13).

4.5.4.5 Online social participation

Ten studies (18%) reported on online social participation, with six reporting on social media use (nos. 17, 20, 27, 30, 35, 37), one on live action role playing games (no. 32), and two on multiplayer online videogames (no. 16, 41). Of the six studies that reported on social media use, none included participants with co-occurring intellectual disability. Rates of use varied from 41-86% of participants using social media (nos. 17, 27, 30, 32), with as many as 93% having reported to use the internet at least monthly (no. 27). One study (no. 27) reported no significant difference in social media and internet use between adults with autism and a neurotypical comparison group. For young adults with autism in college, social media was reported to be an important element of involvement in college life, allowing them to connect with other students and acting as an avenue for social communication (nos. 35, 37). Another study (no. 20) reported that adults with autism used social media to share information about their interests and hobbies, share comedic videos, or photos of their artwork.

Three studies reported on involvement in online videogames that involved interaction with other players (nos. 16, 32, 41). All studies involved predominantly male, young adults (aged 18 to 24 years). Only one (no. 16) included participants with intellectual disability. A range of reasons were reported for why individuals chose to play online social video games, including socialisation (playing with friends and meeting new people online), skill (improving competence, ability and skill level in the game), escape (immersion in the game, escaping the real world), relieving boredom or stress, and having fun. When comparing enjoyment in exergame play (physical activity videogames) between playing alone and with another person, one study (no. 16) reported that playing with a partner (in this case, a typically developing peer) increased enjoyment.

4.5.5 Impact of Community Participation on Wellbeing

Eight studies reported on the impact of community participation on wellbeing, with mixed results. Wellbeing outcomes included quality of life and life satisfaction (n = 7), and mental health (n = 1).

4.5.5.1 Quality of life and life satisfaction

Seven studies (nos. 1, 4, 26, 30, 50, 53ab, 54) reported on the relationship between community participation and quality of life and life satisfaction. Only one of these studies included participants with co-occurring intellectual disability (no. 4).

Overall, significant relationships were reported between engagement in community and social activities and wellbeing, however, the medium and high risk of bias of these studies should be considered. Fewer difficulties with participation in society (as measured by the World Health Organisation Disability Assessment Schedule (Ustun, Nostanjsek, Chatterji, & Rehm, 2010)) was reported to be associated with greater life satisfaction (no. 26). One study (no. 1) of college students reported that "hanging out" with friends was the only significant predictor of subjective wellbeing, when compared with participation in clubs, sports, and hobbies. However, another study (no. 4) involving young and older adults (age 24–55 years) reported that involvement in recreational activities lessened the negative impact of stress on quality of life, and did so more than involvement in social activities. One study (no. 30) reported a significant difference in self-reported happiness between social media users and non-users, with social media users reporting greater happiness, however, nearly all participants in the study used social media regularly, resulting in biased reporting of differences between groups. Self-reported loneliness scores were also reported to decrease following engagement in adult social groups, held monthly to facilitate engagement in

recreational community activities (no. 50), however, baseline data for loneliness was not reported, and the number of sessions attended was not reported.

One study (no. 54) explored the outcomes of a structured social planning intervention. They reported that this intervention was effective in improving social activities and quality of life (measured by social interaction, academic achievement and employment activity). The three male college students in this experimental case series, all with autism without intellectual disability, increased the number of social activities they participated in as well as improved their academic scores, and gained employment following the intervention.

Two records (nos. 55ab) reported one study, examining the outcomes of a 12-month leisure programme intervention for adults with autism. The intervention aimed to encourage participants to engage in a wide range of leisure and recreational activities and reported significant improvements in stress levels and adaptive behaviour skills, as well as some improvements in cognition for participants involved in the intervention compared to controls.

4.5.5.2 Mental health

Only one study reported on the relationship between community participation and mental health for adults with autism. In a longitudinal study, Taylor, Adams, and Bishop (2017) examined the relationship between involvement in both structured and unstructured social activities during high school and in the year after leaving high school and internalising symptoms (age 17-22 years). They found no relationship between engagement in social activities and internalising symptoms either before or after high school completion, and noted that social activities were not associated with change in internalising symptoms. No research has looked at the relationship between community engagement and mental health in mid-late adulthood.

4.5.6 Barriers and Facilitators to Improved Community Participation

Thirty studies (52%), including nine intervention studies, identified a number of factors that both supported and impeded community participation.

4.5.6.1 Barriers to community participation

Nine studies discussed various factors that impacted the ability for adults with autism to engage in community activities. These included person-centred factors, such as internalising problems, sensation issues, anxiety, and attention difficulties (nos. 28, 29, 31, 45), lack of interest, lack of necessary planning and organising skills, the ability or a preference to spend time alone (nos. 31, 45, and 46), and communication and social skill difficulties (nos. 34, 35).

A number of environmental factors were identified as barriers to community participation. These largely included lack of appropriate resources and opportunities (nos. 29, 44, 45, 46), including lack of availability of resources and programmes suitable to the individual's needs, goals, and interests (no. 46), as well as the opportunity for engagement in more isolating social activities, such as online social media and gaming, potentially limiting the motivation to participate in face-to-face community activities (no. 37). Further, factors related to parents were also identified, including parent attitudes towards and concerns about participation (i.e. whether they valued particular activities) (no. 45), difficulty gauging their child's satisfaction with various activities, and the need for parents to spend time organising and facilitating participation in activities (no. 44).

4.5.6.2 Facilitators to improved community participation

Thirteen studies identified a number of factors that supported improved community participation. Person-centred factors included younger age (no. 27), and fewer internalising (anxious and depressive) symptoms (nos. 27, 28). One study (no. 6) found that higher daily living skills were associated with increased attendance at religious services, however, another

reported no association between living skills and community participation (no. 13). A number of qualitative studies reported a range of factors that motivated adults with autism to participate in community activities. These included feeling a sense of belonging (no. 39), socialisation with friends and others who share the same interests (nos. 42, 43) and, particularly for online gaming and social media, an opportunity to relieve boredom or stress, and to improve skills and competence (no. 42).

Environmental factors were largely centred around parent or family factors, and resources and opportunities. Higher socioeconomic status and family income was identified as a facilitating increased participation in three studies (nos. 21, 23, 45), although it was not found to be a significant predictor of leisure satisfaction in another study (no. 27). Other factors, such as living independently (no. 10), being in a relationship (no. 24), and parental attitudes and habits (no. 45) were also found to support community participation. Access to resources, support (case management, financial support, access to support staff), and access to and participation in structured programmes, both in adolescence and adulthood, were identified as crucial factors in facilitating community participation for adults with autism (nos. 22b, 23, 28, 33, 37, 43, 45). However, one study found that access to resources (e.g. nearby bus stops or grocery stores) was not associated with attendance at social skills groups (no. 6).

4.5.6.3 Interventions to improve community participation

Nine studies reported on interventions and programmes that aimed to increase independent community participation for adults with autism. Two case studies (nos. 51, 58) used video prompting on personal devices (an iPad and a tablet respectively) to teach a particular community skill (shopping). Each study included a female adult with autism and moderate to severe intellectual disability. Both interventions involved the participant following instructions and guidance on an iPad or tablet to complete an independent shopping task (for example, place an item in a shopping cart). While in one case study (no. 58) the participant

was able to successfully perform the tasks post-intervention, and at follow up, the participant in the other study (no. 51) still required some level of support from the investigator in prompting and navigating the iPad.

One study also reported on the effectiveness of an iPad intervention to teach leisure skills to six adults with autism and intellectual disability (no. 56). While the authors reported that independent leisure engagement increased following the intervention, the leisure skills taught were isolated to the specific apps used during the intervention, and generalisation to other apps or games on the iPad, or leisure activities outside of the iPad, were not explored.

Two studies evaluated existing community support programs aimed at improving social skills and enhancing community participation (nos. 49, 55). The studies reported positive outcomes of a community support scheme (no. 55) and a community social programme (no. 49) attended by adults with autism. They reported that engagement in the programmes provided an avenue for adults with autism to participate in a wide range of community activities with support, and that this increased engagement lead to improved socialisation, development of friendships, and improved skill development. However, neither of these studies reported what the group programme sessions consisted of or how many were attended over the study period. Neither study included baseline measurement, with retrospective assessment on perceived change in behaviour post treatment, significantly limiting the conclusions that can be drawn on the efficacy of the support programs.

Four studies reported on social, leisure, and education intervention programmes designed to improve social participation (nos. 47, 48, 54, 57), all with positive results. Structured social planning and support interventions (10 and 33 weeks respectively) were implemented in two studies (nos. 48, 54), and reported that following the intervention, participants increased the number and variety of weekly social and community activities they participated in. Further,

both studies reported increased social satisfaction and wellbeing. These studies were both case series, multiple baseline designs, and were conducted with a small number ($n = 3$ in both studies) of college students with autism and no intellectual disability.

Another study reported on a six-month controlled trial of a leisure programme, also involving adults with autism and no intellectual disability (no. 57). A significant increase in solitary leisure engagement for the experimental group when compared to controls was reported, however, there was no significant change in community activity participation (for example, attendance at organised groups). This intervention was not randomised, nor was the intervention applied consistently within the treatment group. Two sub-groups were formed, each receiving differently focused interventions, with results pooled and reported as one. Finally, a randomised controlled trial evaluated the impact of a two-week language education intervention on improving social participation for adults with autism and no intellectual disability (no. 47). The authors reported a significant increase in social participation post-intervention for the experimental group when compared to controls, and that this was maintained at follow-up two months post-treatment.

4.6 DISCUSSION

The aims of this systematic review were to (1) synthesise the available information on how, and how frequently adults with autism participate in the community, (2) identify the benefits of community participation on wellbeing, and (3) identify barriers and facilitators to engagement in the community. While many studies were identified that met inclusion criteria, the risk of bias across the studies was predominantly moderate (59%) to high (32%). There was considerable variability in terms of methodology, age ranges, and definitions of community participation. As a result, caution is warranted in interpreting the outcomes of the included research studies. A minority of studies included and reported on adults with co-

occurring intellectual disability, and so the results of this systematic review are more likely to demonstrate the experience of community participation for adults without intellectual disability.

It is evident that adults with autism participate in the community in a variety of ways, including participation in leisure, recreation, community, religious, and online activities. Adults with autism spend a lot of time engaged in solitary activities, however, as few studies compared this engagement to other populations, it is unclear if solitary participation in fact differs from other groups. When compared to typically developing peers, the two studies that explored this reported different outcomes for different age groups. Young adults with autism engaged significantly more in solitary activities than peers (aged 16 to 25 years; no. 29), although no significant difference was found in mid-late adulthood (age 25 to 70 years; no. 27). This may reflect changes in participation for adults without autism, in that they may increase their solitary activities as they get older, however, neither study looked at changes in solitary engagement over time.

Participation in organised groups was reported to be greater than for typically developing peers in some studies (no. 13), while participation in other community activities was significantly less, or no different than the general population (no. 12ab, 13, 22). Adults with autism may be more likely to attend organised groups as these are structured and part of a routine, and mostly organised and supported by others, factors that were cited as important in contributing to greater participation (nos. 14, 23, 28). Other community activities, however, may be more likely to require support of others (for example, navigating a bus to get to the movies, working out how to buy tickets), with limited availability of this type of support and limited access to resources highlighted as significant barriers to adults with autism being able to independently engage in the community (nos. 29, 44, 45, 46). Few studies asked participants what support they received, whether from parents of professional support

workers, while attending organised or community activities (no. 5, 28). This is an important area to explore further as the limited data suggests that these supports and resources are often absent but are instrumental to improving community participation. While these studies demonstrate that adults with autism perhaps participate in organised and community activities regularly, and in some cases, more often than typically developing peers, choice and control over what activities they attend, and what activities are meaningful to them, has received almost no attention in the literature. While one study found that a third of participants with autism expressed a desire to be involved in regular groups and clubs if they were not already (no. 2), another reported that participants often found it difficult and turned to solitary activities instead (no. 34). Future research should continue to ask adults with autism what they desire in community participation and what supports they need to achieve their goals.

Involvement in religious activities was common, and benefits were reported by adults, including feeling a sense of belonging to a community (no. 21). Importantly, all but one of the studies that explored religious involvement was conducted in the USA. The remaining study was conducted in Australia (no. 13) and found a much lower rate of participation in religious activities. This may be reflective of different cultures and the role of religion in different countries, in addition to the differences between religious denominations on involvement in community and religious activities. For example, more positive outcomes seen within a sample of adults with autism living in Utah, USA have been suggested to be influenced by the expectations of community service within the Church of Jesus Christ of Latter-Day Saints and the community fostered within this religion (Farley et al., 2009). Future research should further explore the role of religion in different countries and cultures and identify the role of religion in providing support for adults with autism.

Participation in online social and gaming activities and platforms was an emerging theme in the literature. Although these are seemingly solo leisure activities, they often served as a form

of social engagement for adults with autism. While based on a small number of participants, most often without intellectual disability, the qualitative literature suggests that the social nature of online videogames and videogames that involved playing against others provided an avenue of socialisation that eliminated many of the barriers adults with autism experience when socialising with others face-to-face (no. 32, 40). This highlights the need for future research to explore what adults with autism find meaningful and explore ways to support these interests. Particularly for individuals with additional mental health concerns, such as anxiety, online social participation may be a helpful way to engage in the community in a way that is comfortable to them.

Community participation was found overall to improve life satisfaction and subjective wellbeing, and decrease loneliness, with interventions aiming to improve engagement in the community also reporting significant improvements in overall wellbeing. There were however, very few studies that explored the relationship between community participation and mental health for adults with autism, particularly in mid-late adulthood. Longer-term effects of the impact of community participation on mental health problems are an essential area for future research.

4.6.1 Limitations of Existing Research

Although a large number of studies were identified that explored various elements of community participation for adults with autism, a number of limitations were evident. Most apparent was the limited number of studies that included participants with autism and co-occurring intellectual disability. Only 26% of studies included any participants with intellectual disability, and 41% excluded them. As many as 49-70% of adults with autism are estimated to have a co-occurring intellectual disability (Fombonne, 2003; Loomes, Hull, & Mandy, 2017), therefore the inclusion of adults with co-occurring intellectual disability in research is critical to ensuring representation of all adults with autism. Further, individuals

with intellectual disability in addition to autism may have different experiences of community involvement, and experience different barriers to inclusion, than those with autism without an intellectual disability. While the intervention studies demonstrate that community skills can be taught, and community participation can be improved with the appropriate supports, most of these studies did not include individuals with co-occurring intellectual disability. The studies that did include participants with intellectual disability involved teaching specific skills or tasks, often using a tablet device, with the skills leant not generalisable to other situations. Future studies should take this into account and design interventions that can teach relevant skills and improve community participation, whether independent or supported, for all adults with autism.

There were inconsistencies in the definition and measurement of community participation activities and the time frames for reporting frequency of participation, making it difficult to compare rates of participation across studies. In addition, few studies compared the community participation types and rates of adults with autism to other populations, such as the general population or people with other disabilities. It was therefore difficult to determine whether adults with autism do in fact experience restricted community participation when compared to others. Further, the moderate to high risk of bias in 91% of studies is important to consider, and a significant degree of caution should be placed on the reliability of any conclusions that can be drawn.

4.6.2 Strengths and Limitations of the Current Review

The systematic review was conducted in accordance with PRISMA guidelines following a pre-registered protocol. This review utilised a broad definition of community participation, and included both quantitative and qualitative studies, allowing for a comprehensive understanding of community participation in adulthood. There were however, some limitations in methodology. All data coding was completed by one reviewer, and therefore

interrater reliability could not be determined. Further, risk of bias assessments were conducted via consensus discussion between the authors (LAC, RLB, and KMG), rather than assessed independently. Independent coding of data and assessment of risk of bias, followed by assessment of interrater reliability, would have strengthened this process.

4.6.3 Future Directions

Future research needs to involve adults with autism and ask them directly what kinds of community activities they are interested in, and what supports could be put in place to enable to them to participate. This review has highlighted that many adults with autism have a desire to be involved in social and community activities, however, a number of factors, including lack of resources and services, availability of appropriate activities, and supports, prohibit them from engaging in activities that are meaningful for them. Issues relating to stigma and the attitudes of others in the community, however, were not identified as barriers to community participation in the studies in this review, despite the literature suggesting that misperceptions and misunderstandings by other people are often a barrier to social participation (Mitchell, Sheppard, & Cassidy, 2021). Further exploration of these barriers in relation to community participation for adults with autism is an important step in promoting inclusion. In addition, future research should consider the prospect of employment and education services and programmes as avenues to promote community participation. Employment and education have been identified by young adults with autism and intellectual disabilities as sources of community participation, meaningful engagement and contribution, and socialisation, with lack of access to these sources identified as an additional barrier to community participation and inclusion (Anderson et al., 2021; Gray et al., 2014a; Parmenter & Knox, 1991).

Future research should also explore whether there is a difference in quality of life and life satisfaction for those who engage in purely solitary activities when compared to those who

engage in a wider range of social and group activities. While research has highlighted that greater community participation results in improved mental health and quality of life for the general population (Andrews et al., 2015), this review highlights that the evidence for adults with autism is lacking. Further, many studies considered objective quality of life recorded by general measures or questionnaires most often completed by parents or caregivers. It is important to gain an insight as to how the adults with autism themselves view their quality of life and satisfaction with their activities.

Further, these studies must include adults with autism both with and without co-occurring intellectual disability. Well-designed intervention studies that include adults with autism and a range of degree of intellectual disability are needed to further examine the effectiveness of structured social planning and leisure programmes in improving community participation, as currently they have only been shown to be beneficial for those without intellectual disability. Recruitment and sample selection should target community samples of adults with autism, inclusive of individuals with co-occurring intellectual disability. Adults of all ages, particularly older adults, should be included to support further understanding of changes in community participation engagement and desires as individuals get older. Consistent use of established community participation measures, such as the Index of Community Involvement, would allow for better comparisons across studies by measuring engagement in the same activities and over the same time period.

4.6.4 Conclusion

Many adults with autism participate in leisure, recreational, and community activities, however, there are still a large number of adults who do not. Gaining an understanding of the activities and support adults with autism want to receive, as well as furthering our understanding of the impacts of increased community participation on mental health and wellbeing, are essential steps in improving community inclusion and life satisfaction for

adults with autism. Internationally, government policies and programmes that aim to promote community participation for adults should ensure they consider the individual, in terms of their desires, as well as their strengths and areas where they may need additional support.

REFERENCES

*studies included in the systematic review

*Akabogu, J., Nnamani, A., Otu, M. S., Uloh-Bethels, A. C., Ukoha, E., Iyekekpolor, O. M., . . . Ike, C. V. (2020). Effects of a language education intervention on social participation among emerging adults with autism. *Journal of International Medical Research, 48*, 300060519839510. doi:10.1177/0300060519839510

Anderson, C., Butt, C., & Sarsony, C. (2021). Young adults on the autism spectrum and early employment-related experiences: Aspirations and obstacles. *Journal of Autism and Developmental Disorders, 51*, 88-105. doi: 10.1007/s10803-020-04513-4

Andrews, J., Falkmer, M., & Girdler, S. (2015). Community participation interventions for children and adolescents with neurodevelopmental intellectual disability: A systematic review. *Disability and Rehabilitation, 37*(10), 825-833. doi:10.3109/09638288.2014.944625

*Ashbaugh, K. E. (2017). *Assessing the effectiveness of structured social planning for college students with autism spectrum disorder in the context of a multiple-baseline across participants design.* (Doctoal dissertation). Available from ProQuest Dissertations & Theses Global database. (UMI No. 10190673)

*Ashburner, J. K., Bobir, N. I., & van Dooren, K. (2018). Evaluation of an innovative interest-based post-school transition programme for young people with autism spectrum disorder. *International Journal of Disability, Development and Education, 65*(3), 262-285. doi:10.1080/1034912X.2017.1403012

Askari, S., Anaby, D., Bergthorson, M., Majnemer, A., Elsabbagh, M., & Zwaigenbaum, L. (2015). Participation of children and youth with autism spectrum disorder: A scoping review. *Review Journal of Autism and Developmental Disorders, 2*, 103-114. doi:10.1007/s40489-014-0040-7

*Bailey, K. M., Frost, K. M., Casagrande, K., & Ingersoll, B. (2020). The relationship

between social experience and subjective well-being in autistic college students: A

mixed methods study. *Autism, 24*(5), 1081-1092. doi:10.1177/1362361319892457

*Baldwin, S., & Costley, D. (2016). The experiences and needs of female adults with high-

functioning autism spectrum disorder. *Autism, 20*(4), 483-495.

doi:10.1177/1362361315590805

*Billstedt, E., Gillberg, I. C., & Gillberg, C. (2011). Aspects of quality of life in adults

diagnosed with autism in childhood: A population-based study. *Autism, 15*, 7-20.

doi:10.1177/1362361309346066

*Bishop-Fitzpatrick, L., Smith DaWalt, L., Greenberg, J. S., & Mailick, M. R. (2017).

Participation in recreational activities buffers the impact of perceived stress on quality

of life in adults with autism spectrum disorder. *Autism Research, 10*(5), 973-982.

doi:10.1002/aur.1753

*Bourdeau, A. B. (2019). *Quantitative analysis of adult social group participation on autism

symptomatology, social skills, and loneliness.* (Doctoal dissertation). Available from

ProQuest Dissertations & These Global databases. (UMI No. 27665757)

*Buchanan, A. M., Miedema, B., & Frey, G. C. (2017). Parents' perspectives of physical

activity in their adult children with autism spectrum disorder: A socio-ecological

approach. *Adapted Physical Activity Quarterly, 34*(4), 401-420.

doi:10.1123/apaq.2016-0099

*Burckley, E., Tincani, M., & Guld Fisher, A. (2015). An iPad-based picture and video

activity schedule increases community shopping skills of a young adult with autism

spectrum disorder and intellectual disability. *Developmental Neurorehabilitation,

18*(2), 131-136. doi:10.3109/17518423.2014.945045

*Carter, E. W., Kleinert, H. L., LoBianco, T. F., Sheppard-Jones, K., Butler, L. N., & Tyree, M. S. (2015). Congregational participation of a national sample of adults with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities, 53*(6), 381-393. doi:10.1352/1934-9556-53.6.381

*Cashin, A., Smith, J., McQueen, R., & Stein, T. (2020). Evaluation of a social gaming programme for young adults with Autism Spectrum Disorder. *Collegian, 27*(2), 174-178. doi:10.1016/j.colegn.2019.06.001

*Chan, D. V., Klinger, M. R., Adkisson, K. A., & Klinger, L. G. (2020). Examining environmental predictors of community participation for adults with autism spectrum disorder using geographic information systems (GIS). *Journal of Autism and Developmental Disorders, 51*(7), 2531-2537. doi:10.1007/s10803-020-04660-8

*Chen, Y. W., Bundy, A. C., Cordier, R., Chien, Y. L., & Einfeld, S. L. (2015). Motivation for everyday social participation in cognitively able individuals with autism spectrum disorder. *Neuropsychiatric Disease and Treatment, 11*, 2699-2709. doi:10.2147/NDT.S87844

*Chen, Y. W., Bundy, A. C., Cordier, R., Chien, Y. L., & Einfeld, S. L. (2016). The experience of social participation in everyday contexts among individuals with autism spectrum disorders: An experience sampling study. *Journal of Autism and Developmental Disorders, 46*(4), 1403-1414. doi:10.1007/s10803-015-2682-4

*Chen, Y. W., Bundy, A. C., Cordier, R., Chien, Y. L., & Einfeld, S. L. (2017). A cross-cultural exploration of the everyday social participation of individuals with autism spectrum disorders in Australia and Taiwan: An experience sampling study. *Autism, 21*(2), 231-241. doi:10.1177/1362361316636756

*Chi, W. C., Chang, K. H., Escorpizo, R., Yen, C. F., Liao, H. F., Chang, F. H., . . . Liou, T. H. (2014). Measuring disability and its predicting factors in a large database in

Taiwan using the World Health Organization Disability Assessment Schedule 2.0. *International Journal of Environmental Research and Public Health, 11*(12), 12148-12161. doi:10.3390/ijerph111212148

*Daley, T. C., Weisner, T., & Singhal, N. (2014). Adults with autism in India: A mixed-method approach to make meaning of daily routines. *Social Science & Medicine, 116*, 142-149. doi:10.1016/j.socscimed.2014.06.052

*DaWalt, L. S., Usher, L. V., Greenberg, J. S., & Mailick, M. R. (2019). Friendships and social participation as markers of quality of life of adolescents and adults with fragile X syndrome and autism. *Autism, 23*(2), 383-393. doi:10.1177/1362361317709202

*Farley, M., Cottle, K. J., Bilder, D., Viskochil, J., Coon, H., & McMahon, W. (2018). Mid-life social outcomes for a population-based sample of adults with ASD. *Autism Research, 11*, 141-152. doi:10.1002/aur.1897

Farley, M., McMahon, W., Fombonne, E., Jenson, W., Miller, J., Gardner, M., Block, H., Pingree, C., Ritvo, E., Ritvo, R., & Coon, H. (2009). Twenty-year outcome for indiviiduals with autism and average or near-average cognitive abilities. *Autism Research, 2*, 109-118. doi: 10.1002/aur.69

*Felce, D., Perry, J., Lowe, K., & Jones, E. (2011). The impact of autism or severe challenging behaviour on lifestyle outcome in community housing. *Journal of Applied Research in Intellectual Disabilities, 24*(2), 95-104. doi:10.1111/j.1468-3148.2010.00571.x

*Finke, E. H., Hickerson, B. D., & Kremkow, J. M. D. (2018). "To be quite honest, if it wasn't for videogames I wouldn't have a social life at all": Motivations of young adults with Autism Spectrum Disorder for playing videogames as leisure. *American Journal of Speech-Language Pathology, 27*(2), 672-689. doi:10.1044/2017_AJSLP-17-0073

Fombonne, E. (2003). Epidemiological surveys of autism and other pervasive developmental

    disorders: An update. *Journal of Autism and Developmental Disorders, 33*(4), 365-

    382. doi:10.1023/A:1025054610557

*Galler, S. (2013). *Voices of young adults with autism and their perspective on life choices*

    after secondary education. (Doctoral dissertation). Available from ProQuest

    Dissertations & Theses Global database. (UMI No. 3564256)

*Garcia-Villamisar, D. A., & Dattilo, J. (2010). Effects of a leisure programme on quality of

    life and stress of individuals with ASD. *Journal of Intellectual Disability Research,*

    54(7), 611-619. doi:10.1111/j.1365-2788.2010.01289.x

*Garcia-Villamisar, D. A., & Dattilo, J. (2011). Social and clinical effects of a leisure

    program on adults with autism spectrum disorder. *Research in Autism Spectrum*

    Disorders, 5, 246-253. doi:10.1016/j.rasd.2010.04.006

*Gray, K. M., Keating, C. M., Taffe, J. R., Brereton, A. V., Einfeld, S., Reardon, T. C., &

    Tonge, B. J. (2014a). Adult outcomes in autism: Community inclusion and living

    skills. *Journal of Autism and Developmental Disorders, 44*(12), 3006-3015.

    doi:10.1007/s10803-014-2159-x

Gray, K. M., Piccini, A., Keating, C. M., Taffe, J. Parmenter, T. J., Hofer, S., Einfeld, S. L.,

    & Tonge, B. J. (2014b). Outcomes in young adulthood: Are we achieving community

    participation and inclusion? *Journal of Intellectual Disability Research, 58*(8), 734-

    745. doi: 10.1111/jir.12069

*Haertl, K., Callahan, D., Markovics, J., & Sheppard, S. S. (2013). Perspectives of adults

    living with autism spectrum disorder: Psychosocial and occupational implications.

    Occupational Therapy in Mental Health, 29, 27-41.

    doi:10.1080/0164212X.2012.760303

Hedley, D., Uljarevic, M., Cameron, L., Halder, S., Richdale, A., & Dissanayake, C. (2017).

  Employment programmes and interventions targeting adults with autism spectrum

  disorder: A systematic review of the literature. *Autism, 21*(8), 929-941.

  doi:10.1177/1362361316661855

Hong, Q. N., Pluye, P., Bujold, M., & Wassef, M. (2017). Convergent and sequential

  synthesis designs: Implications for conducting and reporting systematic reviews of

  qualitative and quantative evidence. *Systematic Reviews, 6*(61). doi: 10.1186/s13643-

  017-0454-2

*Howlin, P., Goode, S., Hutton, J., & Rutter, M. (2004). Adult outcomes for children with

  autism. *Journal of Child Psychology and Psychiatry, 45*(2), 212-229.

  doi:10.1111/j.1469-7610.2004.00215.x

*Jennes-Coussens, M., Magill-Evans, J., & Koning, C. (2006). The quality of life of young

  men with Asperger syndrome: A brief report. *Autism*, 10(4), 403-414.

  doi:10.1177/1362361306064432

*Jones, J. A. (2016). *The social experiences of young adults with autism as they transition*

  from high school to college. (Doctoral dissertation). Available from ProQuest

  Dissertations & Theses Global database. (UMI No. 10141671)

*Joshi, M. (2020). Living alone and with autism. *Journal of Psychosocial Research, 15*, 171-

  180. doi:10.32381/JPR.2020.15.01.14

*Jozkowski, A. C., & Cermak, S. A. (2019). Moderating effect of social interaction on

  enjoyment and perception of physical activity in young adults with autism spectrum

  disorders. *International Journal of Developmental Disabilities, 66*(3), 222-234.

  doi:10.1080/20473869.2019.1567091

*Kersten, M., Coxon, K., Lee, H., & Wilson, N. J. (2020). "In their own time": Parents gently

  push their autistic youth towards independent community mobility and participation.

Journal of Autism and Developmental Disorders, 50(8), 2806-2818.

doi:10.1007/s10803-020-04384-9

*Kidney, C. A. (2016). *Rethinking autism, communication, and community involvement:*

Exploring involvement in online communities, communication preference, autistic

identity and self-determination. (Doctoral dissertation). Available from PDXScholar

Dissertations and Theses. (Paper 2224)

*Koegel, L. K., Ashbaugh, K. E., Koegel, R. L., Detar, W. J., & Regester, A. (2013).

Increasing socialization in adults with Asperger's syndrome. *Psychology in the*

Schools, 50(9), 899-909. doi:10.1002/pits.21715

*Koffer Miller, K. H., Mathew, M., Nonnemacher, S. L., & Shea, L. L. (2018). Program

experiences of adults with autism, their families, and providers: Findings from a focus

group study. *Autism, 22*(3), 345-356. doi:10.1177/1362361316679000

*Lin, L. Y., Yu, S. N., & Yu, Y. T. (2012). A study of activities of daily living and

employment in adults with autism spectrum disorders in Taiwan. *International*

Journal of Rehabilitation Research, 35(2), 109-115.

doi:10.1097/MRR.0b013e32835108b1

*Lin, S. W., Chiu, T. Y., Liou, T. H., Yen, C. F., & Chen, H. G. (2020). The relationship of

urbanization and performance of activity and participation functioning among adults

with developmental disabilities in Taiwan. *International Journal of Environmental*

Research and Public Health, 17(20). doi:10.3390/ijerph17207553

*Liu, E. X., Carter, E. W., Boehm, T. L., Annandale, N. H., & Taylor, C. E. (2014). In their

own words: The place of faith in the lives of young people with autism and

intellectual disability. *Intellectual and Developmental Disabilities, 52*(5), 388-404.

doi:10.1352/1934-9556-52.5.388

Loomes, R., Hull, L., & Mandy, W. P. L. (2017). What is the male-to-female ratio in Autism

    Spectrum Disorder? A systematic review and meta-analysis. *Journal of American*

    Academy of Child and Adolescent Psychiatry, 56(6), 466-474. doi:j.jaac.2017.03.013

*Macleod, A. (1999). The Birmingham community support scheme for adults with Asperger

    syndrome. *Autism, 3*(2), 177-192. doi:10.1177/1362361399003002007

*Marquette, J. M. (2007). *Autism and post high school transition to community assisted*

    living: Parental perceptions. (Doctoral dissertation). Available from ProQuest

    Dissertations & Theses Global database. (UMI No. 3268831)

*Mashat, A., Wald, M., & Parsons, S. (2016). Investigating the use of social media

    technologies by adults with autism spectrum disorder in Saudi Arabia. In M. Antona

    & C. Stephanidis (Eds.), *Universal access in human-computer Interaction. Users and*

    context diversity (pp. 224-236): Springer International Publishing Switzerland.

Mason, D., Capp, S. J., Stewart, G. R., Kempton, M. J., Glaser, K., Howlin, P., & Happé, F.

    (2021). A meta-analysis of outcome studies of autistic adults: Quantifying effect size,

    quality, and meta-regression. *Journal of Autism and Developmental Disorders, 51*,

    3165-3179. doi:10.1007/s10803-020-04763-2

*Mazurek, M. O., Engelhardt, C. R., & Clark, K. E. (2015). Video games from the

    perspectives of adults with autism spectrum disorder. *Computers in Human Behavior,*

    51, 122-130. doi:10.1016/j.chb.2015.04.062

*McCollum, M., LaVesser, P., & Berg, C. (2016). Participation in daily activities of young

    adults with high functioning autism spectrum disorder. *Journal of Autism and*

    Developmental Disorders, 46(3), 987-997. doi:10.1007/s10803-015-2642-z

*McEvoy, L. J. (2016). *Understanding socialisation for young adults with high functioning*

    autism spectrum disorder utilizing massively multiplayer online role-playing games.

(Doctoral dissertation). Available from ProQuest Dissertations & Theses Global

database. (UMI No. 10159195)

*Mehling, M. H., & Tasse, M. J. (2014). Empirically derived model of social outcomes and

predictors for adults with ASD. *Intellectual and Developmental Disabilities, 52*(4),

282-295. doi:10.1352/1934-9556-52.4.282

*Mehling, M. H., & Tasse, M. J. (2015). Impact of choice on social outcomes of adults with

ASD. *Journal of Autism and Developmental Disorders, 45*(6), 1588-1602.

doi:10.1007/s10803-014-2312-6

Mitchell, P., Sheppard, E., & Cassidy, S. (2021). Autism and the double empathy problem:

Implications for development and mental health. British Journal of Developmental

Psychology, 39, 1-18. doi: 10.1111/bjdp.12350

Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & The PRISMA Group. (2009). Preferred

reporting items for systematic reviews and meta-analyses: The PRISMA Statement.

PLoS Med, 6(7), e1000097. doi:10.1371/journal.pmed.1000097

Monash Centre for Health Research and Implementation. (2014). *Evidence synthesis program*

template for critical appraisal of a cohort study. Melbourne: Monash Centre for

Health Research and Implementation.

*Müller, E., & Cannon, L. (2016). Parent perspectives on outcomes and satisfaction levels of

young adults with autism and cognitive impairments. *Focus on Autism and Other*

Developmental Disabilities, 31(2), 92-103. doi:10.1177/1088357614528800

*Müller, E., Schuler, A., & Yates, G. B. (2008). Social challenges and supports from the

perspective of individuals with Asperger syndrome and other autism spectrum

disabilities. *Autism, 12*(2), 173-190. doi:10.1177/1362361307086664

*Myers, E., Davis, B. E., Stobbe, G., & Bjornson, K. (2015). Community and social

participation among individuals with autism spectrum disorder transitioning to

adulthood. *Journal of Autism and Developmental Disorders, 45*(8), 2373-2381. doi:10.1007/s10803-015-2403-z

*Nepo, K., Tincani, M., & Axelrod, S. (2020). Teaching mobile device-based leisure to adults with autism spectrum disorder and intellectual disability. *Focus on Autism and Other Developmental Disabilities, 36*(2), 83-94. doi:10.1177/1088357620943500

*Nichols, C., Block, M. E., Bishop, J. C., & McIntire, B. (2019). Physical activity in young adults with autism spectrum disorder: Parental perceptions of barriers and facilitators. Autism, 23(6), 1398-1407. doi:10.1177/1362361318810221

Orsmond, G. I., Krauss, M. W., & Seltzer, M. M. (2004). Peer relationships and social and recreational activities among adolescents and adults with autism. Journal of Autism and Developmental Disorders, 34(3), 245-256. doi:10.1023/B:JADD.0000029547.96610.df

*Palmen, A., Didden, R., & Korzilius, H. (2011). An outpatient group training programme for improving leisure lifestyle in high-functioning young adults with ASD: A pilot study. Developmental Neurorehabilitation, 14(5), 297-309. doi:10.3109/17518423.2011.595433

Parmenter, T. R., & Knox, M. (1991). The post-school experiences of young people with a disability. *International Journal of Rehabilitation Research, 14*(4), 281-291. doi: 10.1097/00004356-199112000-00001

*Parsons, M. B., Reid, D. H., & Lattimore, L. P. (2009). Increasing independence of adults with autism in community activities: A brief, embedded teaching strategy. *Behavior Analysis in Practice, 2*(2), 40-48. doi:10.1007/BF03391747

*Pearlman-Avnion, S., Cohen, N., & Eldan, A. (2017). Sexual well-being and quality of life among high-functioning adults with autism. *Sexuality and Disability, 35*(3), 279-293. doi:10.1007/s11195-017-9490-z

*Ratcliff, K., Hong, I., & Hilton, C. (2018). Leisure participation patterns for school age

    youth with autism spectrum disorders: Findings from the 2016 National Survey of

    Children's Health *Journal of Autism and Developmental Disorders, 48*(11), 3783-

    3793. doi:10.1007/s10803-018-3643-5

*Schmidt, L., Kirchner, J., Strunz, S., Brozus, J., Ritter, K., Roepke, S., & Dziobek, I. (2015).

    Psychosocial functioning and life satisfaction in adults with autism spectrum disorder

    without intellectual impairment. *Journal of Clinical Psychology, 71*(12), 1259-1268.

    doi:10.1002/jclp.22225

Scott, M., Milbourn, B., Falkmer, M., Black, M., Bolte, S., Halladay, A., . . . Girdler, S.

    (2019). Factors impacting employment for people with autism spectrum disorder: A

    scoping review. *Autism, 23*(4), 869-901. doi:10.1177/1362361318787789

*Stacey, T. L., Froude, E. H., Trollor, J., & Foley, K. R. (2019). Leisure participation and

    satisfaction in autistic adults and neurotypical adults. *Autism, 23*(4), 993-1004.

    doi:10.1177/1362361318791275

Steinhausen, H. C., Mohr Jensen, C., & Lauritsen, M. B. (2016). A systematic review and

    meta-analysis of the long-term overall outcome of autism spectrum disorders in

    adolescence and adulthood. *Acta Psychiatrica Scandinavica, 133*(6), 445-452.

    doi:10.1111/acps.12559

*Taylor, J. L., Adams, R. E., & Bishop, S. L. (2017). Social participation and its relation to

    internalizing symptoms among youth with autism spectrum disorder as they transition

    from high school. *Autism Research, 10*(4), 663-672. doi:10.1002/aur.1709

Tint, A., Maughan, A. L., & Weiss, J. A. (2017). Community participation of youth with

    intellectual disability and autism spectrum disorder. *Journal of Intellectual Disability

    Research, 61*(2), 168-180. doi:10.1111/jir.12311

*Totsika, V., Felce, D., Kerr, M., & Hastings, R. P. (2010). Behavior problems, psychiatric

symptoms, and quality of life for older adults with intellectual disability with and

without autism. *Journal of Autism and Developmental Disorders, 40*(10), 1171-1178.

doi:10.1007/s10803-010-0975-1

*Turcotte, P., Côté, C., Coulombe, K., Richard, M., Larivière, N., & Couture, M. (2015).

Social participation during transition to adult life among young adults with high-

functioning autism spectrum disorders: Experiences from an exploratory multiple case

study. *Occupational Therapy in Mental Health, 31*(3), 234-252.

doi:10.1080/0164212X.2015.1051641

Ustun, T. B., Nostanjsek, N., Chatterji, S., & Rehm, J. (Eds.). (2010). *Measuring Health and

Disability: Manual for WHO Disability Assessment Schedule (WHODAS 2.0).* World

Health Organisation, Switzerland: WHO Press.

Verdonschot, M. M., de Witte, L. P., Reichrath, E., Buntinx, W. H., & Curfs, L. M. (2009).

Community participation of people with an intellectual disability: A review of

empirical findings. *Journal of Intellectual Disability Research, 53*(4), 303-318.

doi:10.1111/j.1365-2788.2008.01144.x

*Wang, H. Y., & Berg, C. (2014). Participation of young adults with high-functioning autism

in Taiwan: A pilot study. *OTJR: Occupation, Participation and Health, 34*, 41-51.

doi:10.3928/15394492-20131209-01

*Ward, D. M. (2016). *Happiness and life satisfaction predicted by social media use in adults

with autism spectrum disorder.* (Doctoral dissertation). Available from ProQuest

Dissertations & Theses Global database. (UMI No. 10137513)

Wells, G. A., Shea, B., O'Connell, D., Peterson, J., Welch, V., Losos, M., & Tugwell, P.

(2019). The Newcastle-Ottawa Scale (NOS) for assessing the quality of

nonrandomised studies in meta-analyses.

World Health Organisation. (2001). *International Classification of Functioning, Disability, and Health: ICF*. World Health Organisation, Geneva. https://apps.who.int/iris/handle/10665/42407

CHAPTER 5: CURRENT STUDY

This chapter reviews the limitations of the existing literature and provides a rationale for the current study. The chapter outlines the overarching aim of this thesis and details the specific aims and hypotheses of each of the three empirical studies undertaken.

5.1 LIMITATIONS OF EXISTING LITERATURE

One of the most significant limitations of the existing outcome research literature for adults with autism is the lack of inclusion of participants with co-occurring intellectual disability. We know that the rates of co-occurring intellectual disability and autism are high, and that presence of co-occurring intellectual disability is often a large factor in influencing outcome, however, many studies do not include adults with intellectual disability (Zimmerman, Ownsworth, O'Donovan, Roberts, & Gullo, 2018). This limits the ability to generalise the findings to all adults with autism, particularly a group of adults who are likely to have differing needs for services and supports, as well as varying ideas of what a *good* outcome looks like.

Further, there is a lack of longitudinal studies systematically evaluating elements of outcome in adulthood. Many of the longitudinal studies conducted have focused particularly on overall social outcome, with variable findings reported (Steinhausen, Mohr Jensen, & Lauritsen, 2016). This is likely due to the differences in sample characteristics, in particular, variation in autism severity, inclusion of participants with co-occurring intellectual disability, and a wide age range at follow up (Steinhausen et al., 2016). For example, many studies focus on adults with Asperger's syndrome or those of average intellectual functioning, specifically excluding those who have a co-occurring intellectual disability and more severe autism symptoms (Helles, Gillberg, Gillberg, & Billstedt, 2017; Howlin, 2000; Howlin, Moss, Savage, & Rutter, 2013). Longitudinal studies are critical in providing a framework for understanding

how factors and experiences in childhood and adolescence can impact on outcomes and opportunities as adults.

Adult outcome research has largely focused on young adults, with most studies involving participants with a mean age of approximately 24 years (Magiati, Wei Tay, & Howlin, 2014), and few studies involving older adults. As a result, our knowledge of what the experience of adulthood is like for individuals with autism is often limited to very young adults, with an understanding of the longer life course for adults with autism not as well understood. While there are studies that are including individuals in middle- and late-adulthood (for example, Mason et al. (2019), age 55 years or older; Moss, Mandy, & Howlin (2017), age range 33-68), these are more limited.

When exploring outcome itself, the majority of adult outcome studies have focused on a composite overall outcome rating, with fewer studies considering the individual factors that contribute to this overall outcome. While they may note some description of living arrangements, employment, and social relationships, in-depth evaluation of these outcomes, including factors that may impact these in adulthood, has not received as much attention. Further understanding of these factors is crucial in identifying where adults need additional supports and services.

Further, the systematic review undertaken (manuscript presented in Chapter 4) highlighted a number of gaps and limitations in our current knowledge surrounding community participation for adults with autism, particularly surrounding barriers and facilitators to participation, and the overall mental health and wellbeing benefits of participation in the community. The review also highlighted that only a third of the existing community participation literature included, or reported on, adults with co-occurring intellectual disability, consistent with the research more broadly on outcomes for adults with autism.

5.2 RATIONALE FOR CURRENT STUDY

Adults with autism are particularly vulnerable to *poor* outcomes in adulthood, clearly demonstrated by the literature (Howlin & Magiati, 2017; Mason et al., 2021; Steinhausen et al., 2016). *Poor* outcomes have been found in a wide range of areas, including independent living, employment, education, community participation, social inclusion, and relationships (Chamak & Bonniau, 2016; Eaves & Ho, 2008; Howlin & Magiati, 2017), highlighting the ongoing difficulty individuals with autism experience throughout adulthood. However, while the research demonstrates significant difficulties in these areas for many adults with autism, there are inconsistencies between research studies in terms of sample and design, limiting the generalisability of results. Further research is needed to continue to examine these social and community outcomes in adulthood in a sample of adults with a range of autism diagnoses and degree of intellectual disability, in order to gain a more comprehensive understanding of the difficulties faced by adults across the autism spectrum. The current thesis will aim to address this gap by exploring the specific social and community inclusion outcomes that have been discussed throughout the previous chapters (including independent living, employment and daytime activity, engagement in higher education, friendships, loneliness and social satisfaction, and participation in the wider community) in a sample of adults with autism and a wide range of degree of intellectual disability. Establishing the current rates of inclusion and participation in these areas for adults with autism in Australia, and comparing these to general population rates, is important in determining whether adults are experiencing more limited inclusion than their typically developing peers.

Poor outcomes have been found regardless of degree of intellectual disability or autism severity (Taylor & Mailick, 2014), suggesting that these factors do not account for poor outcomes alone. Some cross-sectional research studies have been undertaken to examine some of the factors related to various elements of adult outcome, such as employment or

independent living, however, the findings are limited. Degree of intellectual disability and autism symptom severity, as well as personal factors, such as age, gender, and co-occurring behaviour and emotional problems, and external factors, such as socioeconomic status, have all been identified as factors that are likely to impact outcome in adulthood, however research findings are limited and inconsistent. Further, few longitudinal studies examining childhood predictors of outcome have been undertaken. As a result, areas to target for intervention in childhood are not well known or supported by evidence. The second study of this thesis will seek to explore the childhood factors specified above and establish whether they are predictive of adult outcomes. Longitudinal studies to date have not comprehensively explored the impact of behaviour and emotional problems, including mental health disorder diagnoses, on adult outcomes.

As highlighted in Chapter 4 of this thesis, factors that predict wider community participation for adults with autism have been reported in few studies, with inconsistent results. The third study in this thesis will address this gap using a well-established measure of community participation for adults with disability to enable comparison of community participation rates with other samples and explore a range of factors that may impact community participation. Socioeconomic disadvantage, lack of independent living, and limited social and communication skills have been implicated in the literature as impacting community participation, however there is little empirical evidence to support this. Exploring these factors is a key aim of this thesis. In addition, the limited inclusion of adults with co-occurring intellectual disability in community participation research studies makes it difficult to determine the effect of intellectual disability on an individual's ability to participate in the community, however, the third study in this thesis aims to address this gap by looking at the relationship between degree of intellectual disability and community participation frequency and variety. Further, the impact of behaviour and emotional problems, including diagnosis of

a mental health disorder, will be explored. To date, this relationship has only been explored in a small number of studies in young adults.

While it is clear that adults with autism continue to experience difficulty and poor outcomes, the evidence base is limited. Further research is needed to continue to build knowledge and understanding of the areas in which adult with autism are facing difficulty, and the factors associated with these outcomes. This evidence is important in identifying where supports, services, and interventions are needed to best support those with autism throughout adulthood. Further, while the research overwhelmingly points to poor outcomes for adults with autism, a considerable number of adults achieve good outcomes. Looking more closely at this group and what factors are driving a more positive outcome is also needed. Greater understanding of positive influential factors provides a framework for the areas that are important to encourage and develop through intervention of support.

5.3   THE CURRENT STUDY

This study is embedded within the larger framework of an ongoing longitudinal study, the Australian Child to Adult Development (ACAD) study. The ACAD study follows a community sample of individuals with autism, recruited as children and adolescents in 1991 (Time 1), continuing throughout adolescence and adulthood to the current time period (Time 6) (Einfeld & Tonge, 1996a, 1996b; Tonge & Einfeld, 2003). Further details of the ACAD study, including recruitment, diagnostic assessment, and follow-up procedures, are reported in Chapter 6.

The current study is ideally placed to address a number of the gaps in the literature. The longitudinal nature of this study allows childhood predictors of adult outcomes to be examined, in addition to exploring outcomes for a group of individuals with autism as adults. The current time point of this longitudinal study involves adults in mid-adulthood (late 20's

to early 40's), with a wide range of degree of intellectual disability, from severe intellectual disability to average intellectual functioning.

This study will contribute to the existing body of knowledge in furthering understanding of the various aspects of outcomes in adulthood (community and social inclusion, and community participation), as well as the factors, both in childhood and adulthood, associated with these outcomes. In particular, this study aimed to identify the childhood predictors of adult outcomes which have not been well established in the literature, such as behaviour and emotional problems. The results of this study can be used to inform service providers of the areas in which adults with autism are in greatest need of support and intervention. As a result, the outcomes of this thesis will contribute to enhancing the experiences and quality of life for adults with autism.

5.4   RESEARCH AIMS AND HYPOTHESES

The overarching aim of this thesis was to evaluate the social and community inclusion outcomes for adults with autism and explore the childhood and adulthood factors that contribute to these outcomes. The specific aims and hypotheses for each of the three empirical studies conducted are as follows:

Study 1 (Chapter 7) – "Social and community inclusion outcomes for adults with autism with and without intellectual disability in Australia"

Aims:

1. Determine the overall outcome rating in a population of adults with autism;

2. Explore community inclusion outcomes (living, education, and daytime activity) and determine whether these outcomes differ from the general Australian population;

3. Explore social inclusion outcomes (friendships and social satisfaction); and

4. Compare overall, community, and social inclusion outcomes for those with and without intellectual disability.

It was hypothesised that:

a) The overall outcomes for adults with autism, as defined by the criteria in Howlin et al. (2004), would be predominantly *poor;*

b) Adults with autism would have low rates of independent living, low rates of post-secondary education, and low rates of employment;

c) The rates of independent living, education, and employment would be lower for adults with autism than the general population;

d) Few adults with autism would experience reciprocal friendships, as reported by parents/carers;

e) Adults with autism would report high rates of loneliness and social dissatisfaction; and

f) All of the outcomes described would be significantly lower for adults with co-occurring intellectual disability when compared to those without intellectual disability

Study 2 (Chapter 8) – "Childhood and adulthood predictors of social and community inclusion outcomes for adults with autism"

Aims:

1. Explore the childhood predictors (gender, age, degree of intellectual disability, autism symptomatology, socioeconomic disadvantage, and behaviour and emotional problems) of social and community inclusion outcomes in adulthood (overall outcome, independent living, employment, and friendships); and

2. Explore the adulthood predictors (age, functional skills, autism symptomatology, socioeconomic disadvantage, behaviour and emotional problems, and mental health disorder diagnosis) of social and community inclusion outcomes (overall outcome, independent living, employment, and friendships).

It was hypothesised that:

a) There would be no gender differences seen in overall outcome, rates of independent living, employment, or friendships

b) Age would be a significant predictor of outcome, with older age predicting poorer outcomes

c) Childhood degree of intellectual disability would predict adult outcomes, with adults with more severe intellectual disability in childhood having poorer outcomes in adulthood

d) Functional skills in adulthood would predict outcome, with adults with greater functional skills experiencing better outcomes in adulthood

e) Childhood and adulthood autism symptom severity would predict adult outcome, with individuals with more severe autism symptoms in childhood and in adulthood having poorer outcomes in adulthood

f) Presence of more severe behaviour and emotional problems in childhood and in adulthood would predict poorer outcomes in adulthood

g) Greater socioeconomic disadvantage in childhood and in adulthood would predict poorer outcomes in adulthood

Study 3 (Chapter 9) – "Childhood and adulthood predictors of community participation by adults with autism"

Aims:

1. Explore how adults with autism participate in the community (including how often and in how many different activities);
2. Evaluate the childhood predictors (gender, age, degree of intellectual disability, autism symptomatology, socioeconomic disadvantage, and behaviour and emotional problems) of community participation in adulthood; and
3. Evaluate the adulthood predictors (age, degree of intellectual disability, autism symptomatology, socioeconomic disadvantage, and behaviour and emotional problems, current living arrangements, and current daytime activity) of community participation in adulthood.

It was hypothesised that:

a) Adults with autism would have low rates of community participation (frequency) and participate in a small range of community activities (variety)

b) There would be no gender differences seen in community participation frequency or variety

c) Age would be a significant predictor of adulthood community participation, with older age predicting lower frequency and variety of community participation

d) Childhood and adulthood degree of intellectual disability would predict community participation, with adults with more severe intellectual disability in childhood experiencing lower frequency and variety of community participation

e) Childhood and adulthood autism symptom severity would predict community participation, with individuals with more severe autism symptoms in childhood and in adulthood experiencing frequency and variety of community participation

f) Presence of more severe behaviour and emotional problems in childhood and in adulthood would predict lower rates of community participation frequency and variety in adulthood

g) Greater socioeconomic disadvantage in childhood and in adulthood would predict lower rates of community participation frequency and variety in adulthood

h) Adults living independently would have higher frequency and variety of community participation that adults living with family or in supported accommodation

i) Adults attending regular daytime activities, such as disability specific programs, or mainstream education or employment, would participate in a greater number and variety of community activities that adults with no regular daytime activity.

REFERENCES

Chamak, B., & Bonniau, B. (2016). Trajectories, long-term outcomes and family experiences of 76 adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 46*, 1084-1095. doi:10.1007/s10803-015-2656-6

Eaves, L. C., & Ho, H. H. (2008). Young adult outcome of autism spectrum disorders. *Journal of Autism and Developmental Disorders, 38*, 739-747. doi:10.1007/s10803-007-0441-x

Einfeld, S., & Tonge, B. J. (1996a). Population prevalence of psychopathology in children and adolescents with intellectual disability: I rationale and methods. *Journal of Intellectual Disability Research, 40*(2), 91-98. doi:10.1046/j.1365-2788.1996.767767.x.

Einfeld, S., & Tonge, B. J. (1996b). Population prevalence of psychopathology in children and adolescents with intellectual disability: II epidemiological findings. *Journal of Intellectual Disability Research, 40*(2), 99-109. doi:10.1046/j.1365-2788.1996.768768.x.

Helles, A., Gillberg, I. C., Gillberg, C., & Billstedt, E. (2017). Asperger syndrome in males over two decades: Quality of life in relation to diagnostic stability and psychiatric comorbidity. *Autism, 21*(4), 458-469. doi:10.1177/1362361316650090

Howlin, P. (2000). Outcome in adult life for more able individuals with autism or Asperger syndrom. *Autism, 4*, 63-83.

Howlin, P., & Magiati, I. (2017). Autism spectrum disorder: Outcomes in adulthood. *Current Opinion in Psychiatry, 30*, 69-76. doi:10.1097/YCO.0000000000000308

Howlin, P., Moss, P., Savage, S., & Rutter, M. (2013). Social outcomes in mid- to later adulthood among individuals diagnosed with autism and average nonverbal IQ as

children. *Journal of the American Academy of Child & Adolescent Psychiatry, 52*(6), 572-581. doi:10.1016/j.jaac.2013.02.017

Magiati, I., Wei Tay, X., & Howlin, P. (2014). Cognitive, language, social and behavioural outcomes in adults with autism spectrum disorders: A systematic review of longitudinal follow-up studies. *Clinical Psychology Review, 34*, 73-86. doi:10.1016/j.cpr.2013.11.002

Mason, D., Capp, S. J., Stewart, G. R., Kempton, M. J., Glaser, K., Howlin, P., & Happe, F. (2021). A meta-analysis of outcomes studies of autistic adults: Quantifying effect size, quality, and meta-regression. *Journal of Autism and Developmental Disorders, 51*, 3165-3179. doi:10.1007/s10803-020-04763-2

Mason, D., Mackintosh, J., McConachie, H., Rodgers, J., Finch, T., & Parr, J. R. (2019). Quality of life for older autistic people: The impact of mental health difficulties. *Research in Autism Spectrum Disorders, 63*, 13-22. doi: 10.1016/j.rasd.2019.02.007

Moss, P., Mandy, W., & Howlin, P. (2017). Child and adult factors related to quality of life in adults with autism. *Journal of Autism and Developmental Disorders, 47*, 1830-1837. doi: 10.1007/s10803-017-3105-5

Steinhausen, H.-C., Mohr Jensen, C., & Lauritsen, M. B. (2016). A systematic review and meta-analysis of the long-term overall outcomes of autism spectrum disorders on adolescence and adulthood. *Acta Psychiatrica Scandinavica, 133*, 445-452. doi:10.1111/acps.12559

Taylor, J. L., & Mailick, M. R. (2014). A longitudinal examination of 10-year change in vocational and educational activities for adults with autism spectrum disorders. *Developmental Psychology, 50*(3), 699-708. doi:10.1037/a0034297

Tonge, B. J., & Einfeld, S. (2003). Psychopathology and intellectual disability: the Australian Child to Adult longitudinal study. In L. M. Glidden (Ed.), *International Review of*

Research in Mental Retardation, Volume 26 (pp. 61-91). San Diego, CA: Academic Press.

Zimmerman, D., Ownsworth, T., O'Donovan, A., Roberts, J., & Gullo, M. J. (2018). High-functioning autism spectrum disorder in adulthood: A systematic review of factors related to psychosocial outcomes. *Journal of Intellectual and Developmental Disability, 43*, 2-19. doi:10.3109/13668250.2016.1262010

CHAPTER 6: METHODOLOGY

This chapter outlines the overarching methodology undertaken for this thesis, consisting of three empirical studies conducted within the framework of an existing longitudinal study. The first study is cross-sectional and explores community and social outcomes for adults with autism and compares these outcomes to the general Australian population (results reported in Chapter 7). The second study is longitudinal, exploring the current and childhood predictors of outcomes in adulthood (results reported in Chapter 8). The third study is also longitudinal. It focuses on the experience of community participation in adulthood and the current and childhood predictors of community participation outcomes in adulthood (results reported in Chapter 9).

As the specific measures and analyses used for each study varied, the detailed methodology of each of these studies can be found in the relevant chapters of this thesis. Included in this chapter is the background to the recruitment of the longitudinal sample, the overarching recruitment and data collection procedure undertaken, an overview of the sample at the current time point, a detailed description of each of the constructs and measures used throughout the project, and an overview of the data cleaning and analyses conducted.

6.1 AUSTRALIAN CHILD TO ADULT DEVELOPMENT (ACAD) STUDY

The Australian Child to Adult Development (ACAD) study was established to explore emotional and behavioural difficulties in children with intellectual and developmental disabilities (Einfeld & Tonge, 1996). The community sample, aimed at identifying the entire population of children and adolescents aged 4-18 years with intellectual disability in the selected census areas, involved children and adolescents with a range of developmental disabilities, including autism, Down syndrome, fragile X syndrome, Williams syndrome, and Prader-Willi syndrome. Participants were recruited from regional and metropolitan areas

across Victoria and New South Wales, Australia from 1990-1991 (Einfeld & Tonge, 1996; Tonge & Einfeld, 2003). Data has been collected from participants at multiple time points in the intervening years: Time 1 (1991-1992), Time 2 (1995-1996), Time 3 (1999), Time 4 (2002-2003), and Time 5 (2007-2009).

This thesis will focus on the subset of participants with autism. In addition to data collection at Time 1 through Time 5, participants with autism were also followed up between 2016-2019, forming Time 6 for this cohort. Adult outcomes at Time 6 form the primary focus of the current study, in addition to exploring the childhood (Time 1) predictors of adult outcomes.

6.1.1 ACAD Autism Participants

Children and adolescents with autism ($n = 119$) were recruited from various metropolitan and regional areas in Victoria and New South Wales, Australia in 1991 through health and education agencies, including two community autism assessment services and a specialist school for children with autism (Tonge & Einfeld, 2003). At entry to the study, participants were aged between 2.8 years and 19.8 years (M = 8.7 years, SD = 4.3). Participants were mostly male ($n = 98$, 82.4%), consistent with research on the gender ratios in the autism population at that time. The children and adolescents with autism in this study are likely to be representative of children in the community who had received an autism diagnosis and were receiving services at the time of recruitment (Gray et al., 2014; Tonge & Einfeld, 2003).

6.1.2 Autism Diagnosis

At Time 1, all participants met criteria for autistic disorder according to the Diagnostic and Statistical Manual for Mental Disorder, 3rd edition revised (DSM-III-R) (American Psychiatric Association, 1987), following assessment by a multidisciplinary team (Gray et al., 2014). Participants were re-assessed at Time 2 in order to confirm their diagnosis against

DSM-IV (American Psychiatric Association, 1994) criteria, using structured interviews involving collection of family and developmental history, in addition to completion of the Autism Behavior Checklist (Krug, Arick, & Almond, 1980) and the Childhood Autism Rating Scale (Schopler, Reichler, DeVills, & Daly, 1980). Diagnosis was confirmed by a second clinician through a blind, independent observation of the assessment in 25% of randomly selected cases. Interrater reliability was high (Cohen's $\kappa = .98$) (Gray et al., 2012).

6.1.3 Participation Rates

Participation has been consistently high throughout the longitudinal study. The response rate at Time 2 was 82.4% ($n = 98$), 87.4% at Time 3 ($n = 104$), 84.7% at Time 4 ($n = 100$), and 76.7% at Time 5 ($n = 89$). A high level of participation has been maintained over the course of the study due to the extensive efforts of the research team to keep in contact with the families and keep track of them when they move (Tonge & Einfeld, 2003). Contact details of next of kin have been collected at each time point to assist with contacting families of participants should they move or change contact details.

6.2   PROCEDURE

6.2.1   Ethics

Ethics approval for the current project was obtained from Monash University Human Research Ethics Committee (project number CF15/1045 – 2015000486; see Appendix A for copy of approval). Informed consent was obtained from the legal guardian of the participant, as well as from the participant themselves where either (a) they were their own guardian, or (b) they were deemed to have the capacity to provide informed consent. Parents/guardians were provided with an Explanatory Statement and signed consent forms were obtained prior to completion of questionnaires and interviews (see Appendix B for copies of parent/carer explanatory statement and consent form). Participants were also provided with a plain

language Explanatory Statement, and signed consent was obtained from them where possible (see Appendix C for copies of self-report explanatory statement and consent form). In some cases ($n = 2$), the participant did not want to participate themselves, but gave consent for their parents to participate on their behalf. 6.2.2   Time 6 Recruitment

A letter of invitation explaining the current study was sent to the parents or guardians of all participants in the ACAD study who had consented at previous time points to be contacted by the research team in the future. Parents/guardians were followed up with a telephone call approximately two weeks after sending the letter to discuss the study and determine whether they were interested in being involved. Throughout the course of the longitudinal study, researchers have requested contact details of next of kin or friends from parents of participants so parents could still be contacted if they moved. These contact details were used if the family was unable to be contacted at their previously known address. In some instances, families current contact details were traced by utilising publicly available records (for example, electoral roll, online telephone books).

During the initial telephone call, the researcher discussed with the parent or guardian whether the participant was also interested in taking part in the study and whether they would be able to complete a questionnaire and interview. Where relevant, the researcher requested permission from parents/guardians to speak with the participant's professional carer, for example, when the participant was living in residential or supported accommodation and did not see their parents regularly.

Parent/carer questionnaires were completed by someone who knew the participant well, and were either completed by the participant's parents, their carer, or both. Questionnaires were sent to the relevant responded via mail. Interviews were also completed with either parents or carers, depending on who was best suited to providing the required information. Interviews

were arranged for a time and place convenient for the interviewee, most often in their home or at their workplace. Two researchers attended all interviews (the student researcher and a research assistant). In addition, self-report questionnaires and interviews were offered to all participants, and completed by the participant themselves where they were able and willing to do so. This was an important element of the research project, in providing a platform for the individual with autism to express their view on their current experiences and any barriers or facilitators they perceived to have impacted them in relation to independent living, employment, community engagement, and mental health. Some adults consented to complete some aspects of the research study but not others and were given the opportunity to participate to the extent that was most comfortable for them. For some participants, parents were not involved in the study or did not complete some parts of the questionnaire and interview protocol. This was due to parents no longer being involved in their child's life, being unwilling to participate, parents were deceased, or parents being an inappropriate reporter of their child's current life, particularly for participants who were independent and did not see their parents regularly. In these instances, carer data was used, and self-report data used where carer data was not available (e.g. the participant did not have a carer).

6.3   TIME 6 SAMPLE

Eighty-four adults with autism participated at Time 6 (response rate of 75%, excluding $n = 7$ participants that had died since Time 1). Participants were aged 26.80 – 44.10 years (M = 34.10, SD = 4.49), and were mostly male (81%). Participant characteristics at Time 1 and Time 6 are presented in Table 6.1.

Table 6.1 Participant characteristics at Time 1 and Time 6

	Time 1 ($n = 119$)	Time 6 ($n = 84$)
Male (%)	98 (82%)	68 (81%)
Mean age (SD)	8.7 (4.3)	34.21 (4.49)
Age range (years)	2.8 – 19.8	26.75 – 44.15
Degree of intellectual disability		
Normal (%)	11 (9%)	14 (17%)
Borderline (%)	16 (13%)	13 (15.5%)
Mild (%)	29 (24%)	13 (15.5%)
Moderate (%)	46 (39%)	21 (25%)
Severe (%)	17 (14%)	22 (26%)
Profound (%)	0 (0%)	1 (1%)

There was no significant difference between those who participated at Time 6 and those who did not in terms of degree of intellectual disability, χ^2 (4, $n = 119$) = .05, $p = .97$, or emotional and behavioural problems at Time 1 (DBC), $t(117) = 1.50$, $p = .14$. There was a significant difference between participants and non-participants in terms of socioeconomic disadvantage at Time 1, with participants at Time 6 having a significantly lower Index of Relative Socioeconomic Disadvantage (IRSD) score than non-participants ($t(117) = 3.97$, $p < .001$. See Table 6.2 for a comparison of Time 1 participant characteristics for those who did and did not participate at Time 6 and Table 6.3 for reasons of non-participation in the current study.

Table 6.2. Comparison of Time 1 participant characteristics for Time 6 participants and non-participants

Time 1 Characteristics	Time 1 participants (n = 119)		p value
	Participated at Time 6 (*n* = 84)	**Did not participate at Time 6** (*n* = 35)	
Male (%)	68 (81%)	30 (86%)	.54
Mean age (SD)	8.96 (4.62)	8.12 (3.36)	.27
Age range (years)	2.78 – 19.81	2.88 – 16.25	
Degree of intellectual disability			.97
Normal/borderline (%)	23 (27%)	4 (11%)	
Mild (%)	16 (19%)	13 (37%)	
Moderate (%)	33 (39%)	13 (37%)	
Severe (%)	12 (14%)	5 (14%)	
Mean socioeconomic disadvantage (SD)	1011.96 (44.76)	1056.37 (75.33)	.00
Mean DBC TBPS MIS (SD)	0.67 (0.24)	0.59 (0.23)	.14

DBC TBPS MIS = Developmental Behaviour Checklist Total Behaviour Problem Score – Mean Item Score

Table 6.3. Reasons for non-participation at Time 6

Reason	*n* (%)
Deceased	7 (6%)
Declined to participate	11 (9%)
Unable to locate	17 (14%)
Total	*35 (29%)*

6.4   MEASURES

Data was collected from parents or carers of participants at each time point of the study via questionnaire and/or interview. Information was also collected from the participant themselves at Time 6 where possible (*n* = 30). Described below are the measures used at Time 1 and Time 6, relevant to the current study. Table 6.4 summarises the variables and

measures used, along with the study they were used in, the time point they were collected, and whether they were used as a predictor or an outcome variable.

Table 6.4. Summary of variables and measures, time point collected, and relevant study

Variable	Measure	Time point	Study	Variable type
Socioeconomic disadvantage	Index of Relative Socioeconomic Disadvantage	Time 1 & 6	2, 3	Predictor
Degree of intellectual disability	Four categories: severe/profound, moderate, mild, and borderline/average	Time 1 & 6	1, 2, 3	Predictor
Functional skills	Adaptive Behavior Assessment System	Time 6	2	Predictor
Autism symptomatology	DBC2 Autism Screening Algorithm Autism Diagnostic Interview-Revised	Time 1 Time 6	2, 3	Predictor
Behaviour and emotional problems	DBC2 Parent and Adult forms Mental health disorder diagnosis	Time 1 & 6 Time 6	2, 3	Predictor
Community inclusion	Living arrangements Daytime activity Educational attainment	Time 6	1, 2 3	Outcome Predictor
Social inclusion	Friendships Modified Worker Loneliness Questionnaire	Time 6	1, 2	Outcome
Community participation	Index of Community Involvement	Time 6	3	Outcome
Australian general population comparison	ABS 2016 Census data; living arrangements, educational attainment, employment	Time 6	1	Outcome comparison

DBC2 = Developmental Behavior Checklist 2; ABS = Australian Bureau of Statistics

6.4.1 Demographics

Demographic information, including age, sex, and postcode of current location, were collected at Time 1 and Time 6 via questionnaire.

6.4.1.1 Socioeconomic disadvantage

The Socio-Economic Indexes for Areas (SEIFA) (Australian Bureau of Statistics, 2016b) was used as a measure of socioeconomic disadvantage, based on the postcode of where the participant was living at the time of data collection. The SEIFA is produced by the Australian Bureau of Statistics, ranking areas in Australia based on socioeconomic advantage and disadvantage using a range of information gathered in the Census (Australian Bureau of Statistics, 2016b). The SEIFA produces a number of indexes, including the Index of Relative Socioeconomic Disadvantage (IRSD), which was used in the current study. A low score indicates relatively greater disadvantage, for example, more households with low income, many people with no formal qualifications, and high rates of people in low skill occupations (Australian Bureau of Statistics, 2016b). The IRSD was determined for each participant based on where they were living at Time 1 and again at Time 6.

6.4.2 Cognitive and Adaptive Functioning

Data on cognitive and adaptive functioning was collected from parents or carers at Time 1 and at Time 6 and was used to inform categorisation of degree of intellectual disability as well as provide information on current functioning skills of participants.

6.4.2.1 Degree of intellectual disability

Participants were grouped according to their degree of intellectual disability at Time 1 (no intellectual disability, mild intellectual disability, moderate intellectual disability, or severe intellectual disability), defined according to criteria for intellectual disability set out in DSM-IV (American Psychiatric Association, 1994). Degree of intellectual disability was informed

by results of existing cognitive assessments (most commonly a relevant Wechsler measure as determined by the child's age (Wechsler, 1974, 1991), or the Stanford-Binet Intelligence Scale (Thorndike, Hagen, & Sattler, 1986)) provided to the research team by the parents/carers of participants where available. Where no current cognitive assessment results were available, a cognitive assessment was conducted by a member of the research team (Gray et al., 2014).

Degree of intellectual disability was reviewed and classified again at Time 6. Classification was determined for each participant by two researchers (Professor Gray and the student researcher) following criteria set out in DSM-IV (American Psychiatric Association, 1994) and DSM-5 (American Psychiatric Association, 2013) for intellectual disability. A range of information collected at Time 6 was used to inform classification, including overall and item scores on the Adaptive Behavior Assessment Schedule Third Edition (ABAS-3) (Harrison & Oakland, 2015), items on the Index of Social Competence (McConkey & Walsh, 1982), and results of cognitive testing using the Wechsler Abbreviated Scale of Intelligence, 2nd edition (WASI-II) (Wechsler, 2011).

6.4.2.2 Adaptive Behavior Assessment System Third Edition (ABAS-3)

The ABAS-3 is a standardised measure of adaptive skills and behaviours, providing an overview of current adaptive skills needed to effectively and independently care for oneself (Harrison & Oakland, 2015). Respondents are required to rate each item on whether the individual can independently engage in the task or behaviour, and if so, how frequently. Each item is rated on the following scale: 0 (is not able), 1 (never (or almost never) when needed), 2 (sometimes when needed), or 3 (always (or almost always) when needed)).

The ABAS-3 assesses adaptive skills across 10 areas; Communication, Functional Academics, Self-Direction, Leisure, Social, Community Use, Home Living, Health and

Safety, Self Care, and Work (where the individual is working either part-time or full-time). Raw scores are calculated for each skill area by summing the total of each item in the skill area. Scaled scores can then be calculated for each skill area (M = 10, SD = 3).

In addition, the ABAS-3 provides a General Adaptive Composite (GAC) score, as well as standard scores in three adaptive domains; Conceptual, Social, and Practical. The Conceptual domain comprises the Communication, Functional Academics, and Self-Direction skill areas, the Social domain comprises the Social and Leisure skill areas, and the Practical domain comprises the Community Use, Health and Safety, Home Living, Self-Care, and Work skill areas. The GAC is a total score involving all of the skill areas. The GAC and adaptive domains are scored by summing the scaled scores from the relevant adaptive skill areas, and obtaining standard scores (M = 100, SD = 10).

The ABAS-3 Adult Form was completed at Time 6. Respondents were either the participant's parent or professional carer who knew the participant well. In a small number of cases (*n* = 6), a parent or professional carer was not an appropriate respondent, for example, where the participant was living independently and did not see their parents regularly. In these situations, the participants completed the ABAS-3 Adult Form themselves.

The ABAS-3 has excellent internal consistency, with reliability coefficients for the GAC ranging from 0.94 – 0.99, and for the adaptive skill areas, ranging from 0.80 – 0.99, acceptable test-retest reliability (correlation coefficients from 0.73 – 0.85 for the adaptive domains, and 0.86 for the GAC), and acceptable inter-rater reliability (0.80 – 0.87 for adaptive domains, 0.85 – 0.88 for GAC domains with and without work) (Harrison & Oakland, 2015). However, evident in the current study was the considerable influence of floor effects (i.e. a wide range of raw scores on each skill area converted to a small range of scaled scores). Similar floor effects have been seen in other studies assessing adaptive and

functional skills in individuals with intellectual disability (for example, Fusar-Poli et al., 2017). In Study 2, current functional skills were considered as a predictor of outcome. In order to ensure maximum detail was utilised in analyses without losing important data, an overall raw score was calculated based on the sum of the raw scores of the individual skill areas, consistent with the approach taken by Fusar-Poli et al. (2017). The Work skill area was excluded from this calculation as it was only applicable to and completed by a small number ($n = 19$) of participants.

6.4.2.3 Wechsler Abbreviated Scale of Intelligence-II (WASI-II)

The WASI-II is a standardised measure of cognitive ability (Wechsler, 2011). It is a brief version of the Wechsler Adult Intelligence Scale, consisting of four subtests: Block Design, Vocabulary, Matric Reasoning, and Similarities. The WASI-II provides an estimate of general cognitive ability in terms of a Full Scale Intelligence Quotient (FSIQ) score (M = 100, SD = 15), as well as scores in Verbal Comprehension and Perceptual Reasoning.

The WASI-II was conducted with participants at Time 6 in order to assess their current level of cognitive functioning. In some cases, the assessment was not able to be performed, for example, if the participant could not be encouraged to sit down and complete the tasks ($n = 11$), if attempting the assessment would cause significant disruption to routine ($n = 2$), or if the participant did not consent or was unavailable ($n = 3$). Results of the WASI-II were used to inform classification of degree of intellectual disability.

6.4.2.4 Index of Social Competence

The Index of Social Competence is a 16-item scale that measures an individual's skill level across three main areas – Communication, Self-Care, and Community (McConkey & Walsh, 1982). The Index of Social Competence asks respondents to indicate the participant's best level of functioning across a range of daily skill areas: Handicaps (vision, hearing, and

epilepsy); Communication (instructions, speech, non-verbal communication); Self-Care (eating, personal needs, mobility, use of hands, around the house, preparing food); and Community (reading, writing, time, money). Subscale scores are calculated by summing the responses within each skill area. The range of scores for each subscale is: Additional Handicaps, 3 – 9; Communication Skills, 2 – 8; Self-Care Skills, 6 – 26; and Community Skills, 4 – 20. Higher scores indicate more impaired daily living skills.

The Index of Social Competence is specifically designed to be appropriate for adults with intellectual disability. The measure has demonstrated good interrater reliability, high internal consistency, and good construct validity (McConkey & Walsh, 1982; McEvoy & Dagnan, 1993). At Time 6 the Index of Social Competence was completed by a parent or professional carer, as well as by the participant themselves where possible. The responses of the parent or carer were used in the first instance, except in some circumstances where it was not appropriate to ask a parent to complete the questionnaire ($n = 6$), in which case the self-report responses were used. Responses to the Index of Social Competence were used to inform classification of degree of intellectual disability.

6.4.3 Autism Symptomatology and Diagnosis

As described previously, all participants were determined to have a diagnosis of autism upon study entry at Time 1. Autism diagnosis was consistently reviewed throughout the study, with all participants continuing to meet current diagnostic criteria. In order to assess autism symptomatology more closely, the Autism Screening Algorithm of the Developmental Behavior Checklist 2 completed at Time 1, and the Autism Diagnostic Interview-Revised (ADI-R) completed with a parent or carer of each participant at Time 6, were reviewed for childhood and current autism symptomatology.

6.4.3.1 *Developmental Behavior Checklist 2 Autism Screening Algorithm*

The Developmental Behavior Checklist 2 Autism Screening Algorithm (DBC2-ASA; Brereton, Tonge, Mackinnon, & Einfeld, 2002; Gray, Tonge, Einfeld, Gruber, & Klein, 2018) is calculated from the DBC2 (Gray et al., 2018) and can be used as a reliable tool for screening for autism. Information on the DBC2 is provided in section 6.4.4.1 below. The DBC2-ASA consists of a number of items from the DBC2 reflecting symptoms of autism, for example, *avoids eye contact, preoccupied with one or two interests*, *repeated movements e.g. hand flapping,* and *stares at lights or spinning objects*. While the DBC2 ASA is generally used as an autism screening tool, it was used in the current study as a measure of childhood autism symptomatology. The DBC2 was completed by parents/caregivers at Time 1, with the DBC2 ASA scores reflecting participant's autism symptomatology at that time. Higher scores reflect greater symptomatology.

6.4.3.2 *Autism Diagnostic Interview – Revised*

The Autism Diagnostic Interview-Revised (ADI-R) is a structured interview consisting of 93 items, conducted with parents or caregivers, gathering information on autism related behaviours, including developmental history and current behaviours (Rutter, Le Couteur, & Lord, 2003). The ADI-R is follows standardised procedures, with responses to each item being coded by the interviewer, across eight areas: background, including family, education, previous diagnoses, and medications; overview of behaviour; early development and developmental milestones (e.g. *age when parents first noticed something was not quite right in language, relationships, or behaviour; age when first walked unaided*); language acquisition and loss of language or other skills (e.g. *age of first single words; age of first phrases*); language and communication functioning (e.g. *overall level of language*; *reciprocal conversation; neologisms/idiosyncratic language*); social development and play (e.g. *showing and directing attention; seeking to share enjoyment with others; friendships; social*

disinhibition); interests and behaviours (e.g. *unusual preoccupations; circumscribed interests; sensory interests; complex mannerisms or stereotyped body movements*); and other clinically relevant behaviours (e.g. *epilepsy; aggression*). Items are coded based on both 'current' and 'most abnormal 4-5 years' behaviours. Some items are coded based on 'current' and 'ever', whereby the most severe presentation of the behaviour throughout the individual's life is coded.

The ADI-R assesses behaviours across three domains: Domain A: Qualitative Abnormalities in Reciprocal Social Interaction (hereafter to as the Social domain), Domain B: Qualitative Abnormalities in Communication (hereafter referred to as the Communication domain), and Domain C: Restricted, Repetitive, and Stereotyped Patterns of Behavior (hereafter referred to as the Restricted and Repetitive Behavior domain). A 'diagnostic' and 'current behaviour' algorithm are available, with total scores calculated for each of these domains. For the 'diagnostic' algorithm only, an additional domain is calculated; Domain D: Abnormality of Development Evident at or Before 36 Months. Each domain consists of relevant items from the interview across a range of sub-areas. The Social domain includes behaviours such as failure to use nonverbal behaviours to regulate social interaction, failure to develop peer relationships, lack of shared enjoyment, and lack of socioemotional reciprocity. The Communication domain includes lack of, or delay in, spoken language and failure to compensate through gestures, lack of varied spontaneous make-believe or social imitative play ('diagnostic' algorithm only), relative failure to initiate or sustain conversational interchange (verbal subjects only), and stereotyped, repetitive, or idiosyncratic speech (verbal subjects only). The Restricted and Repetitive Behavior domain includes encompassing preoccupation or circumscribed pattern of interest, apparently compulsive adherence to non-functional routines or rituals, stereotyped and repetitive motor mannerisms, and preoccupation with parts of objects or non-functional elements of material.

In this study, information gathered from the ADI-R was used to inform current Autism Spectrum Disorder diagnosis against DSM-5 criteria (American Psychiatric Association, 2013), as well as to gather detailed information on current autism related behaviours. At Time 6, ADI-R interviews were conducted with someone who knows the participant well and sees them regularly, for example, a parent or professional carer (n = 79 interviews completed, n = 5 did not agree to participate in an interview). Interviews were conducted at a time and place convenient to the interviewee, either in their home, residential accommodation, or over the telephone. In some instances, interviews were undertaken with professional carers to ascertain current symptomatology, and separately with a parent to determine historical symptoms (n = 14). Where a participant did not have a professional carer and the parent/s were still in regular contact with their child, the complete ADI-R was conducted with the parent (n = 45). In some cases, the participant was living completely independently and did not see their parents regularly (in most instances, due to living in different states). In these circumstances, only the historical information was gathered from the parents (n = 6). There were also circumstances where parents were not available for the historical element of the interview (either deceased or did not consent to participate). In these circumstances, only current symptomatology was determined via interview with a professional carer (n = 11).

For this thesis, only current algorithm domain scores were used as a measure of current autism symptoms. Mean scores were calculated for each of the current domain algorithm scores rather than using the summed scores. This was due to the differing number of items contributing to the overall Communication domain algorithm score depending on the verbal ability of the individual. Mean scores were therefore calculated for all three domain algorithm scores to provide a more consistent approach to analysis. Further, for Study 2, one of the items contributing to the Social domain algorithm (item 65; Friendships) was used as an

outcome variable. Therefore, this item was removed when calculating the Social domain mean algorithm score for this study only.

6.4.4 Behaviour and Emotional Problems

Information on behaviour and emotional problems has been collected consistently at each time point of the ACAD study. The Developmental Behavior Checklist 2 was completed by parents or professional carers at Time 1 and Time 6 to assess behaviour and emotional problems. Current mental health symptoms were also assessed at Time 6, via completion of an interview with a parent or carer, as well as with the participant where possible. The information collected in the interview was used to inform consensus diagnosis of mental health disorders.

6.4.4.1 Developmental Behavior Checklist 2

The Developmental Behavior Checklist 2 (DBC2; Gray et al., 2018) is a measure of behaviour and emotional problems in children, adolescents, and adults with intellectual and developmental disabilities. It is an informant-report checklist of behaviour and emotional problems over the previous six months. Two versions were used in the current study, depending on the participants age: DBC2-Parent version (DBC2-P), used at Time 1 when participants were aged 4-18 years old, and the DBC2-Adult version (DBC2-A) at Time 6 when participants were all older than 18 years. The DBC2-P consists of 95 items, and the DBC2-A consists of 107 items. Respondents are asked to rate each item on a scale of 0 (not true as far as you know), 1 (somewhat true or sometimes true), or 2 (very true or often true).

A Total Behavior Problem Score can be calculated as a measure of overall behaviour and emotional problems, in addition to scores on five subscales. The DBC2-P includes the following subscales and sample items: Disruptive (e.g. *deliberately runs away; kicks or hits others; is very active or restless)*, Self-Absorbed (e.g. *bangs head; flicks, taps, or twirls*

objects repeatedly; smells, tastes, or licks objects), Communication Disturbance (e.g. *arranges objects or routine in a strict order; repeats the same word or phrase over and over; stands too close to others*), Anxiety (e.g. *cries easily for no reason; covers ears or is distressed when hears particular sounds; fears particular things or situations*), and Social Relating (e.g. *avoids eye contact; doesn't respond to others' feelings; resists being cuddled, touched, or held*). The DBC2-A consists of three of the same subscales (Disruptive, Self-Absorbed, and Social Relating), and two different subscales: Communication and Anxiety Disturbance (e.g. *has bizarre speech; overly affectionate; tense, anxious, or worried*), and Depressive (e.g. *appears depressed, down, or unhappy; has a loss of appetite; has lost self-care skills*).

A Mean Item Score (MIS) can also be calculated, by dividing the total score by the number of items. The MIS is a useful way of comparing subscales when they are made up of different numbers of items with the added benefit of being reported on the same scale as the items themselves (i.e. ranging from 0 to 2) (Taffe, Tonge, Gray, & Einfeld, 2008). The MIS were therefore calculated for the Total Behaviour Problem Scale, as well as for each of the five subscales. The DBC2-P and DBC2-A have demonstrated acceptable test-retest reliability, inter-rater reliability, and validity (Mohr, Tonge, & Einfeld, 2005; Mohr, Tonge, Einfeld, & Taffe, 2011).

6.4.4.2 Structured Clinical Interview for DSM-5, Research Version (SCID-5)

The SCID-5 is a semi-structured clinical interview used to gather information relevant to mental health problems and diagnoses according to DSM-5 (First, Williams, Karg, & Spitzer, 2015). The SCID-5 Research version used in this study consists of a range of core and optional modules evaluating Mood Symptoms and Disorders, Psychotic Disorders and Associated Symptoms, Anxiety Disorders, Obsessive-Compulsive and Related Disorders, Sleep-Wake Disorders (optional), Feeding and Eating Disorders, Somatic Symptom and

Related Disorders (optional), Externalising Disorders, and Trauma and Stressor-Related Disorders. The SCID-5 Research version allows for customisation to the researcher needs. For this study, the SCID-5 was modified to include all optional modules and disorders, as well as assessment of psychotic symptoms.

In this study, the SCID-5 was conducted with parents or carers of participants, as well as with the participant themselves where possible (n = 34). Participants with sufficient language skills who wanted to be involved were interviewed on their own (n = 25), sometimes with their parent or carer present if requested (n = 9). Where participants did not have the necessary language and communication skills, or the participant did not want to participate in an interview, the interview was instead completed with a parent or carer (n = 45). All interviews were conducted by a research assistant or principal investigator of the ACAD project, who were all trained in the use of the SCID-5. The SCID-5 protocol was followed, with background information collected first, followed by administration of the screening module, where all questions included in the screening module were asked. Further questions were asked about specific diagnoses where indicated by the screening module. The focus of the interviews was on current symptomatology, with historical information only being asked where indicated by the SCID-5 protocol, for example, when asking about past mood symptoms.

6.4.4.3 Diagnosis of mental health disorders

Symptom level information gathered in the SCID-5 interview, along with information gathered from all other measures including the DBC2, was used to determine mental health diagnoses against DSM-5 (American Psychiatric Association, 2013). De-identified, detailed case reports were put together for each participant, including other relevant information such as IQ and adaptive functioning results, daily activities and living arrangements, and current health. Each case report considered potential DSM-5 diagnoses based on the information

gathered in the SCID-5 and other measures. For individuals with intellectual disability, the Diagnostic Manual Intellectual Disability 2 (DM-ID-2; Fletcher, Barnhill, Cooper, & National Association for the Dually Diagnosed, 2017) was consulted to determine if different presentations of symptoms were to be considered for a diagnosis. All case report documents were independently reviewed by a panel of the principal investigators of the ACAD project, all experts in the field of mental health and intellectual and developmental disabilities. A consensus decision was made by the panel as to the final diagnoses for each participant. For this thesis, all participants were categorised as to whether or not they had any mental health disorder diagnoses.

6.4.5 Community Inclusion Outcomes

Information on a range of community inclusion outcomes was gathered via completion of a range of questionnaires at Time 6. Questionnaires were completed by a parent or carer, as well as the participant themselves where possible. The questions asked relating to current living arrangements, educational attainment, and current employment or daytime activity can be found in Appendix D.

6.4.5.1 Living arrangements

Respondents were asked to record the current living arrangements of the participant, including (i) whether they are currently living in supported accommodation for people with a disability, at home with parents, at home with other family, with a spouse/partner, with friends, alone, or other arrangements; (ii) how many people living with them have a disability; (iii) how much paid disability support they receive (hours per week), and (iv) the financial arrangements of the living situation (e.g. property in own name or family's name, rent in own name or family's name, or lease owned by disability services).

6.4.5.2 Educational attainment

The highest level of education achieved by the participant was recorded, and categorised according to the Australian Standard Classification of Education (Australian Bureau of Statistics, 2001): Year 9 or below, Year 10, Year 11, Year 12, Certificate I/II, Certificate III/IV, Advanced Diploma, Bachelor Degree, Graduate Diploma/Graduate Certificate, or Postgraduate Degree. If the highest level of education achieved was in high school, respondents were also asked to indicate whether the participant attended a special school for students with a disability. In addition, information was recorded on any education courses currently being undertaken.

6.4.5.3 Daytime activity

Information regarding the participant's main daytime activities over the previous month was recorded, including (i) unemployment, (ii) volunteer work, (iii) organised day activity program, and number of hours per week, (i) paid job in a mainstream workforce with support, including number of hours worked and number of hours or support received per week, (v) paid job in a mainstream workforce without support, including number of hours worked, or (vi) sheltered workshop or disability enterprise, including hours worked per week.

6.4.5.4 Overall outcome rating

An overall outcome rating was calculated for each participant following the criteria set out by Howlin et al., 2004. The overall outcome rating is determined based on a sum of scores assigned to each of three areas: Work, Friendship, and Independence. The scoring for each of these areas can be seen in Table 6.5 below. The student researcher initially assigned scores to each participant for each of the three areas, with the information then reviewed by Professor Gray. Final scores were determined via discussion between Professor Gray and the student researcher, with no disagreement.

Table 6.5. Howlin et al., 2004 criteria for calculation of overall outcome rating

Code	Description
Work	
0	Employed or self-employed and mainstream education
1	Voluntary work/job training or low-pay scheme
2	Supported/sheltered employment
3	Special centre/no occupation
Friendship	
0	One or more relationships with someone in approximately the same age group, involving sharing of personal activities and interests, outside of a prearranged group, and with reciprocity and mutual responsiveness
1	One or more relationships that involve some personal shared activities outside of a prearranged situation, but limited in terms of interests or reciprocity
2	Personal relationship involving seeking of some kind of contact, but only in a group situation
3	No peer relationships that involve selectivity and sharing
Independence	
0	Living independently
1	In semi-sheltered accommodation (or still at home) but with high degree of autonomy
2	Living with parents, some limited autonomy
3	In residential accommodation with some limited autonomy
4	Specialist autistic or other residential accommodation, or at home with parents/family, with little or no autonomy
5	In hospital care or at home because nowhere else would accept the individual

The overall outcome rating is determined as follows:

0 = Very Good Outcome (total score 0 – 2); 1 = Good Outcome (total score 3 – 4); 2 = Fair Outcome (total score 5 – 7); 3 = Poor Outcome (total score 8 – 10); 4 = Very Poor Outcome (total score 11).

6.4.6 Social Inclusion Outcomes

Information on social inclusion outcomes, including friendships and experiences of loneliness and social satisfaction were collected. Friendships were assessed using the current coding of the item 65 of the ADI-R, completed with parents or carers. Loneliness and social satisfaction was assessed via a self-report questionnaire, the Modified Worker Loneliness Questionnaire.

6.4.6.1 Friendships

As previously described, the ADI-R was completed with parents or carers to gather information on current autism symptomatology. Within the ADI-R, item 65 assesses the quality and quantity of the individual's friendships. The current coding on this item was used as a measure of friendship at Time 6. The item is coded as described in Table 6.6 below. For analyses, friendship data was collapsed into three categories; 0 = one or more relationships, 1/2 = some limited peer relationships, and 3 = no peer relationships.

Table 6.6. ADI-R friendship item coding (Rutter et al., 2003)

ADI-R Code	Description
0	One or more relationships with person in approximately own age group with whom subject shares non-stereotyped activities of personal variety; whom subject sees outside prearranged group (such as club); and with whom there is definite reciprocity and mutual responsiveness
1	One or more relationships that involve some personal shared activities outside a prearranged situation, with some initiative taken by subject, but limited in terms of restricted interests (e.g. model railways) or less than normal responsiveness/reciprocity
2	People with whom subject has some kind of personal relationship involving seeking of contact, but only in group situations (such as club, church, etc.) or in school or at work
3	No peer relationships that involve selectivity and sharing

Note: ADI-R item 65 coding descriptions (Rutter et al., 2003), ADI-R Interview Protocol, page 60

6.4.6.2   *Modified Worker Loneliness Questionnaire*

The Worker Loneliness Questionnaire (Chadsey-Rusch, DeStefano, O'Reilly, Gonzalez, & Collet-Klingenberg, 1992) is a self-report measure of loneliness and social satisfaction at work in adults with intellectual disability (see Appendix E for a copy of the measure). The modified version used in this study was developed by Stancliffe and Keane (2000) in order to measure loneliness and social satisfaction in adults with intellectual disability irrespective of their current working arrangements. The Modified Worker Loneliness Questionnaire (Stancliffe & Keane, 2000) is a self-report 12-item questionnaire with a 3-point response scale (yes, sometimes, no), consisting of two domains: Aloneness and Social Dissatisfaction. In this study, this scale was completed by the adult participant themselves where possible.

Scores for each domain range from 0 to 12, with higher scores indicating higher levels of loneliness or dissatisfaction. Scores are calculated by summing the respective items for each scale, with certain items being reverse-scored. The scale has good test-retest and interrater reliability (Chadsey-Rusch et al., 1992).

6.4.7 Community Participation Outcomes

Information on how the participant was engaged and involves in the community at Time 6, and whether they usually required support, was collected via completion of a questionnaire by the parent/carer or the participant themselves.

6.4.7.1 Index of Community Involvement-Revised

The Index of Community Involvement-Revised (Raynes, Sumpton, & Pettipher, 1989) is a 16-item scale that assesses the frequency and variety of a person's participation in social, community, and leisure activities over the previous month, except for the final item which assesses frequency of holidays taken in the past 12 months (see Appendix F for a copy of the measure). The ICI was developed for use with adults with intellectual disability living in

residential settings. Each item is rated based on how often the adult participated in a range of social and community activities over the past month on a 6-point scale, from 0 (no participation) to 5 (5 or more times). Additionally, participants are asked to indicate whether the adult participant engaged in these activities independently, with parents, or with carers. Items include, for example, *been to a café/restaurant; been shopping; been to a sports event; been to a bank.*

Scores for both the variety and frequency of social and community participation, as well as level of independence, can be determined from the ICI. *Variety* is scored by calculating the number of activities that have been participated in at least once over the previous month (range 0 to 16), indicating the range and variety of activities the participant engages in. *Frequency* is scored by summing the total of all items (range 0 to 80), indicating how often or how many times the participant has engaged in community activities.

The ICI has demonstrated good internal consistency (Cronbach's alpha ranging from 0.59 to 0.77), and test-retest reliability (Cronbach's alpha = 0.8) (Taylor-Roberts, Strohmaier, Jones, & Baker, 2018) in intellectual disability populations.

At Time 6, the ICI was completed by a parent or professional carer, as well as by the participant themselves where possible. Responses provided by the participant themselves were used in the first instance, with parent or carer responses only used if self-report data was unavailable.

6.4.8 Australian Population Comparison Data

Data for the general Australian population was collected from the Australian Bureau of Statistics (ABS) in order to compare Time 6 social outcomes for the sample of adults with autism with the general Australian population. The 2016 Census (Australian Bureau of Statistics, 2016a) was used as it most closely aligns with the time period of data collection for

Time 6 of this study. Data was extracted for adults aged 25 – 44 years from the 2016 Census using the TableBuilder function on the ABS website for living arrangements, highest level of educational attainment, and employment status. The extracted data includes responses from a total of 6,513,390 people in the relevant age group. This age group was selected as it fits most closely with the age range of participants in the current study.

6.4.8.1 ABS Living Arrangements

Information is gathered on current living situation for all people who complete the Census in Australia. For the purposes of this study, living situation was extracted from the question asking respondents to indicate their relationship to the reference person in the household. Respondents were categorised as *living in the family home* if they responded that they were a "non-dependent natural or adopted child" or "non-dependent step-child" of the household reference person. *Living independently* was determined by those who responded they were the "lone person" in the household or living with a partner*,* defined by those who responded they were "husband, wife or partner in a registered marriage or de facto marriage". No Australian population data was available for adults living in supported accommodation.

6.4.8.2 ABS Educational Attainment

Respondents in the 2016 Census are asked to indicate their highest level of educational attainment according to the following categories: postgraduate, graduate diploma, Bachelor's degree, advanced diploma, certificate III & IV, certificate I & II, secondary school (Year 12, Year 11, Year 10, Year 9, or below).

6.4.8.3 ABS Employment

Current employment status was categorised according to whether respondents were employed in the labour force (full time or part time), or not in the labour force.

6.5 DATA ANALYSIS

While specific analyses and outcome and predictor variables varied across the three empirical studies, the overall data cleaning and preparation was the same. This preliminary cleaning and preparation is explained below, with the detailed explanation of analyses for each paper included in the relevant chapter.

6.5.1 Descriptive, Frequency, and Missing Data

For all empirical studies (Study 1, 2, and 3), descriptive statistics (means and standard deviations) were calculated for all continuous demographic, outcome, and predictor variables. Frequency data (n, %) were calculated for all categorical demographic, outcome, and predictor variables. There was some missing data at Time 6 due to unreturned questionnaires, missing information in questionnaires, participants declining to participate in all elements of data collection, or inappropriate respondents available. Table 6.7 below summarises the missing data for all variables across the three studies. Pairwise deletion was used across all analyses to handle missing data (Pallant, 2011). No outliers were identified.

Table 6.7. Description of missing data

Variable	N	Reasons
ABAS-3	5	$n = 1$ missing items; $n = 4$ questionnaire not returned
IRSD	1	Suburb of current address unknown
ADI-R current algorithm scores	15	$n = 6$ information required for algorithm missing; $n = 9$ no current ADI-R interview completed
Mental health disorder diagnoses	5	Did not participate in mental health interview
DBC2-A	9	$n = 3$ questionnaire not returned; $n = 6$ no appropriate respondent
Overall outcome rating	1	Participant living in prison at time of data collection and therefore comparative scores could not be assigned
Index of Community Involvement	2	Questionnaire not returned

ABAS-3 = Adaptive Behavior Assessment System 3; IRSD = Index of Relative Socioeconomic Disadvantage; ADI-R = Autism Diagnostic Interview-Revised; DBC2-A = Developmental Behaviour Checklist 2 – Adult

6.5.2 Assessment of Multicollinearity

Studies 2 and 3 evaluated both childhood and adulthood predictors of social and community inclusion (Study 2) and community participation (Study 3) outcomes in adulthood. Correlations were performed between all Time 1 predictor variables, and between all Time 6 predictor variables to assess for multicollinearity. The childhood (Time 1) predictor variables were the same across both Study 2 and 3 (degree of intellectual disability, age, sex, socioeconomic disadvantage, behaviour and emotional problems, and autism symptoms). Table A.1 demonstrates the correlations between Time 1 predictor variables (Appendix G). For Study 2, the adulthood (Time 6) predictor variables included functional skills, age, sex, socioeconomic disadvantage, autism symptoms, behaviour and emotional problems, and diagnosis of a mental health disorder. Table A.2 shows the correlations between the Time 6 predictor variables (Appendix H). For Study 3, adulthood (Time 6) predictor variables included degree of intellectual disability, age, sex, socioeconomic disadvantage, living arrangements, daytime activity, autism symptoms, behaviour and emotional problems, and

diagnosis of a mental health disorder. Table A.3 shows the correlations between the Time 6 predictor variables for Study 3 (Appendix I).

Using a cut-off point or .90 (for r or rho, relevant to the measurement of the variable) (Pallant, 2011), no multicollinearity was detected. The only highly correlated variables were between subscale and total scores of the same scale as expected (for example, the DBC2 Total Behavior Problem Scale was highly associated with all DBC2 subscales). For regression analyses, either subscale scores or total scores were used to avoid problems with singularity. The correlation between the ADI-R Social and Communication domains was .70 for Study 2 (calculated with friendship item removed) and .72 for Study 3. While under the threshold set for multicollinearity, these are strong correlations as per Cohen (1988). Given the DSM-5 diagnostic criteria for Autism Spectrum Disorder, with one of the two major criteria being impairments in social interaction and communication, these two ADI-R domains were combined for analysis into one ADI-R Social/Communication domain score.

6.5.3 Associations between Predictor Variables and Outcome Variables

For Studies 2 and 3, correlations, t-tests, or ANOVAs were performed to determine associations between outcome and predictor variables, as relevant to the data. Pearson's correlations were conducted between continuous outcome and predictor variables, and Spearman's rho was conducted when there were categorical outcome or predictor variables. Correlation matrices were included in the manuscript for Study 2 and can therefore be found in Chapter 8. The results of these tests for Study 3 were not included in the manuscript. They can be found in Table A.4 and Table A.5 in Appendices J and K respectively. Significance was set at $p < .05$ for all correlation analyses. Correlations were used when describing the relationships between predictors and outcome variables and were also used to determine which predictor variables should be included in regression analyses.

When selecting predictor variables to include in regression analyses, the strength and significance of the associations were considered. Strength of relationship was determined following Cohen (1998). The type of regression analysis conducted was determined by outcome variable. Multinomial logistic regressions were conducted where there were categorical outcome variables with multiple levels (Study 2 - overall outcome rating; 3 levels, living arrangement; 3 levels, employment; 3 levels, friendships; 3 levels), binary logistic regression where there were two levels (Study 2 - hours spent in daytime activity), and multiple linear regression where the outcome was continuous (Study 3 - community participation frequency and community participation variety). Before running all regressions, all assumptions were checked and met.

6.6   ROLE OF THE STUDENT RESEARCHER

I contributed to participant tracing and recruitment and data collection at Time 6, along with the project team. In terms of data collection, I scored and entered data from questionnaires (self-report and parent/carer report) into SPSS. I completed 72 out of 79 ADI-R interviews, 17 out of 79 mental health (SCID-5) interviews and was involved in the mental health disorder consensus diagnosis process for all participants. I completed Time 6 data entry and cleaning, as well as all analyses, with support from a university statistics consultant and Professor Gray.

<center>**REFERENCES**</center>

American Psychiatric Association. (1987). *Diagnostic and Statistical Manual for Mental Disorders* (3rd ed.). Washington, DC: American Psychiatric Association.

American Psychiatric Association. (1994). *Diagnostic and Statistical Manual for Mental Disorders* (4th ed.). Washington, DC: American Psychiatric Association.

American Psychiatric Association. (2013). *Diagnostic and Statistical Manual for Mental Disorders* (5th ed.). Washington, DC: American Psychiatric Association.

Australian Bureau of Statistics. (2001). Australian Standard Classification of Education (ASCED). Retrieved from https://www.abs.gov.au/ausstats/abs@.nsf/0/F501C031BD9AC9C5CA256AAF001FCA33?opendocument

Australian Bureau of Statistics. (2016a). Census of Population and Housing. Retrieved from https://www.abs.gov.au/websitedbs/censushome.nsf/home/2016

Australian Bureau of Statistics. (2016b). Census of Population and Housing: Socio-Economic Indexes for Areas (SEIFA). Retrieved from https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/2033.0.55.001~2016~Main%20Features~SOCIO-ECONOMIC%20INDEXES%20FOR%20AREAS%20(SEIFA)%202016~1

Brereton, A. V., Tonge, B. J., Mackinnon, A. J., & Einfeld, S. L. (2002). Screening young people for autism with the Developmental Behavior Checklist. *Journal of the American Academy of Child & Adolescent Psychiatry, 41*(11), 1369-1374. doi:10.1097/01.CHI.0000024838.94814.A5

Chadsey-Rusch, J., DeStefano, L., O'Reilly, M., Gonzalez, P., & Collet-Klingenberg, L. (1992). Assessing the loneliness of workers with mental retardation. *Mental Retardation, 30*(2), 85-92. doi:10.3109/00048679209068309

Cohen, J. W. (1988). *Statistical Power Analysis for the Behavioral Sciences* (2nd edition ed.). Hillsdale, NJ: Lawrence Erlbaum Associates.Einfeld, S., & Tonge, B. J. (1996). Population prevalence of psychopathology in children and adolescents with intellectual disability: I rationale and methods. *Journal of Intellectual Disability Research, 40*(2), 91-98. doi:10.1046/j.1365-2788.1996.767767.x.

First, M. B., Williams, J. B. W., Karg, R. S., & Spitzer, R. L. (2015). *User's Guide for the Structured Clinical Interview for DSM-5 Disorders, Research Version (SCID-5-RV)*. Arlington, VA: American Psychiatric Association.

Fletcher, R. J., Barnhill, J., Cooper, S., & National Association for the Dually Diagnosed. (2017). *DM-ID-2: Diagnostic Manual, Intellectual Disability: A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability*. Kingston, New York: NADD.

Fusar-Poli, L., Brondino, N., Orsi, P., Provenzani, U., De Micheli, A., Ucelli de Nemi, S., . . . Politi, P. (2017). Long-term outcome of a cohort of adults with autism and intellectual disability: A pilot prospective study. *Research in Developmental Disabilities, 60*, 223-231. doi:10.1016/j.ridd.2016.10.014

Gray, K. M., Keating, C. M., Taffe, J., Brereton, A. V., Einfeld, S., & Tonge, B. J. (2012). Trajectory of behavior and emotional problems in autism. *American Journal of Intellectual and Developmental Disabilities, 117*(2), 121-133. doi:10.1352/1944-7588-117-2.121

Gray, K. M., Keating, C. M., Taffe, J. R., Brereton, A. V., Einfeld, S. L., Reardon, T. C., & Tonge, B. J. (2014). Adult outcomes in autism: Community inclusion and living skills. *Journal of Autism and Developmental Disorders, 44*, 3006-3015. doi:10.1007/s10803-014-2159-x

Gray, K. M., Tonge, B. J., Einfeld, S., Gruber, C., & Klein, A. (2018). *Developmental Behavior Checklist 2 (DBC2) (Manual)*. Torrance, CA: Western Psychological Services.

Harrison, P. L., & Oakland, T. (2015). *Adaptive Behavior Assessment System, Third Edition*. Torrance, CA: Western Psychological Services.

Krug, D. A., Arick, J., & Almond, P. (1980). Behavior checklist for identifying severely handicapped individuals with high levels of autistic behavior. *Journal of Child Psychology and Psychiatry, 21*(3), 221 - 229. doi:10.1111/j.1469-7610.1980.tb01797.x

McConkey, R., & Walsh, J. (1982). An index of social competence for use in determining the service needs of mentally handicapped adults. *Journal of Mental Deficiency Research, 26*, 47-61. doi:10.1111/j.1365-2788.1982.tb00128.x

McEvoy, J., & Dagnan, D. J. (1993). The psychometric properties of the Index of Social Competence: A British replication. *The Irish Journal of Psychiatry, 14*(2), 286 - 292. doi:10.1080/03033910.1993.10557931

Mohr, C., Tonge, B. J., & Einfeld, S. (2005). The development of a new measure for the assessment of psychopathology in adults with intellectual disability. *Journal of Intellectual Disability Research, 49*, 469-480. doi:10.1111/j.1365-2788.2005.00701.x

Mohr, C., Tonge, B. J., Einfeld, S., & Taffe, J. (2011). *Manual for the Developmental Behaviour Checklist for Adults (DBC-A)*. Australia: The University of Sydney and Monash University.

Pallant, P. (2011). *SPSS Survival Manual* (4th ed.). Crows Nest, NSW: Allen & Unwin.

Raynes, N., Sumpton, R., & Pettipher, C. (1989). *The Index of Community Involvement - Revised*. Manchester, UK: University Department of Social Policy and Social Work.

Rutter, M., Le Couteur, A., & Lord, C. (2003). *Autism Diagnostic Interview-Revised*. Los

   Angeles, CA: Western Psychological Services.

Schopler, E., Reichler, R. J., DeVills, R. F., & Daly, K. (1980). Toward objective

   classification of childhood autism: Childhood Autism Rating Scale (CARS). *Journal

   of Autism and Developmental Disorders, 10*, 91-103. doi:10.1007/bf02408436

Stancliffe, R. J., & Keane, S. (2000). Outcomes and costs of community living: A matched

   comparison of group homes and semi-independent living. *Journal of Intellectual and

   Developmental Disability, 25*(4), 281-305. doi:10.1080/13668250020019584

Taffe, J. R., Tonge, B. J., Gray, K. M., & Einfeld, S. L. (2008). Extracting more infomation

   from behaviour checkists by using components of mean based scores. *International

   Journal of Methods in Psychiatric Research, 17*(4), 232-240. doi:10.1002/mpr.260

Taylor-Roberts, L., Strohmaier, S., Jones, F., & Baker, P. (2018). A systematic review of

   community participation measures for people with intellectual disabilities. *Journa of

   Applied Research in Intellectual Disabilities, 32*(3), 706-718. doi:10.1111/jar.12565

Thorndike, R. L., Hagen, E. P., & Sattler, J. M. (1986). *Stanford-Binet Intelligence Scale* (4th

   ed.). Itasca, IL: Riverside.

Tonge, B. J., & Einfeld, S. (2003). Psychopathology and intellectual disability: the Australian

   Child to Adult longitudinal study. In L. M. Glidden (Ed.), *International Review of

   Research in Mental Retardation, Volume 26* (pp. 61-91). San Diego, CA: Academic

   Press.

Wechsler, D. (1974). *Manual for the Wechsler Intelligence Scale for Children-Revised*. New

   York: Psychological Corporation.

Wechsler, D. (1991). *The Wechsler Intelligence Scale for Children* (3rd ed.). San Antonia,

   TX: Psychological Corporation.

Wechsler, D. (2011). *Manual for the Wechsler Abbreviated Scale of Intelligence-Second Edition*. Bloomington, MN: Pearson.

CHAPTER 7: STUDY 1 – "SOCIAL AND COMMUNITY INCLUSION OUTCOMES FOR ADULTS WITH AUTISM WITH AND WITHOUT INTELLECTUAL DISABILITY IN AUSTRALIA"

7.1   PAPER COMMENTARY

This chapter presents a paper submitted for publication to the Journal of Intellectual Disability Research. This paper has been formatted to the specific requirements of the journal. Headings and page numbers have been renumbered and reformatted to allow for consistency within this thesis.

The aims of this study were to first determine an overall outcome rating for adults with autism, following criteria set out in the literature and used within other studies, to gain and understanding of the overall outcome for adults with autism in Australia, and how this compares to research internationally. Second, to explore the community inclusion outcomes, being independent living, employment, and education, for adults with autism in Australia, and compare these outcomes with the general Australian population. Third, social inclusion outcomes, including friendships and social satisfaction were explored. Finally, the impact of co-occurring intellectual disability on each of these domains of outcome was explored.

Cameron, L. A., Tonge, B. J., Howlin, P., Einfeld, S. L., Stancliffe, R. J., & Gray, K. M. (submitted). Social and community inclusion outcomes for adults with autism with and without intellectual disability in Australia. *Journal of Intellectual Disability Research.*

7.2 ABSTRACT

Background. Research suggests that adults with autism tend to have *poor* outcomes. Outcomes have mostly been defined by objective factors, such as employment and living situation, with less attention being paid to subjective experiences of social satisfaction, loneliness, and friendships.

Method. Eighty-four adults with autism (mean age 34.2 years, SD = 4.5; 67% with co-occurring intellectual disability), recruited as children and adolescents, participated in the current study. Adult social and community inclusion outcomes were explored.

Results. Participants predominantly lived with family or in supported accommodation, did not pursue higher education, and mostly participated in day activity programmes. Most had limited friendships. Overall outcome was *poor* for 57%, and *good/very good* for 34%. Adults with intellectual disability generally had poorer outcomes.

Conclusion. Adults with autism encountered numerous difficulties in leading an independent life. Adults with co-occurring intellectual disability were most likely to experience difficulties, however outcomes ranged from *poor* to *very good* for adults without intellectual disability. Appropriate resources and programmes are crucial for adults with autism to support them to have the choice to live independently.

7.3 INTRODUCTION

Research on outcomes in adulthood for individuals with Autism Spectrum Disorder (hereafter referred to as autism) has predominantly explored objective measures of outcome. Several studies have used summary ratings (*good, fair, poor*), comprised of a range of variables, including independent living, employment, and friendships, to describe outcome in adulthood. Widely used criteria (Howlin *et al.* 2004) describe a *Very Good/Good* outcome as achieving a high level of independence, having some friends, and a job, and a *Poor/Very*

Poor outcome requiring specialist accommodation and/or a high level of support, having little to no autonomy, and no friendships. Two systematic reviews (Mason *et al.* 2021; Steinhausen *et al.* 2016) concluded that adults with autism generally have *poor* outcomes. Steinhausen *et al.* (2016) concluded nearly half (48%) achieved *poor/very poor* outcomes, 31% achieved a *fair* outcome, and only 20% achieved a *good* outcome. A more recent review, including additional outcome studies, reported similar results (Mason *et al.* 2021). Half of the adults (49%) had *poor* outcomes, 27% had *fair*, and only 20% had *good* outcomes.

There is, however, considerable variation in outcome research findings that cannot be explained simply in terms of cohort age or sample selection. In some studies no participants achieved a *good* outcome (Billstedt *et al.* 2005; Cedurland *et al.* 2008); others reported over 40% achieving a *good* outcome (Pickles *et al.* 2020). The impact of co-occurring intellectual disability is important. The Billstedt and Cedurland studies included participants with co-occurring intellectual disability, while the Pickles study did not. In their meta-analysis, Mason *et al.* (2021) found that higher IQ in adulthood was positively correlated with *good* outcomes and negatively with *poor* outcomes; however, IQ only significantly predicted *poor* outcomes (it did not predict *good* or *fair* outcomes), and childhood IQ did not predict outcome when controlling for other variables. Despite evidence that degree of intellectual disability impacts outcomes in adulthood, it is clear this is not the sole factor, and the impact of other variables, such as age, sex, socioeconomic status, autism symptom severity, and mental health (Howlin and Magiati 2017), warrants further exploration.

Howlin and Magiati (2017) highlighted that while there is some disagreement between outcome studies, it is clear that outcomes for adults with autism, in terms of independent living, employment, and relationships, are poorer than those of same age typically developing peers as well as those with other developmental disabilities. Few adults live independently, with most continuing to live with family or in supported accommodation, regardless of

intellectual level (Howlin *et al.* 2013; Eaves and Ho 2008; Gray *et al.* 2014; Billstedt *et al.* 2005), and unemployment, or underemployment, is high (Kamio *et al.* 2012; Howlin *et al.* 2013).

While current research is important for exploring outcomes, as well as being a useful way to compare various populations, measures of outcome often fail to capture the individual experiences of adults with autism and their wellbeing and social satisfaction. The literature suggests that adults with autism have limited friendships (Howlin *et al.* 2013) and social participation (Orsmond *et al.* 2013), and often experience greater loneliness than typically developing peers (Mazurek 2014). Despite this, some adults are satisfied with more limited social interaction or seeing friends only occasionally (Ee *et al.* 2019). Although friendship is a key variable used in calculating adult overall outcome ratings, it is most often rated by parents or caregivers, leaving a gap in our understanding of how adults with autism perceive their own friendships and their satisfaction with social participation.

The current study of a population of adults with autism aimed to: (1) determine their overall outcome rating; (2) explore community inclusion outcomes (living, education, and daytime activity) and determine whether these outcomes differ from the general Australian population; (3) explore social inclusion outcomes (friendships and social satisfaction); (4) compare overall, community, and social outcomes for those with and without intellectual disability. It was hypothesised that: (1) the overall outcome for adults with autism, as defined by the criteria in Howlin et al. (2004), would be predominantly *poor*; (2) adults with autism would have low rates of independent living, post-secondary education, and employment, and these rates would be lower than that seen in the general Australian population; (3) few adults with autism would experience reciprocal friendships, as reported by parents/carers, and would self-report high rates of loneliness and social dissatisfaction; and (4) all of the

outcomes described would be significantly lower for adults with co-occurring disability when compared to those without intellectual disability.

7.4 METHOD

7.4.1 Sample

Participants were recruited for the Australian Child to Adult Development (ACAD) Study from Victoria and New South Wales, Australia in 1991 through health and education agencies (Einfeld and Tonge 1996a; Einfeld and Tonge 1996b; Gray *et al.* 2012). Data were collected at six time points: Time 1 (1991-1993), Time 2 (1995-1996), Time 3 (1999), Time 4 (2002-2003), Time 5 (2007-2009), and Time 6 (2016-2019).

At entry to the study, participants were likely to be representative of all children in the community who had an autism diagnosis and were receiving services (Tonge and Einfeld 2003). All participants met criteria for DSM-III-R Autistic Disorder (American Psychiatric Association [APA] 1987) following assessment by a multidisciplinary team at study entry. Participants were reassessed at Time 2 to confirm diagnosis against DSM-IV criteria (APA 1994; Gray *et al* 2012). At Time 6 the Autism Diagnostic Interview-Revised (ADI-R; Rutter *et al.* 2003) was completed, and current Autism Spectrum Disorder diagnoses were reviewed for all participants against the DSM-5 criteria (APA 2013). All participants met current DSM-5 criteria for Autism Spectrum Disorder.

7.4.2 Measures

7.4.2.1 Degree of intellectual disability

At Time 1 (age 2.8-19.8 years), participants were categorised into four groups according to their degree of intellectual disability: no intellectual disability, mild, moderate, or severe (see Gray *et al.* (2014)). At Time 6, current degree of intellectual disability was reviewed and categorised following DSM-IV (APA 1994) and DSM-5 (APA 2013) criteria by consensus

diagnosis between two authors (L.A.C and K.M.G). Time 6 categorisation was based on a range of assessments, including cognitive (Wechsler Abbreviated Scale of Intelligence, 2nd edition; Wechsler 2011), adaptive functioning (Adaptive Behavior Assessment System-3; Harrison and Oakland 2015), and daily living skills (Index of Social Competence; McConkey and Walsh 1982).

7.4.2.2 Overall Outcome Rating

An overall adult outcome rating was calculated for each participant based on the criteria of Howlin *et al.* (2004) in which scores are assigned to current living status, employment, and friendships. The total score provides an overall outcome rating (*Very Good, Good, Fair, Poor*, or *Very Poor*). Ratings were determined by consensus discussion between two authors (L.A.C and K.M.G).

7.4.2.3 Community inclusion

Information on current living arrangements, highest level of educational attainment, and current daytime activities was collected using a parent/carer and/or self-report questionnaire. Living arrangements were grouped into three categories: *independent* (living alone, with a partner, or with friends), *with family* (parents, sibling, or other family member), and *supported accommodation* (group disability accommodation). Educational attainment was categorised according to the Australian Standard Classification of Education (ASCED; Australian Bureau of Statistics 2001); Year 10 or below, Year 11, Year 12, Certificate, Diploma, Bachelor, Postgraduate. Attendance at mainstream or special schools was noted. Current daytime activities included volunteer work, organised day activity programme, paid employment with/without additional support, sheltered workshop/disability enterprise, education course, and no organised daytime activity. Total number of hours engaged in daytime activities per week was also recorded.

7.4.2.4 Social inclusion

Friendship was assessed using the current rating of a single item (number 65) rom the ADI-R (Rutter *et al.* 2003), completed with a parent/caregiver. The item on friendships assesses the quality and quantity of the participants friendships, providing a score from 0 (one or more appropriate relationships) to 3 (no peer relationships).

Loneliness and social dissatisfaction were assessed using the Modified Worker Loneliness Questionnaire (Chadsey-Rusch *et al.* 1992), a self-report measure designed to assess aloneness and social dissatisfaction in individuals with intellectual disability. It is a 12-item questionnaire with a 3-point response scale. It consists of two domains: Aloneness and Social Dissatisfaction. Scores for each domain range from 0-12, with higher scores indicating higher levels of loneliness or social dissatisfaction.

7.4.2.5 Australian population community inclusion

Community inclusion data for the Australian general population was obtained from the 2016 Australian Census (Australian Bureau of Statistics 2016). TableBuilder software within the ABS system was used to extract relevant data for the population aged 25-44 years – the group closest in age to the study sample. Current living arrangement data were divided into *independent* (those who indicated they lived alone, with a partner, or in a group household), and *with family* (those who indicated they were the non-dependent child of the household reference person). Highest level of educational attainment was categorised following ASCED (Australian Bureau of Statistics 2001). Current employment was divided into *working in the labour force* or *not in the labour force.*

7.4.3 Procedure

All participants were invited to participate at each time point and were sent a questionnaire to be completed by a parent or carer, and, at Time 6, the adult themselves where possible. At

Time 6, interviews were also conducted with parents/carers. Ethics approval was obtained from Monash University Human Research Ethics Committee (CF15/1045-2015000486). Informed consent was provided by parents/carers, and where possible, the adult themselves.

7.4.4 Statistical Analyses

Descriptive data (M, SD) and frequencies (n, %) were calculated for each variable. Fisher's exact tests and t-tests were used to evaluate differences in outcome based on presence or absence of intellectual disability. Significance was set at $p < .05$.

7.5 RESULTS

At Time 6, 84 participants completed the questionnaire (response rate of 75% excluding the seven participants who have died since Time 1). Participants were aged between 26.8 and 44.2 years (M = 34.2, SD = 4.5), and 81% ($n = 68$) were male. (See Table 7.1 for participant demographic details at Times 1 & 6). There was no significant difference between those who participated at Time 6 and those who did not in terms of Time 1 degree of intellectual disability, χ^2 (4, $n = 119$) = .05, $p = .97$.

Table 7.1. Sample demographics

	Time 1 $n = 119$	Time 6 $n = 84$
Male	98 (82%)	68 (81%)
Mean age (SD)	8.7 (4.3)	34.2 (4.5)
Age range (years)	2.8 – 19.8	26.8 – 44.2
Degree of intellectual disability		
Average	11 (9%)	14 (17%)
Borderline	16 (13%)	13 (15%)
Mild	29 (24%)	13 (15%)
Moderate	46 (39%)	21 (25%)
Severe/profound	17 (14%)	23 (27%)

7.5.1 Overall Outcome Rating in Adulthood (Time 6)

Overall outcome scores (Howlin *et al.* 2004) were calculated for all participants except one (this individual was in prison at the time of data collection, and comparative scores for living status and employment could not be determined). Table 7.2 shows frequencies for each outcome category for the sample overall, as well as the breakdown for those with and without intellectual disability. The majority of the sample achieved a *Poor* or *Very Poor* outcome (58% *n* = 48), with less than 20% (*n* = 16) achieving a *Very Good* outcome. There was a significant difference between participants with and without an intellectual disability (Fisher's exact test, $p < .001$); individuals without intellectual disability were more likely to have a *Very Good* or *Good* outcome (74%, *n* = 20) and those with intellectual disability were more likely to have a *Poor* or *Very Poor* outcome (80%, *n* = 45).

Table 7.2. Overall outcome rating Time 6

| | Total sample (*n* = 83) *n* (%) | Intellectual disability | | | |
		Average/ borderline (*n* = 27) *n* (%)	Mild (*n* = 12) *n* (%)	Moderate (*n* = 21) *n* (%)	Severe/ profound (*n* = 23) *n* (%)
Very Good	16 (19%)	13 (48%)	3 (25%)	0 (0%)	0 (0%)
Good	12 (15%)	7 (26%)	4 (33%)	1 (5%)	0 (0%)
Fair	7 (8%)	4 (15%)	3 (25%)	0 (0%)	0 (0%)
Poor	47 (57%)	3 (11%)	2 (17%)	20 (95%)	22 (96%)
Very Poor	1 (1%)	0 (0%)	0 (0%)	0 (0%)	1 (4%)

Note: Overall outcome rating not calculated for *n* = 1 participant

7.5.2 Community Inclusion in Adulthood (Time 6)

Frequencies of current living arrangements, highest level of education, and employment are presented in Table 7.3.

Table 7.3. Community inclusion outcomes (total *n* = 84)

	Time 6 *n* (%)
Living arrangements	
Supported group accommodation	33 (39%)
With family	35 (41%)
Independently	16 (19%)
Highest level of education	
Secondary school	
Special school	55 (65%)
Mainstream school (Year 10 or below)	4 (5%)
Mainstream school (Year 11 or 12)	8 (10%)
Certificate/Diploma	11[†] (13%)
Bachelor's Degree	5[‡] (6%)
Postgraduate Degree	1 (1%)
Current daytime activity[§]	
Organised day activity (day programme)	47 (56%)
Employed in paid job *without support*	20 (24%)
Employed in paid job *with support*	2 (2 %)
Sheltered workshop or disability enterprise	4 (5%)
Volunteer work	2 (2%)
Education course	4 (5%)
No activity	9 (11%)

[†] *n* = 3 currently enrolled; [‡] *n* = 1 currently enrolled; [§]total greater than 100% as some participants involved in more than one daytime activity

7.5.2.1 Current living arrangements

Most participants continued to live with family (42%, *n* = 35) or in supported group accommodation (39%, *n* = 33), with only 19% (*n* = 16) living independently. Two participants who lived with family were living relatively independently in a separate unit on their parent's property and many had a high degree of autonomy. Additional paid support in the home was limited for participants living independently; only three participants received

additional support, from 3-12 hours per week. Five participants living with family received between 1-20 hours per week of support. Most participants living in supported accommodation received full time care, however two participants were living in more independent supported housing and received support for self-care activities for 3-4 hours per day. The majority of those living in supported accommodation had moderate to severe/profound intellectual disability (88%, *n* = 29), while those living independently were predominantly without intellectual disability (81%, *n* = 13) (Figure 7.1a).
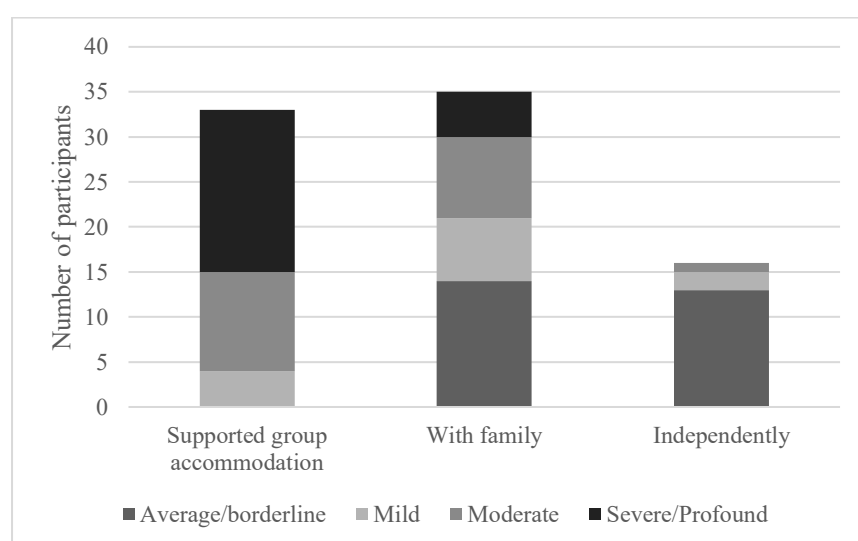
Figure 7.1a. Current living arrangements by degree of intellectual disability

7.5.2.2 Highest level of education

Most participants' highest level of education was secondary school (80%, *n* = 67), with 82% (*n* = 55) of these in a special school. Some participants (13%, *n* = 11) had pursued further education post-secondary school, completing training certificates and diplomas. Four participants (5%) were still enrolled in their course at the time of data collection. Two of these courses were designed for adults with intellectual and other disabilities, focussing on workplace and independent living skills. Six participants (7%) had completed university degrees (*n* = 5 bachelor's degrees, *n* = 1 master's degree), including one participant currently completing a bachelor's degree. Only one participant with moderate intellectual disability

completed post-secondary education; no participants who completed university degrees had intellectual disability (Figure 7.1b).
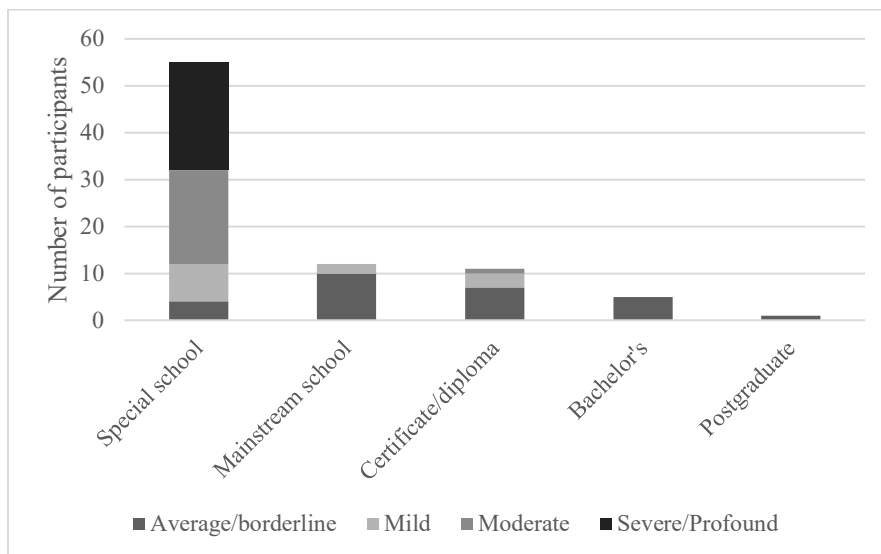

Figure 7.1b. Highest level of education by degree of intellectual disability

7.5.2.3 Current daytime activity

Most participants (56%, *n* = 47) were attending organised day programmes for people with disability. Day programmes involved activities such as group outings to local cafes and activity centres, craft, and gardening activities, with support from paid professional support workers. While most participants (83%, *n* = 39) attended day programmes for 20 hours or more per week, 13% (*n* = 6) attended 10-19 hours, and 2 participants (4%) attended for fewer than 10 hours. One participant attended a day programme in addition to undertaking an education course. Four participants (5%) were employed in sheltered workshops or disability enterprises. Participation in these programmes ranged from 14-26 hours per week. Participants attending organised day programmes mostly had moderate to severe/profound intellectual disabilities (72%, *n* = 41). Some (*n* = 10) participants with no or mild intellectual disability were also attending disability-specific activities (Figure 7.1c).

Twenty-two participants (26%) were employed in the mainstream workforce. Two participants worked in permanent positions and received additional support in the workplace. A further 20 participants (24%) were employed in the mainstream workforce without any additional support. Hours of work varied from 2-42 hours per week. Of the 20 participants employed without support, nine (45%) worked full time hours (38-42 hours per week), four (20%) worked 20-30 hours per week, two (10%) worked 10-19 hours per week, and five (25%) worked fewer than 10 hours per week. All of those in paid work were participants with mild or no intellectual disability (Figure 7.1c).

Two participants volunteered for a few hours per week in addition to their organised day programme. Twelve participants (14%) were unemployed. Three of these participants were, however, undertaking education courses, with the remaining nine participants (11%) not involved in any daytime activity. Five participants (55%) who had no daytime activity did not have intellectual disability (Figure 1c). Of those who had no regular daytime activity, time was spent mostly online ($n = 2$), working on projects ($n = 1$), searching for work ($n = 1$), and caring for elderly relatives ($n = 1$). Four participants had no daily activities.
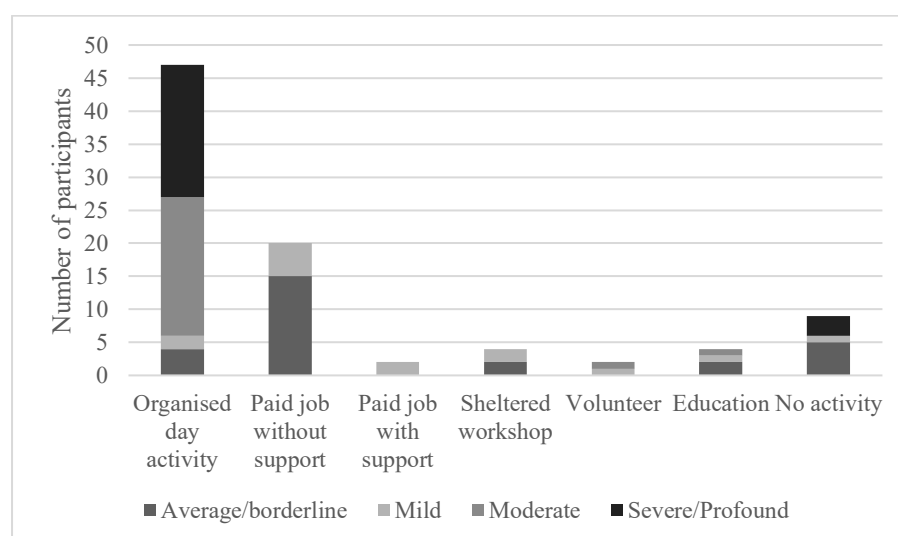

Figure 7.1c. Current daytime activity by degree of intellectual disability

7.5.2.4 Comparison to Australian population

Data on current living arrangements and current employment status were extracted for a total of 6,513,390 people aged between 25-44 years living in Australia. Figures 7.2a, 7.2b, and 7.2c show comparisons between the data from the current study and the Australian general population. When comparing living arrangements, only 8% of adults in the Australian population continued to live with their families, compared with 42% of the current sample. Conversely, 72% of the Australian population lived independently, compared with only 19% of the current sample. There were no general Australian population comparison data available for living in supported accommodation. Only 31% of the current sample were engaged in the workforce compared with 70% of the Australian population, while 69% and 15% of the current and general Australian population respectively were not participating in the labour force. Few adults with autism participated in post-secondary education, with 11 (13%) completing certificates or diplomas and only 5 (7%) completing a university degree. Comparatively, 31% of the Australian population completed certificates or diplomas and another 32% have a university degree.
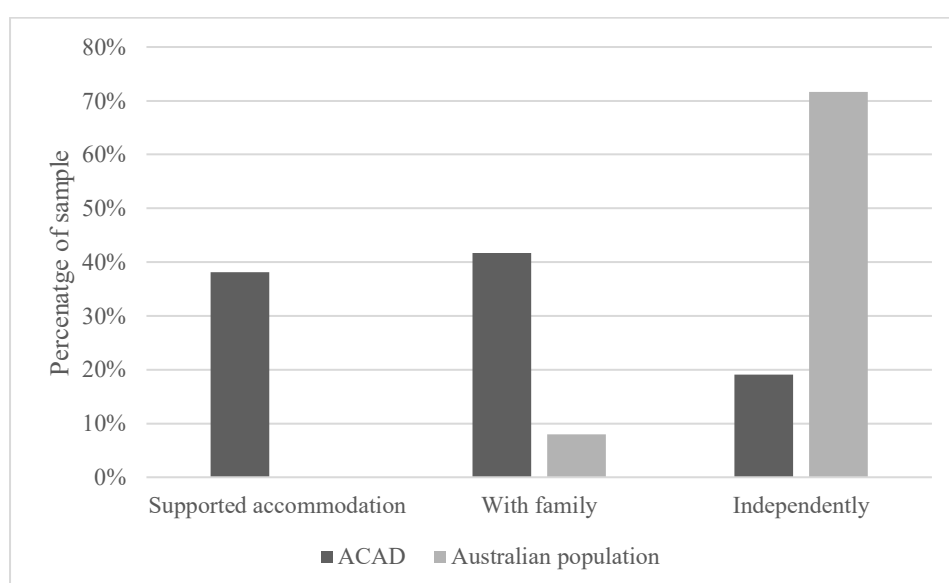

Figure 7.2a. Comparison of living arrangements between ACAD autism sample and Australian general population
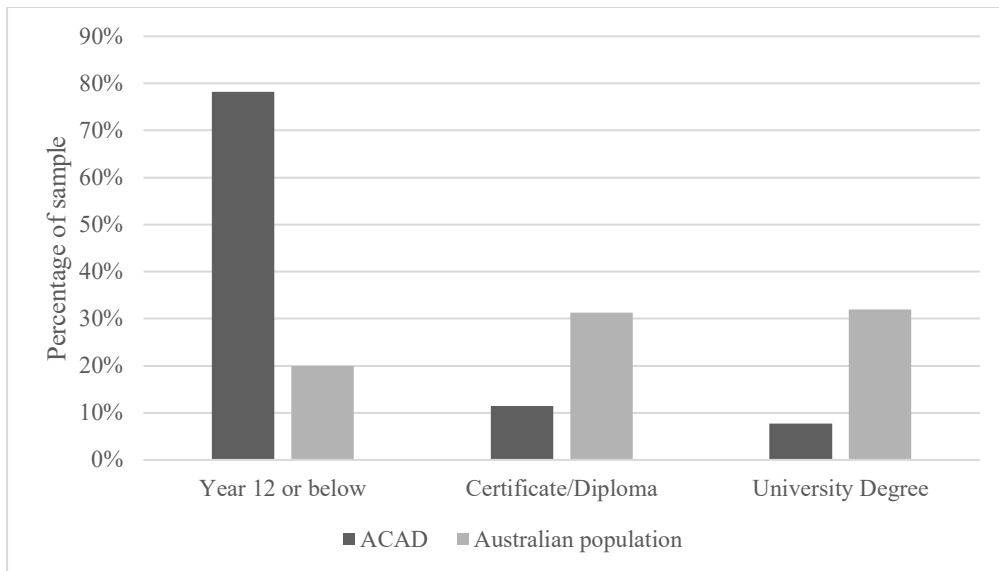
Figure 7.2b. Comparison of highest educational attainment between ACAD autism sample and Australian general population
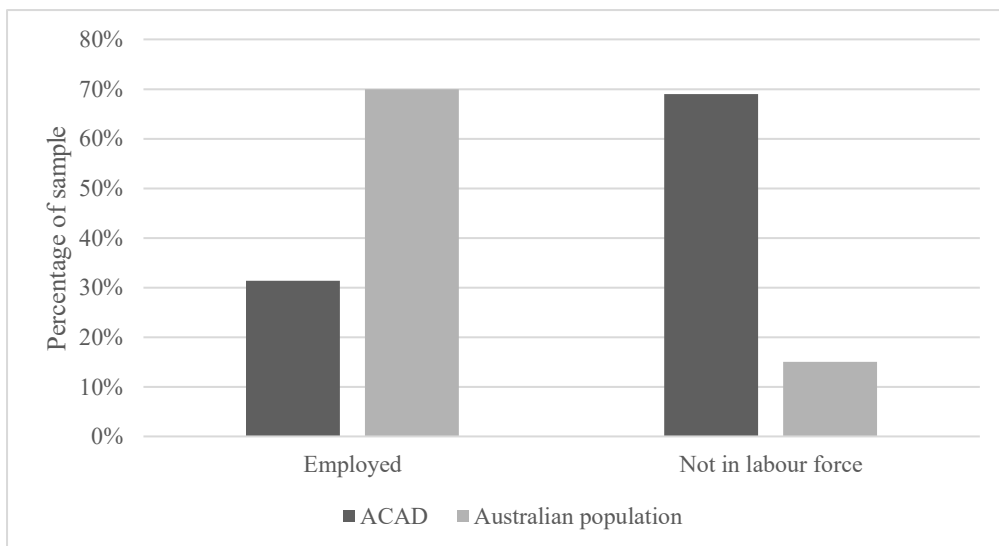

Figure 7.2c. Comparison of engagement in the labour force between ACAD autism sample and Australian general population

7.5.3 Social Inclusion in Adulthood (Time 6)

Current friendship information was available from the ADI-R for 75 participants. Twelve participants (16%) had one or more friendships with peers involving sharing of personal interests and activities that include reciprocity and mutual responsiveness. Eight participants (11%) had one or more relationships with peers, although limited in terms of shared interests

or reciprocity. Fifteen (20%) had some limited relationships with others, and over half (53%, *n* = 40) had no peer relationships.

The Modified Worker Loneliness Questionnaire was completed as a self-report measure by 28 participants (33% of the sample). Most participants (71%, *n* = 20). who completed this questionnaire did not have an intellectual disability. Scores for the Aloneness subscale ranged from 0-12 (M = 4.0, SD = 3.0), and for the Social Dissatisfaction subscale from 0-7 (M = 2.6, SD = 2.3). When comparing participants with and without intellectual disability, no significant differences were found for scores on the Aloneness (*t*(26) = -.51, *p* = .62) or Social Dissatisfaction (*t*(26) = -.53, *p* = .60) subscales.

7.6   DISCUSSION

This study considers a range of important outcomes for adults with autism in Australia. Findings suggest that adults with autism experience a number of difficulties with community and social inclusion.

7.6.1 Overall Outcome

When compared with other autism populations, the overall social functioning outcomes in this Australian sample were comparable to those of Howlin *et al.* (2004) (United Kingdom) and Farley *et al.* (2017) (USA). Similar rates of *Poor/Very Poor* outcomes were seen across all three samples (46%–58%). Slightly more participants in the Australian sample were considered to have achieved a *Good/Very Good* outcome (33.8%) when compared with the Howlin and Farley samples (22% and 20% respectively), with far fewer participants in the Australian sample achieving a *Fair* outcome (8.4%). Similarly, both *good* and *poor* outcomes seen in the current Australian sample were comparatively higher than those reported in the Steinhausen and Mason systematic reviews and meta-analyses (*good* outcome: 34% in the Australian sample and 20% in each of the reviews; *poor* outcome: 58% in Australian sample

and 48-49% in the reviews). This could be due to scores particularly in the employment variable, being more likely to be at the extreme ends of the scoring metric described by Howlin *et al.* (2004). Most Australian participants were either employed without support (24%) or involved in an organised day programme/no activity (67%), scoring a 0 or 3 on this factor respectively. Few (2%) were involved in any kind of supported employment (i.e. a score of 1 or 2).

Overall outcome scores have been widely used throughout the autism adult outcome literature to date and were determined in this study to provide a comparison of the current sample to other well-known samples of adults with autism. These scores have provided a basis for describing what adulthood looks like for people with autism, highlighting that many face ongoing challenges with independent living, education, and employment. However, overall scores allow little room for nuance, potentially providing an overly simplistic view of adult outcomes, demonstrated by the current study. For example, as was apparent in the current sample, an individual may achieve an employment score of 0, indicating that they are currently engaged in regular employment, but this score may not reflect the fact that the individual is only working for one or two hours per week. While achieving employment is important, the amount of time spent in employment also needs to be considered. Further, scores related to independent living may be biased; while some individuals who are living with family may be capable of living independently, financial, or other stressors may prevent them from doing so. These are important areas for further exploration in order to identify the barriers and therefore supports needed, to allow individuals to have a choice in how they live. While overall outcome ratings provide a helpful picture of broad outcomes in adulthood, the lack of nuance and limited ability to capture relevant individual circumstances highlights that these ratings should not be used in isolation to describe and evaluate outcomes for adults with autism, and future research should move away from focusing on these ratings.

7.6.2 Community Inclusion

The results of this study demonstrate that adults with autism continue to be disadvantaged in terms of key aspects of independent living (Gray *et al.* 2014), particularly when compared to the general Australian population. They were more likely to be living at home with family, not pursue post-secondary education, and be unemployed than the general population. The impact of co-occurring intellectual disability on community inclusion outcomes was clear; adults with moderate to severe/profound intellectual disability were over-represented in supported living, participation in unpaid daytime activities, such as day activity programmes, and lower levels of education achieved.

Higher rates of independent living were reported in this Australian sample compared to others in the US, UK, and Sweden (Farley *et al.* 2017; Billstedt *et al.* 2005; Eaves and Ho 2008; Howlin *et al.* 2013), in addition to lower rates of living in supported group accommodation (Farley *et al.* 2017; Billstedt *et al.* 2005; Howlin *et al.* 2013). When considering the influence of intellectual disability on living situation, the results of the current study were comparable to those of Lord *et al.* (2020): participants without intellectual disability were more likely to be living independently or with family, and those with intellectual disability predominantly living in supported group homes or with family. For adults living independently or with family, few were in receipt of additional paid support.

Participation in the labour force was limited, particularly when compared to the general Australian population Although a quarter of participants (26%), were involved in the mainstream workforce, hours of work per week were limited. Similar rates of employment are reported in other studies (Howlin *et al.* 2013; Farley *et al.* 2017). Further, while the majority (56%) of the current sample was involved in organised day programmes, a disturbing number of participants (11%, *n* = 9) had no regular daytime activity at all. This was a large increase in the numbers without any daytime activity since the previous timepoint

of the ACAD study (Time 5; Gray *et al.* 2014), where only one participant had no daytime activity. This figure was, however, considerably lower than the rates of unemployment/no activity reported in other studies, with as many as 20-55% of adults unemployed (Farley *et al.* 2017; Howlin *et al.* 2013). Of particular concern is the fact that most (55%) participants without a daytime activity did not have an intellectual disability, highlighting the lack of availability of suitable resources and activities for adults with autism, including those without intellectual disability.

Despite evidence that community inclusion for adults with autism is challenging, it is encouraging to see that there were a number of adults who were living and working independently. Future research should continue to explore the factors that support adults to live and work more independently and examine how these elements can be incorporated into interventions and programmes to further assist individuals to achieve their goals. Community engagement and participation in recreational activities should also be considered in future research.

7.6.3 Social Inclusion

Seventy-three percent of participants had either no peer relationships or limited peer relationships, and 16% had close friendships, as reported by parents/carers. Similar rates were identified by Howlin *et al.* (2013), also using parent-report, in a population of adults with autism without intellectual disability. They found 77% of participants did not have any, or had limited, peer relationships, and only 9% had a close friend. However, among individuals who were able to self-report on the loneliness questionnaire in the current study, 86% reported that they had friends, and 54% reported that they had lots of friends. These higher rates of friendships are similar to those in other self-report studies. For example, Mazurek (2014) noted that 60% of participants reported having a close or best friend, although they do not indicate whether any participants had intellectual disability. Future research should

further explore the experiences of friendships for adults with autism and the impact on their quality of life and mental health. Continuing to use both self-report and parent/carer report is important in furthering understanding of how adults experience friendships and how their views differ from those of their parents/carers.

The self-report Modified Worker Loneliness Questionnaire provided some important insights into the experiences of a subset of individuals. Whilst only completed by a small proportion of the sample (n = 28, 33%), the results suggest that respondents were largely satisfied with their social environment and friendships. Similar findings were reported using the same measure for a group of adults with disabilities living in group homes in Australia (Stancliffe and Keane 2000). While the loneliness data is limited, results indicate that further investigation of feelings of social satisfaction and loneliness for adults with autism is warranted given the disparity between parent/carer reported friendships and self-reported friendships and social satisfaction. Future research should explore how adults experience loneliness and how social satisfaction can be improved. It is important that this information is gained directly from adults with autism themselves. Self-report measures of satisfaction may differ from the informant-report measures traditionally used in the literature. Measures of social satisfaction and loneliness validated for use with individuals with co-occurring intellectual disability, such as the Satisfaction with Life Questionnaire (Lucas-Carrasco & Salvador-Carulla, 2012) should be used to allow adults to self-report their experiences, rather than relying on others to provide their interpretations.

7.6.4 Limitations

The cohort effect in this population is important to consider. As participants were recruited in the early 1990's when they were children and adolescents, the results reported are likely to reflect identification and diagnostic practices at that time. In addition to changes in diagnostic criteria in the intervening years, there have been considerable changes in supports and

services provided for individuals with autism, impacting on each individual's experience and outcome. The results therefore may not be generalisable to children diagnosed since this study began. However, this study does point to a number of areas where adults with autism may experience additional challenges and barriers compared to the general Australian population, irrespective of when they received an autism diagnosis. Further, while there was a decline in sample size from Time 1 ($n = 119$) to Time 6 ($n = 84$), there was no significant difference in degree of intellectual disability between Time 6 participants and non-participants.

Clinical assessment measures, such as the ADI-R (Rutter *et al.* 2003) and ADOS (Lord *et al.* 2012), were not available when the study commenced. However, autism diagnoses were made based on clinical best practice at the time, using the current DSM diagnostic criteria. Diagnoses were reviewed and confirmed for all participants according to the DSM-IV and DSM-5 diagnostic criteria during the course of the study. Further, the overall outcome rating score for each participant was determined via consensus between two authors (LAC and KMG), and was not rated independently. No interrater reliability could be performed, however, there was no disagreement between the authors on the final ratings determined for each participant.

The current study sought to gather self-report data directly from adults with autism, however, the number of participants who were willing and able to self-report was limited. Although the self-report questionnaires, particularly in relation to friendships and loneliness, provided important findings, future research would benefit from exploring the experience of adults with autism in a larger sample. This will require the adaptation or development of measures to support participation of more people with autism.

7.6.5 Conclusion

This study highlights that adults with autism and co-occurring moderate to severe/profound intellectual disability are at greater risk for poor outcomes in adulthood, characterised by ongoing requirement of care and support, limited engagement in employment, and restricted friendships. However, participants with no or mild intellectual disability also experienced outcomes ranging from *poor* to *very good,* indicating that intellectual ability is not the sole factor determining outcome in adulthood. Further exploration of other factors impacting outcome should be a focus of future research. Modifiable factors, such as functional skills, are of particular importance as these can be targeted in interventions aimed at improving skills to further support adults. The higher rates of *good* outcomes, including independent living, seen in the current study compared to previous studies is encouraging. Nevertheless, the majority of participants still experience considerable difficulties, highlighting the need for more appropriate and effective resources to support adults with autism to live more independently and participate in their community as they desire.

REFERENCES

American Psychiatric Association (1987) *Diagnostic and Statistical Manual for Mental Disorders.* American Psychiatric Association, Washington, DC

American Psychiatric Association (1994) *Diagnostic and Statistical Manual for Mental Disorders.* American Psychiatric Association, Washington, DC

American Psychiatric Association (2013) *Diagnostic and Statistical Manual for Mental Disorders.* American Psychiatric Association, Washington, DC

Australian Bureau of Statistics (2001) *Australian Standard Classification of Education (ASCED)* [Online]. Australian Bureau of Statistics. Available: https://www.abs.gov.au/ausstats/abs@.nsf/0/F501C031BD9AC9C5CA256AAF001F CA33?opendocument (accessed 23 September 2020).

Australian Bureau of Statistics (2016) *Census of Population and Housing* [Online]. Available: https://www.abs.gov.au/websitedbs/censushome.nsf/home/2016 (accessed 23 September 2020).

Billstedt E., Gillberg C. & Gillberg C. (2005) Autism after adolescence: Population-based 13- to 22-year follow-up study of 120 individuals with autism diagnosed in childhood. *Journal of Autism and Developmental Disorders,* **35,** 351-360. 10.1007/s10803-005-3302-5.

Cedurland M., Hagberg B., Billstedt E., Gillberg I. C. & Gillberg C. (2008) Asperger Syndrome and autism: A comparative longitudinal follow-up study more than 5 years after original diagnosis. *Journal of Autism and Developmental Disorders,* **38,** 72-85. 10.1007/s10803-007-0364-6.

Chadsey-Rusch J., DeStefano L., O'Reilly M., Gonzalez P. & Collet-Klingenberg L. (1992) Assessing the loneliness of workers with mental retardation. *Mental Retardation,* **30,** 85-92.

Eaves L. C. & Ho H. H. (2008) Young adult outcome of autism spectrum disorders. *Journal of Autism and Developmental Disorders,* **38,** 739-747. 10.1007/s10803-007-0441-x.

Ee D., Hwang Y. I., Reppermund S., Srasuebkul P., Troller J. N., Foley K. & Arnold S. R. C. (2019) Loneliness in adults on the autism spectrum. *Autism in Adulthood,* **1,** 182-193. 10.1089/aut.2018.0038.

Einfeld S. & Tonge B. J. (1996a) Population prevalence of psychopathology in children and adolescents with intellectual disability: I rationale and methods. *Journal of Intellectual Disability Research,* **40,** 91-98. 10.1046/j.1365-2788.1996.767767.x.

Einfeld S. & Tonge B. J. (1996b) Population prevalence of psychopathology in children and adolescents with intellectual disability: II epidemiological findings. *Journal of Intellectual Disability Research,* **40,** 99-109. 10.1046/j.1365-2788.1996.768768.x.

Farley M. A., Cottle K. J., Bilder D., Viskochil J., Coon H. & McMahon W. M. (2017) Mid-life social outcomes for a population-based sample of adults with ASD. *Autism Research,* **11,** 142-152. 10.1002/aur.1897.

Gray K. M., Keating C. M., Taffe J., Brereton A. V., Einfeld S. & Tonge B. J. (2012) Trajectory of behavior and emotional problems in autism. *American Journal of Intellectual and Developmental Disabilities,* **117,** 121-133. 10.1352/1944-7588-117-2.121.

Gray K. M., Keating C. M., Taffe J. R., Brereton A. V., Einfeld S. L., Reardon T. C. & Tonge B. J. (2014) Adult outcomes in autism: Community inclusion and living skills. *Journal of Autism and Developmental Disorders,* **44,** 3006-3015. 10.1007/s10803-014-2159-x.

Harrison P. L. & Oakland T. (2015) *Adaptive Behavior Assessment System, Third Edition.* Western Psychological Services, Torrance, CA

Howlin P., Goode S., Hutton J. & Rutter M. (2004) Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry,* **45,** 212-229. 10.1111/j.1469-7610.2004.00215.x.

Howlin P. & Magiati I. (2017) Autism spectrum disorder: Outcomes in adulthood. *Current Opinion in Psychiatry,* **30,** 69-76. 10.1097/YCO.0000000000000308.

Howlin P., Moss P., Savage S. & Rutter M. (2013) Social outcomes in mid- to later adulthood among individuals diagnosed with autism and average nonverbal IQ as children. *Journal of the American Academy of Child & Adolescent Psychiatry,* **52,** 572-581. 10.1016/j.jaac.2013.02.017.

Kamio Y., Inada N. & Koyama T. (2012) A nationwide survey on quality of life and associated factors of adults with high-functioning autism spectrum disorders. *Autism,* **17,** 15-26. 10.1177/1362361312436848.

Krug D. A., Arick J. & Almond P. (1980) Behavior checklist for identifying severely handicapped individuals with high levels of autistic behavior. *Journal of Child Psychology and Psychiatry,* **21,** 221 - 229. 10.1111/j.1469-7610.1980.tb01797.x

Lord C., McCauley J. B., Pepa L. A., Huerta M. & Pickles A. (2020) Work, living, and the pursuit of happiness: Vocational and psyschosocial outcomes for young adults with autism. *Autism,* **24,** 1691-1703. 10.1177/1362361320919246.

Lord, C., Rutter, M., DiLavore, P. C., Risi, S., Gotham, K., & Bishop, S. (2012) *Autism Diagnostic Observation Schedule, 2nd edition*. Western Psychological Services, Torrance, CA.

Lucas-Carrasco, R., & Salvador-Carulla, L. (2012) Life satisfaction in persons with intellectual disability. *Research in Developmental Disabilities,* **33**, 1103-1109. 10.1016/j.ridd.2012.02.002

Mason D., Capp S. J., Stewart G. R., Kempton M. J., Glaser K., Howlin P. & Happe F. (2021) A meta-analysis of outcomes studies of autistic adults: Quantifying effect size, quality, and meta-regression. *Journal of Autism and Developmental Disorders*, **51,** 3165-3179. 10.1007/s10803-020-04763-2.

Mazurek M. O. (2014) Loneliness, friendship, and well-being in adults with autism spectrum disorder. *Autism,* **18,** 223-232. 10.1177/1362361312474121.

McConkey R. & Walsh J. (1982) An index of social competence for use in determining the service needs of mentally handicapped adults. *Journal of Mental Deficiency Research,* **26,** 47-61. 10.1111/j.1365-2788.1982.tb00128.x.

Orsmond G. I., Shattuck P. T., Cooper B. P., Sterzing P. R. & Anderson K. A. (2013) Social participation among young adults with an autism spectrum disorder. *Journal of Autism and Developmental Disorders,* **43,** 2710-2719. 10.1007/s10803-013-1833-8.

Pickles A., McCauley J. B., Pepa L. A., Huerta M. & Lord C. (2020) The adult outcome of children referred for autism: Typology and prediction from childhood. *The Journal of Child Psychology and Psychiatry,* **61,** 760-767. 10.1111/jcpp.13180.

Rutter M., Le Couteur A. & Lord C. (2003) *Autism Diagnostic Interview-Revised.* Western Psychological Services, Los Angeles, CA.

Schopler E., Reichler R. J., DeVills R. F. & Daly K. (1980) Toward objective classification of childhood autism: Childhood Autism Rating Scale (CARS). *Journal of Autism and Developmental Disorders,* **10,** 91-103. 10.1007/BF02408436.

Stancliffe R. J. & Keane S. (2000) Outcomes and costs of community living: A matched comparison of group homes and semi-independent living. *Journal of Intellectual and Developmental Disability,* **25,** 281-305. 10.1080/13668250020019584.

Steinhausen H.-C., Mohr Jensen C. & Lauritsen M. B. (2016) A systematic review and meta-analysis of the long-term overall outcomes of autism spectrum disorders on

adolescence and adulthood. *Acta Psychiatrica Scandinavica,* **133,** 445-452. 10.1111/acps.12559.

Tonge B. J. & Einfeld S. (2003). Psychopathology and intellectual disability: the Australian Child to Adult longitudinal study. In*: International Review of Research in Mental Retardation.* (ed. L. M. Glidden). pp. 61-91. Academic Press, San Diego, CA.

Wechsler D. (2011) *Manual for the Wechsler Abbreviated Scale of Intelligence-Second Edition.* Pearson, Bloomington, MN.

CHAPTER 8: STUDY 2 – "CHILDHOOD AND ADULTHOOD PREDICTORS OF SOCIAL AND COMMUNITY INCLUSION OUTCOMES FOR ADULTS WITH AUTISM"

8.1 PAPER COMMENTARY

This chapter presents a paper submitted for publication to the Journal of Autism and Developmental Disabilities. This paper has been formatted to the specific requirements of the journal. Headings and page numbers have been reformatted to allow for consistency within the thesis.

This study aimed to explore both the childhood and adulthood factors associated with the adult social and community inclusion outcomes identified in Study 1. This study investigated a number of predictors of social and community inclusion outcomes for adults that have not been well studied in the existing literature, for example, socioeconomic disadvantage and behaviour and emotional problems. This study found that childhood degree of intellectual disability and behaviour and emotional problems, as well as adulthood functional skills, behaviour and emotional problems, and autism symptoms, were all important predictors of adult social and community inclusion outcomes. The need for future research to continue to explore what defines a *good* outcome, and how interventions and resources can be tailored to individuals to promote their own best outcome, is discussed.

Cameron, L. A., Tonge, B. J., Howlin, P., Einfeld, S. L., Stancliffe, R. J., and Gray, K. M. (submitted). Childhood and adulthood predictors of social and community inclusion outcomes for adults with autism. *Journal of Autism and Developmental Disabilities.*

8.2 ABSTRACT

Childhood and adulthood factors that influence social and community inclusion outcomes for adults with autism are important to understand. This Australian longitudinal study included 84 adults with autism, followed from childhood and adolescence to adulthood. Childhood and adulthood predictors of social and community inclusion outcomes were investigated. Specifically, personal factors, such as intellectual disability, functional skills, behaviour and emotional problems, and autism symptoms, as well as environmental factors, such as socioeconomic disadvantage, were explored. Childhood degree of intellectual disability and adult functional skills were important predictors of adult outcome, however, other variables also contributed to outcome. Implications related to development of interventions and resources to improve outcomes for adults are discussed.

8.3 INTRODUCTION

Outcomes for adults with autism have been widely reported to be predominantly poor, with nearly half of adults (48-49%) experiencing what is considered a poor outcome when assessed by a rating scale incorporating current employment, living arrangements, and friendships (Howlin, Moss, Savage, & Rutter, 2013; Mason et al., 2021; Steinhausen, Mohr Jensen, & Lauritsen, 2016). Nevertheless, recent systematic reviews and meta-analyses have concluded that approximately 20% of adults achieve a good outcome (Mason et al., 2021; Steinhausen et al., 2016). With increased rates of diagnosis of autism, both in childhood and adulthood, and the ageing of the population of individuals with autism (Lai & Baron-Cohen, 2015; Sonido, Arnold, Higgins, & Hwang, 2020), it is becoming increasingly important to understand what defines a good or poor outcome, and what factors are likely to influence outcomes in adulthood.

Independent living, employment, and social participation, particularly friendships, have been markers of adult outcomes in the general population literature. Across these domains, research suggests that adults with autism are less likely to live independently, gain employment, or maintain meaningful relationships, than both typically developing peers and peers with other developmental disorders (Billstedt, Gillberg, & Gillberg, 2005; Eaves & Ho, 2008; Esbensen, Bishop, Seltzer, Greenerg, & Taylor, 2010; Gray et al., 2014; Howlin & Magiati, 2017; Howlin et al., 2013). A range of factors, both in childhood and in adulthood, is likely to contribute to outcome in adulthood (Kirby, Baranek, & Fox, 2016), however, inconsistencies in results across studies mean ongoing work is required to further understand not only what is impacting on the ability to achieve an independent life in adulthood, but also what factors are driving the positive outcomes seen in many individuals.

Higher IQ and absence of co-occurring intellectual disability have been identified as predicting greater likelihood of employment, social participation, and independent living (e.g. Billstedt, Gillberg, & Gillberg, 2011; Gray et al., 2014; Howlin, Goode, Hutton, & Rutter, 2004; Lord, McCauley, Pepa, Huerta, & Pickles, 2020; McCauley, Pickles, Huerta, & Lord, 2020), as well as greater likelihood of achieving an overall good outcome (Mason et al., 2021; Steinhausen et al., 2016). However, it is apparent that higher IQ does not inevitably lead to more positive or successful outcomes in adulthood (Howlin, 2021; Mason et al., 2021). Poor outcomes have been reported in many adult samples without co-occurring intellectual disability (Zimmerman, Ownsworth, O'Donovan, Roberts, & Gullo, 2018), suggesting that there are other factors involved.

While the role of IQ on outcomes for adults has been extensively studied, the role of functional skills has received less attention. Discrepancies between IQ and adaptive or functional skills for individuals with autism have been well documented (Kraper, Kenworthy, Popal, Martin, & Wallace, 2017). This gap may explain the differences in outcomes for adults

without intellectual disability, therefore greater understanding of the impact of functional skills is needed. Some studies have reported that higher levels of daily living skills and adaptive functioning are associated with an increased likelihood of independent living, better employment outcomes, and more positive outcomes overall for adults without co-occurring intellectual disability (K. A. Anderson, Shattuck, Cooper, Roux, & Wagner, 2014; McCauley, Pickles, et al., 2020; Roux et al., 2013).

Several studies have reported that early childhood severity of autism symptoms is associated with outcome in adulthood. Higher scores on measures of autism symptoms, such as the Autism Diagnostic Interview-Revised (Rutter, Le Couteur, & Lord, 2003), have been found to be associated with poorer outcomes in adulthood (e.g. Helles, Gillberg, Gillberg, & Billstedt, 2017; Magiati, Wei Tay, & Howlin, 2014) and a positive association between autism symptom severity and self-reported rates of loneliness (Ee et al., 2019) in adulthood has also been reported. However, there are inconsistent results across studies in terms of the impact of symptom severity on outcomes, and few studies include adults with co-occurring intellectual disability (Zimmerman et al., 2018).

Inconsistent results have been reported about the impact of age, gender, and socioeconomic status on outcome (Howlin, 2021). Research on the impact of socioeconomic disadvantage and family income on outcome is also mixed. For example, while Gray et al. (2014) found no relationship between socioeconomic disadvantage and living arrangements, other studies have found that individuals with a higher family income were more likely to live independently, gain employment, and attend post-secondary education (D. K. Anderson, Liang, & Lord, 2014; Kirby et al., 2016). Similarly, data on the impact of age and gender are inconsistent and inconclusive (Mason et al., 2021; Steinhausen et al., 2016; Zimmerman et al., 2018).

The relationship between mental health and behaviour and emotional problems and outcome in adulthood has not been extensively studied. One study suggests that receiving additional psychiatric services in adulthood is associated with poorer outcome (Esbensen et al., 2010). Gray et al. (2014) reported that community inclusion, living arrangements and daytime activities in adulthood were associated with behaviour and emotional problems in childhood and early adolescence; for example, childhood difficulties in these areas predicted the likelihood of being engaged in organised daytime activities for fewer than 20 hours per week in adulthood. A longitudinal study conducted by McCauley, Elias, and Lord (2020) evaluated the trajectory of anxious and depressive symptoms over time and the impact on outcome in adulthood. They found that consistent high levels of anxiety, and high yet fluctuating depression, over time resulted in greater likelihood of achieving a poor outcome in adulthood for those in the higher IQ (IQ above 70) group only, highlighting the complexities in understanding how various factors may interact to predict outcome.

The current study aimed to explore both the childhood and adulthood factors associated with social and community inclusion outcomes (overall outcome, independent living, employment, and friendships) for adults with autism. Childhood factors included gender, age, degree of intellectual disability, autism symptoms, socioeconomic disadvantage, and behaviour and emotional problems. Adulthood factors included age, functional skills, socioeconomic disadvantage, autism symptoms, behaviour and emotional problems, and mental health disorder diagnosis. It was hypothesised better social and community inclusion outcomes would be seen in adults with autism with; younger age, less severe intellectual disability in childhood, greater functional skills in adulthood, lower autism symptom severity in both childhood and adulthood, fewer behaviour and emotional problems in childhood and adulthood, and less socioeconomic disadvantage in both childhood and adulthood. It was predicted that there would be no impact of gender on outcome.

8.4 METHOD

8.4.1 Sample

Participants were recruited for the Australian Child to Adult Development (ACAD) study from a number of metropolitan and regional areas of Victoria and New South Wales, Australia in 1991 through health and education agencies providing services for individuals with autism (Einfeld & Tonge, 1996a, 1996b; Gray et al., 2012). At entry to the study, participants were considered likely to be representative of children in the community who had received an autism diagnosis and were receiving services (Tonge & Einfeld, 2003).

Data collection has occurred over six time points: Time 1 (1991-1993), Time 2 (1995-1996), Time 3 (1999), Time 4 (2002-2003), Time 5 (2007-2009) and Time 6 (2016-2019). Participation throughout the study has remained high, with 84 of the 119 (75%, excluding participants who had died since Time 1) participants recruited at Time 1, participating at Time 6. There was no significant difference between those who participated at Time 6 and those who did not in terms of degree of intellectual disability, χ^2 (4, $n = 119) = .05$, $p = .97$, or behaviour and emotional problems, $t(117) = 1.50$, $p = .14$ at Time 1 (see below for details of measures used).

All participants met criteria for Autistic Disorder according to DSM-III-R (American Psychiatric Association, 1987) following clinical assessment by a multidisciplinary team at study entry. Participants were reassessed at Time 2 to confirm diagnosis against DSM-IV criteria (American Psychiatric Association, 1994; Gray et al., 2014). Diagnoses were reviewed again at Time 6, using all clinical information gathered as part of the study, including the Autism Diagnostic Interview-Revised (ADI-R; Rutter et al., 2003). All Time 6 participants met DSM-5 diagnostic criteria for Autism Spectrum Disorder, based on current symptoms.

8.4.2 Measures

8.4.2.1 *Degree of intellectual disability and functional skills*

At Time 1, participants were grouped into four groups according to their degree of intellectual disability: no intellectual disability, mild, moderate, or severe (see Gray et al. (2014). At Time 6, current degree of intellectual disability was reviewed and classified by two authors (L.A.C and K.M.G) following DSM-IV (American Psychiatric Association, 1994) and DSM-5 (American Psychiatric Association, 2013) criteria. Classification was based on a range of assessments, including adaptive behaviour (Adaptive Behavior Assessment System; Harrison & Oakland, 2015), daily living skills (Index of Social Competence; McConkey & Walsh, 1982), and cognitive (Wechsler Abbreviated Scale of Intelligence; Wechsler, 2011).

At Time 6, the ABAS-3 was used as a measure of current functional skills. The ABAS-3 is a standardised measure of adaptive and functional skills and behaviours. Respondents rate each item on whether the individual can independently display the behaviour from 0 (is not able) to 3 (always (or almost always) when needed). The ABAS-3 results in a standardised Global Adaptive Composite score ($M = 100$, $SD = 15$), as well as scores on three standardised domains ($M = 50$, $SD = 10$). The standardisation process of the ABAS-3, however, resulted in a prominent floor effect for individuals with intellectual disability, whereby a wide range of raw scores on each skill area converts to a small variation of scaled scores. As a result, a total raw score was calculated and used in this study to ensure that no data were lost. Higher scores indicate greater adaptive behaviours. A similar process was undertaken by Fusar-Poli et al. (2017) in their use of the Vineland Adaptive Behavior Scales (Sparrow, Balla, Cicchetti, Harrison, & Doll, 1984).

The ABAS-3 was completed at Time 6 by a parent/caregiver (n = 73) or as self-report (n = 6). ABAS-3 was missing for n = 5 participants. The total raw score was calculated by adding the raw score of each of the nine skill areas together (excluding the 'work' skill area as this only applied to a small number of participants).

8.4.2.2 *Autism symptoms*

The ADI-R (Rutter et al., 2003) was conducted with parents or carers for each participant to gather detailed information on current and childhood autism symptoms. For this study, only the current algorithm ADI-R domain scores were used as a measure of current autism symptomatology. Due to challenges of recall, and as a number of interviews were completed with professional carers and not parents, only current item codes were used in analysis. For the purposes of this study, mean algorithm scores were calculated for each domain (Qualitative Abnormalities in Reciprocal Social Interaction [Social], Qualitative Abnormalities in Communication [Communication], and Restricted, Repetitive, and Stereotyped Patterns of Behavior [Restricted and Repetitive Behavior]) rather than summed scores. This was due to the different number of items contributing to the Communication domain algorithm depending on the verbal ability of the individual. In addition, item 65 (friendships) was used as an outcome variable, and therefore the Social domain was calculated with this item removed. As a result, mean scores provided a more consistent approach across all domains for analyses. Current ADI-R interviews were missing for n = 9 participants, and current domain algorithm scores were unable to be calculated for n = 6 participants due to missing information.

The Developmental Behaviour Checklist 2 Autism Screening Algorithm (DBC2 ASA) (Brereton, Tonge, Mackinnon, & Einfeld, 2002; Gray, Tonge, Einfeld, Gruber, & Klein, 2018) was calculated using Time 1 DBC2-P as a measure of childhood autism symptoms.

The DBC2 ASA is a reliable screening measure for autism, comprising 26 items of the DBC2 assessing core symptoms of autism (Brereton et al., 2002).

8.4.2.3 *Behaviour and emotional problems*

The Developmental Behaviour Checklist 2 (DBC2; Gray et al., 2018) is a measure of behaviour and emotional problems in children, adolescents, and adults with intellectual and developmental disability (Gray et al., 2018). It is an informant-report checklist of behaviour and emotional problems for individuals with intellectual and developmental disabilities over the previous six months. Respondents are asked to rate each item on a scale of 0 (not true as far as you know) to 2 (very true or often true). The DBC2-Parent (DBC2-P) (Time 1) or DBC2-Adult (DBC2-A) (Time 6) was completed by parents or carers. Mean Item Scores (MIS) for the Total Behaviour Problem Score (TBPS), as well as scores on five subscales, were calculated. The MIS has advantages over the raw scores in that it allows for comparison between subscales consisting of different numbers of items (Taffe, Tonge, Gray, & Einfeld, 2008). Time 1 DBC2-P was available for all participants. DBC2-A was missing at Time 6 for $n = 9$ participants.

8.4.2.4 *Overall outcome rating*

An overall outcome rating was calculated for each participant to assess outcome in adulthood following criteria set out in Howlin et al. (2004). Ratings are assigned based on current living arrangement and independence, current employment status, and friendships. An overall outcome score is calculated by adding the ratings for each of these three areas. Overall outcome scores were defined as follows: 0 = *Very Good*, 1 = *Good,* 2 = *Fair,* 3 = *Poor,* 4 = *Very Poor.* Ratings for each participant were determined by consensus discussion between two authors (L.A.C and K.M.G). Higher scores indicate a poorer outcome.

8.4.2.5   Community inclusion outcomes

Information on current living arrangement and current daytime activity was obtained from a parent/carer or self-report questionnaire at Time 6. Living arrangements were classified as independent (living alone, with a partner, or with friends = 1), with family (parents, sibling, or other family member = 2), or supported accommodation (group disability accommodation = 3). Current daytime activity was categorised as: no current daytime activity = 0, disability specific daytime activity (organised day program, sheltered workshop, or disability specific education = 1), and mainstream employment or education = 2. Hours per week spent in daytime activities were also recorded (20 hours or more per week vs. less than 20 hours per week).

8.4.2.6   Social inclusion outcomes

Current friendships at Time 6 were assessed using the current item rating for friendships (item 65) on the ADI-R (Rutter et al., 2003). Friendships are assessed on the quality and quantity of the relationship/s and are rated from 0 (one or more relationships with a person of approximately the same age) to 3 (no peer relationships). For the current study, friendships at Time 6 were categorised as: has one or more relationships (ADI-R code 0); has some peer relationships (ADI-R code 1 or 2); and has no peer relationships (ADI-R code 3).

8.4.2.7   Mental health

At Time 6, detailed interviews were conducted with parents or professional carers of participants, as well as with the participant themselves where possible, to gather information on current mental health concerns using the Structured Clinical Interview for DSM-5, Research version (SCID-5; First, Williams, Karg, & Spitzer, 2015). Symptom level information gathered in the interview was used to inform mental health diagnoses, as determined via consensus clinical case review with a panel of the authors, experts in the field

of mental health and intellectual and developmental disability (K.M.G, B.J.T, P.H, S.L.E). For the purposes of this study, a variable was created regarding presence or absence of a current mental health diagnosis.

8.4.2.8 *Socioeconomic disadvantage*

The Socio-Economic Indexes for Areas (SEIFA), specifically, the Index of Relative Socioeconomic Disadvantage (IRSD) (Australian Bureau of Statistics, 2016) was used as a measure of socioeconomic disadvantage. SEIFA is produced by the Australian Bureau of Statistics, ranking areas in Australia based on socioeconomic advantage and disadvantage using a range of information gathered in the census. The IRSD was determined for each participant based on where they were living in childhood (Time 1) and in adulthood (Time 6). A lower score indicates relatively greater disadvantage.

8.4.3 Procedure

All participants were invited to participate at each time point and were sent a questionnaire to be completed by a parent or carer, and, at Time 6, the adults themselves where possible. At Time 6, interviews were also conducted with parents/carers and the adult participant. Ethics approval was obtained from Monash University Human Research Ethics Committee (CF15/1045-2015000486). Informed consent was provided by parents/carers, and in some cases the adult themselves.

8.4.4 Statistical Analyses

Correlations were performed to explore associations between all predictor variables (childhood and adulthood) and adulthood outcome variables in order to determine variables to enter into regression models. The strength of the association, as well as statistical significance, was considered in this determination. Strength of correlations were interpreted as per Cohen (1988). Logistic regression analyses evaluated the contribution of each

determined predictor variable (childhood and adulthood) to the adult outcome variables. Correlational analyses were conducted between all predictor variables to identify multicollinearity (see Table A.1, Appendix G for Time 1 predictor variables, and Table A.2, Appendix H for Time 6 predictor variables). Using a correlation coefficient cut-off of 0.90 (Pallant, 2011), no multicollinearity was detected. When entering variables into regression models, variables were selected to ensure there was no singularity (Pallant, 2011) (i.e. only total scores or subscale scores were included in the one analysis). Significance was set at $p <$ .05 for interpretation of regression analyses.

To overcome separation issues caused when entering Time 1 degree of intellectual disability into multinomial logistic regression models, the categories of degree of intellectual disability were collapsed into the following groups: average/borderline, mild, and moderate/severe/profound. At Time 6, there were missing data across a number of predictor variables (ABAS ($n = 5$ missing), ADI-R ($n = 9$ missing), DBC2-A ($n = 9$ missing)). To maximise sample size and reduce overfitting in regression models, mean algorithm scores for each of the ADI-R domains (Social, Communication, and Restricted and Repetitive Behaviors) were assessed in a separate regression model.

8.5   RESULTS

At Time 6, participants were aged between 26.8 and 44.2 years ($M = 34.2$, $SD = 4.5$) and 81% ($n = 68$) were male. Sample demographic data of the sample at Time 1 and Time 6 are presented in Table 8.1.

Table 8.1. Sample demographics

	Time 1 _n_ = 119	Time 6 _n_ = 84
Male (%)	98 (82%)	68 (81%)
Mean age (SD)	8.7 (4.3)	34.2 (4.5)
Age range (years)	2.8 – 19.8	26.8 – 44.2
Degree of intellectual disability (n, %)		
Average	11 (9%)	14 (17%)
Borderline	16 (13%)	13 (16%)
Mild	29 (24%)	13 (16%)
Moderate	46 (39%)	21 (25%)
Severe/profound	17 (14%)	23 (27%)
Functional skills		
ABAS total raw score (M, SD) [a]	-	319.86 (200.72)
ABAS range [a]	-	5 – 638
Socioeconomic disadvantage		
Mean IRSD (SD)	1025 (58.9)	998.25 (68.7)
IRSD range	902 – 1179	817 – 1126
DBC2 TBPS MIS [b]	0.64 (0.26)	0.47 (0.27)
Mental health disorder diagnosis [a] (n, %)	-	54 (68%)
Autism symptoms (M, SD)		
DBC2-P ASA	27.45 (10.87)	-
ADI-R Social/Communication [c]	-	2.34 (1.02)
ADI-R Restricted and Repetitive Behaviors [c]	-	0.64 (0.39)

IRSD = Index of Relative Socioeconomic Disadvantage; _DBC2 TBPS_ = Developmental Behavior Checklist 2 Total Behavior Problem Score; _DBC2-P ASA_ = Developmental Behavior Checklist 2 – Parent, Autism Screening Algorithm; _ADI-R_ = Autism Diagnostic Interview – Revised; _MIS_ = mean item score
[a] _n_ = 79
[b] Time 6: _n_ = 75
[c] _n_ = 69, MIS for ADI-R Social/Communication calculated with item 65 (friendships) removed

8.5.1 Outcomes in Adulthood (Time 6)

Frequencies for community and social inclusion outcomes, including overall outcome, living arrangements, daytime activity, hours per week spent in daytime activity, and friendships are provided in Table 8.2.

An overall outcome rating was calculated for all participants except one, as the individual was in prison at the time of data collection and a comparable score for living arrangement and employment was not possible. Most participants had a *Poor/Very Poor* outcome (57%), lived in supported accommodation (39%) or with family (41%), and were predominantly engaged in disability-specific daytime activities (62%), such as organised day programmes or sheltered workshops. Most participants (53%) had no peer relationships. A detailed discussion of the outcomes in adulthood (Time 6) are reported in Cameron et al., 2021.

Table 8.2. Social and community inclusion outcomes in adulthood (Time 6) and Time 1 degree of intellectual disability (N = 84)

Time 6 outcome	N (%)	Time 1 degree of intellectual disability			
		Average/borderline (n = 23)	Mild (n = 16)	Moderate (n = 33)	Severe/Profound (n = 12)
Overall outcome rating^					
Very Good	16 (19%)	8 (50%)	6 (38%)	2 (12%)	0 (0%)
Good	12 (15%)	8 (67%)	3 (25%)	1 (8%)	0 (0%)
Fair	7 (8%)	2 (29%)	3 (43%)	2 (29%)	0 (0%)
Poor	47 (57%)	5 (11%)	4 (9%)	26 (55%)	12 (26%)
Very Poor	1 (1%)	0 (0%)	0 (0%)	1 (100%)	0 (0%)
Living arrangements					
Supported group accommodation	33 (39%)	1 (3%)	4 (12%)	17 (52%)	11 (33%)
With family	35 (42%)	12 (34%)	7 (20%)	15 (43%)	1 (3%)
Independently	16 (19%)	10 (63%)	5 (31%)	1 (6%)	0 (0%)
Current daytime activity					
Mainstream employment or education	23 (27%)	12 (52%)	8 (35%)	3 (13%)	0 (0%)
Disability specific program	52 (62%)	6 (12%)	7 (13%)	27 (52%)	12 (23%)
No daytime activity	9 (11%)	5 (56%)	1 (11%)	3 (33%)	0 (0%)
Hours spent in daytime activity					
20 hours or less	31 (37%)	12 (39%)	5 (16%)	7 (23%)	7 (23%)
More than 20 hours	53 (63%)	11 (21%)	11 (21%)	26 (49%)	5 (9%)
Friendships ‡					
One or more relationships (ADI-R code 0)	12 (16%)	9 (75%)	3 (25%)	0 (0%)	0 (0%)
Some peer relationships (ADI-R code 1 or 2)	23 (31%)	7 (30%)	7 (30%)	8 (35%)	1 (5%)
No peer relationships (ADI-R code 3)	40 (53%)	4 (10%)	3 (8%)	23 (57%)	10 (25%)

^ n = 83 (overall outcome rating not calculated for n = 1 participant); ‡ n = 75 (data missing for n = 9 participants)

ADI-R = Autism Diagnostic Interview - Revised

8.5.2 Childhood (Time 1) Predictors of Adult Outcomes (Time 6)

Correlational analyses were performed between each Time 1 predictor variable and each Time 6 outcome variable (Table 8.3). Predictors with significant correlations with outcomes were entered into multinomial logistic regression analyses for each outcome variable (Table 8.4).

Table 8.3. Correlations (Spearman's rho) between Time 1 predictor variables and Time 6 outcome variables (N = 84)

Time 1 Predictor Variable	Time 6 Outcome Variable				
	Overall outcome^	Living	Daytime activity	Hours in daytime activities	Friendships [‡]
Degree of intellectual disability	-0.65**	0.63**	0.29**	-0.08	-0.63**
Sex	0.07	-0.12	-0.04	0.06	0.04
Age	0.36**	-0.26*	-0.13	-0.06	0.26*
Socioeconomic disadvantage	-0.10	0.06	-0.01	-0.10	0.04
DBC2-P ASA	0.18	-0.23*	-0.05	-0.06	0.34**
DBC2-P TBPS MIS	-0.03	-0.02	0.07	-0.17	0.10
DBC2-P Disruptive MIS	-0.13	0.05	0.07	-0.16	-0.11
DBC2-P Self Absorbed MIS	0.26*	-0.27*	-0.10	-0.02	0.38**
DBC2-P Comm. Dist. MIS	-0.28*	0.21	0.19	-0.25*	-0.08
DBC2-P Anxiety MIS	-0.13	0.13	0.01	-0.25*	-0.07
DBC2-P Social Relating MIS	0.13	-0.21	0.11	0.02	0.28*

DBC2-P = Developmental Behavior Checklist 2 – Parent; *ASA* = Autism Screening Algorithm, *Comm. Dist.* = Communication Disturbance; *MIS* = mean item score
^ $n = 83$ (overall outcome rating not calculated for $n = 1$ participant); [‡] $n = 75$ (data missing for $n = 9$ participants)
* $p < .05$ ** $p < .01$

Table 8.4. Multinomial logistic regression analyses of association between Time 1 predictor variables and Time 6 outcomes (relative risk ratios

or odds ratios) (N = 84)

	Overall outcome [^b]		Living [c]		Daytime activity [d]		Hours in daytime activity [e]	Friendships [‡f]	
	Very Good/Good (RRR)	Fair (RRR)	Supported (RRR)	Independent (RRR)	No activity (RRR)	Mainstream (RRR)	< 20 hours (OR)	Some peer relationships (RRR)	No peer relationships (RRR)
Degree of intellectual disability [a]									
Borderline/average	16.80**	5.74	0.06*	10.71*	10.83**	26.00‡	-	0.00‡	0.00‡
Mild	12.82**	13.06	0.41	8.03	1.86	14.39**	-	0.00‡	0.00
Age	0.83*	0.78	1.04	0.94	-	-	-	1.08	1.17
DBC2-P ASA	-	-	2.21	8.20	-	-	-	0.92	1.04
DBC2-P Self Absorbed MIS	0.03*	0.68	1.74	0.05	-	-	-	11.35	9.27
DBC2-P Comm. Dist. MIS	10.51*	0.81	-	-	-	-	0.37	-	-
DBC2-P Anxiety MIS	-	-	-	-	-	-	0.30	-	-
DBC2-P Social Relating MIS	-	-	-	-	-	-	-	7.04	1.20

Note: only predictor variables significantly correlated with the outcome variable were included in the regression analyses

[^] n = 83 (overall outcome rating not calculated for n = 1 participant); [‡] n = 75 (data missing for n = 9 participants)

DBC2-P = Developmental Behavior Checklist 2 – Parent; *ASA* = Autism Screening Algorithm, *Comm. Dist.* = Communication Disturbance; *MIS* = mean item score; *RRR* = relative risk ratio; *OR* = odds ratio

[a] base value is *moderate/severe/profound*

[b] reference group is *poor/very poor*

[c] reference group is *with family*

[d] reference group is *disability specific*

[e] reference group is *more than 20 hours*

[f] reference group is *one or more peer relationships*

* $p < .05$ ** $p < .01$ ‡ $p < .001$

8.5.2.1   *Overall outcome rating*

Time 1 degree of intellectual disability (rho = -0.65, *p* < .01), Time 1 age (rho = 0.36, *p* < .01), and Self-Absorbed (rho = 0.26, *p* < .05), and Communication Disturbance (rho = -0.28, p < .05) problems (DBC2-P) were all significantly correlated with the overall adult outcome rating (see Table 8.3). A more severe degree of intellectual disability in childhood (Time 1) was associated with poorer overall outcome ratings in adulthood (Time 6). All participants with severe/profound intellectual disability and 81% of those with moderate intellectual disability in childhood had a *Poor/Very Poor* outcome in adulthood. Older age at Time 1 and higher rates of Self-Absorbed behaviours in childhood were associated with a poorer overall outcome rating in adulthood, while higher rates of Communication Disturbance problems in childhood in were associated with a better adult overall outcome rating. Overall behaviour and emotional problems (DBC2-P TBPS) in childhood (Time 1) were not associated with overall outcome rating in adulthood (Time 6).

Multinomial logistic regression using *Poor/Very Poor* as the base value found that Time 1 degree of intellectual disability, child age, Self-Absorbed, and Communication Disturbance behaviour problems significantly predicted overall outcome rating at Time 6 while controlling for the effects of the other variables (see Table 8.4). When compared to participants with moderate/severe/profound intellectual disability, participants with borderline/average and mild intellectual disability were more likely to have a *Very Good/Good* outcome than a *Poor/Very Poor* outcome. Older participants were more likely to have a *Poor/Very Poor* outcome than a *Very Good/Good* outcome. Participants with higher scores on the DBC2-P Self-Absorbed and lower scores on Communication Disturbance at Time 1 were more likely to have a *Poor/Very Poor* than a *Very Good/Good* outcome at Time 6.

8.5.2.2   *Living arrangements*

Time 1 degree of intellectual disability (rho = 0.63, $p < .01$), Time 1 age (rho = -0.26, $p < .05$), autism symptoms (DBC2-P Autism Screening Algorithm) (rho = -0.23, $p < .05$), and Self-Absorbed behaviour problems (DBC2-P) (rho = -0.27, $p < .05$) were all significantly correlated with Time 6 living arrangements (see Table 8.3). No participants with severe intellectual disability in childhood were living independently as adults, and only one participant with no intellectual disability in childhood was living in supported accommodation at Time 6. Older age, and higher rates of Self-Absorbed behaviour problems at Time 1 were associated with increased likelihood of supported living at Time 6.

Multinomial logistic regression, using *living with family* as the base value, indicated that degree of intellectual disability was the only Time 1 variable significantly associated with living arrangement in adulthood (Time 6) when the other variables were controlled for (see Table 8.4). When compared to participants with moderate/severe/profound intellectual disability in childhood, participants with no intellectual disability were less likely to live in supported accommodation and more likely to live independently than with family at Time 6.

8.5.2.3   *Daytime activity*

Only Time 1 degree of intellectual disability was significantly correlated with daytime activity in adulthood (rho = 0.29, $p < .01$; see Table 8.3). All participants with severe/profound intellectual disability were in a disability-specific daytime activity, while participants with no intellectual disability were involved in mainstream activities ($n = 12$, 52%), disability-specific activities ($n = 6$, 26%), and no daytime activity ($n = 5$, 22%) at Time 6.

To explore the predictive value of the levels of Time 1 degree of intellectual disability on Time 6 daytime activity, multinomial logistic regression, with *disability specific* as the base

214

value, was performed. When compared to participants with moderate/severe/profound intellectual disability, participants with borderline/average intellectual disability were more likely to have either no organised daytime activity or be engaged in a mainstream activity than in a disability-specific activity. Participants with mild intellectual disability were more likely to be involved in mainstream activities than disability-specific activities (see Table 8.4).

8.5.2.4 *Friendships*

Item 65 of the ADI-R (current coding) provided information on friendships at Time 6. Time 1 degree of intellectual disability (rho = -0.63, $p < .01$), Time 1 age (rho = 0.26, $p < .05$), autism symptoms (DBC2-P ASA) (rho = 0.34, $p < .01$), and Self-Absorbed (rho = 0.38, $p < .01$) and Social Relating (rho = 0.28, $p < .05$) behaviours (DBC2-P) were all significantly associated with friendships in adulthood (see Table 8.3).

Multinomial logistic regression, using *one or more relationships* (ADI-R current code 0) as the base value, found that Time 1 degree of intellectual disability was associated with friendships in adulthood. Participants with childhood borderline/average and mild intellectual disability in childhood were significantly more likely to have one or more friendships in adulthood than participants with moderate/severe/profound intellectual disability (see Table 8.4).

8.5.3 Adult (Time 6) Correlates of Adult Outcomes (Time 6)

Correlational analyses were performed to explore the relationship between current (Time 6) adulthood variables and adulthood (Time 6) outcomes (see Table 8.5). Predictor variables including demographics, functional skills, and behaviour and emotional problems. Predictors with significant associations with each outcome variable were entered into a logistic regression analysis (see Table 8.6). Current autism symptoms were assessed separately, with

scores the ADI-R algorithm domains (Social/Communication, and Restricted and Repetitive

Behaviors) entered into regressions for each outcome variable (see Table 8.7).

Table 8.5. Correlations (Spearman's rho) between Time 6 predictor variables and Time 6 outcomes

Time 6 Predictor Variable	Time 6 Outcome Variable				
	Overall outcome (n = 83)	Living (n = 84)	Daytime activity (n = 84)	Hours in daytime activity (n = 84)	Friendships (n = 75)
ABAS total[a]	-0.79[‡]	0.69[‡]	0.53[‡]	-0.13	-0.68[‡]
Sex	0.07	-0.12	-0.04	0.06	0.01
Age	0.34[**]	-0.29[**]	-0.13	-0.05	0.22
Socioeconomic disadvantage	-0.14	0.22[*]	0.13	0.10	-0.22
ADI-R Social/Communication[b]	0.68[‡]	-0.66[‡]	-0.32[**]	0.17	0.66[‡]
ADI-R RRB[b]	0.26[*]	-0.16	-0.13	-0.10	0.34[**]
Mental Health disorder[a]	0.22[*]	-0.09	-0.23[*]	-0.07	0.20
DBC2-A TBPS MIS[a]	0.46[‡]	-0.38[**]	0.43[‡]	-0.06	0.40[**]
DBC2-A Disruptive MIS	0.22	-0.33[**]	-0.22	-0.07	0.18
DBC2-A Comm. & Anx. MIS	0.34[**]	-0.19	0.42[‡]	0.11	0.24[*]
DBC2-A Self Absorbed MIS	0.67[‡]	-0.52[‡]	-0.46[‡]	0.07	0.61[‡]
DBC2-A Depressive MIS	0.23[*]	-0.09	-0.31[**]	-0.19	0.14
DBC2-A Social Relating MIS	0.35[**]	-0.27[*]	-0.21	-0.03	0.41[‡]

ABAS = Adaptive Behavior Assessment System; *ADI-R* = Autism Diagnostic Interview – Revised; *RRB* = Restricted and Repetitive Behaviors; *DBC2-P* = Developmental Behavior Checklist 2 – Parent; *Comm. & Anx.* = Communication Disturbance and Anxiety; *MIS* = mean item score
[a]n=5 missing
[b]n=15 missing
* $p < .05$ ** $p < .01$ ‡ $p < .001$

Table 8.6. Multinomial logistic regression analyses of association between Time 6 predictor variables and Time 6 outcomes (relative risk ratios or odds ratios)

	Overall outcome [a]	Living [b]		Daytime activity [c]		Friendships [d]	
	Poor/Very Poor (OR)	Supported (RRR)	Independent (RRR)	No activity (RRR)	Mainstream (RRR)	One or more relationships (RRR)	Some peer relationships (RRR)
Functional skills (ABAS)	0.97*	0.99**	1.01	1.00	1.03**	1.01	1.01
Age	1.19	1.09	0.99	-	-	-	-
Socioeconomic disadvantage	-	1.01	1.01	-	-	-	-
Mental health disorder (yes)	0.09	-	-	0.00	0.43	-	-
DBC2-A Comm. & Anx.	90.77	-	-	0.29	0.00	17.04	2.11
DBC2-A Self-Absorbed	0.03	0.53	2.45	0.82	125.09	0.00	0.10
DBC2-A Disruptive	-	25.52*	36.21	-	-	-	-
DBC2-A Depressive	0.02	-		35.45	1.61	-	-
DBC2-A Social Relating	64.75	0.72	0.06	-	-	0.03	0.39

Note: only predictor variables significantly correlated with the outcome variable were included in the regression analyses

ABAS = Adaptive Behavior Assessment System; *DBC2-A* = Developmental Behavior Checklist 2 – Adult; *Comm. & Anx.* = Communication and Anxiety Disturbance; *OR* = odds ratio; *RRR* = relative risk ratio

[a] comparison is *Very Good/Good;* n=63
[b] reference category is *with family;* n=73
[c] reference category is *disability specific program;* n=69
[d] reference category is *no peer relationships;* n=70

* $p < .05$ ** $p < .01$

8.5.3.1 Overall outcome

Time 6 functional skills (rho = -0.79, $p < .01$), current age (rho = 0.34, $p < .01$), presence of a mental health disorder diagnosis (rho = 0.22, $p < .05$) and Communication and Anxiety Disturbance (rho = 0.34, $p < .01$), Self-Absorbed (rho = 0.67, $p < .05$), Depressive (rho = 0.23, $p < .05$), and Social Relating (rho = 0.35, $p < .01$) behaviour and emotional problems (DBC2-A) were all significantly correlated with overall outcome (see Table 8.5).

Binary logistic regression analyses comparing *Very Good/Good* outcomes with *Poor/Very Poor* outcomes found functional skills (as measured by ABAS-3 total raw score) to be the only significant predictor of overall outcome, when the other predictor variables were controlled for. Adults with a higher level of functional skills were more likely to have a *Very Good/Good* outcome (see Table 8.6).

8.5.3.2 Living arrangements

Current (Time 6) functional skills (rho = 0.69, $p < .01$), age (rho = -0.29, $p < .01$), socioeconomic disadvantage (rho = 0.22, $p < .05$), and Disruptive (rho = -0.33, $p < .05$), Self-Absorbed (rho = -0.52, $p < .01$), and Social Relating (rho = -0.27, $p < .05$) behaviour problems (DBC2-A) were all significantly associated with Time 6 living arrangements (see Table 8.5).

When entered into a multinomial logistic regression using *living with family* as the base value, functional skills and Disruptive behaviours significantly predicted living arrangements at Time 6 (see Table 8.6) when the other significantly correlated variables (age, socioeconomic disadvantage, and Social Relating behaviours) were controlled for. Participants with lower functional skills and higher rates of Disruptive behaviour problems were more likely to be living in supported accommodation than with family.

8.5.3.3　Daytime activity

Time 6 functional skills (rho = 0.53, $p < .01$), Communication and Anxiety Disturbance (rho = 0.42, $p < .01$), Self-Absorbed (rho = -0.46, $p < .01$), and Depressive (rho = -0.31, $p < .01$) behaviour problems (DBC2-A), and presence/absence of a current mental health disorder (rho = -0.23, $p < .05$) were all significantly associated with Time 6 daytime activity (see Table 8.5). When entered into a multinomial logistic regression using *disability-specific activity* as the base value, functional skills significantly predicted daytime activity at Time 6, when behaviour and emotional problems and presence/absence of a current mental health disorder were controlled for (see Table 8.6). Participants with higher levels of functional skills were more likely to be in mainstream employment or education than in disability-specific day activities. No adulthood factors were significantly correlated with hours per week spent in daytime activities at Time 6.

8.5.3.4　Friendships

Time 6 functional skills (rho = -0.68, $p < .01$), Communication and Anxiety Disturbance (rho = 0.24, $p < .05$), Self-Absorbed (rho = 0.61, $p < .01$), and Social Relating (rho = 0.41, $p < .01$) problems (DBC2-A) at Time 6 were significantly correlated with friendships in adulthood (see Table 8.5). Multinomial logistic regression using *no peer relationships* as the base value revealed that no factors significantly predicted friendships in adulthood (see Table 8.6) when the other variables were controlled for.

8.5.4　Relationships between Autism Symptoms (Time 6) and Adult Outcome (Time 6)

Correlations between Time 6 mean ADI-R algorithm scores for each domain (Social/Communication, and Restricted and Repetitive Behaviors) and each Time 6 outcome variable (overall outcome rating, living arrangements, daytime activity, hours spent in

daytime activities, and friendships) are reported in Table 8.5. ADI-R Social/Communication domain was significantly associated with all outcome variables, except for hours spent in daytime activity (overall outcome rating, rho = 0.68; living arrangements, rho = -0.66; daytime activity, rho = -0.32; and friendships, rho = 0.66, all p's < .01). ADI-R Restricted and Repetitive Behaviors was significantly correlated with overall outcome rating (rho = 0.26, p < .05) and friendships (rho = 0.34, p < .01).

Regression analyses further explored the association between the mean ADI-R domain algorithm scores at Time 6 and Time 6 adult outcomes (see Table 8.7). ADI-R Social/Communication significantly predicted overall outcome rating, where participants with higher Social/Communication scores were more likely to have a *Poor/Very Poor* outcome than a *Very Good/Good* outcome at Time 6. ADI-R Social/Communication significantly predicted Time 6 living arrangements, where participants with higher Social/Communication scores were more likely to be living in supported accommodation than with family, and significantly less likely to be living independently than with family. ADI-R Social/Communication significantly predicted Time 6 daytime activity, with participants with higher Social/Communication scores less likely to be in mainstream activities or in no activity than disability-specific activities. ADI-R Social/ Communication, and Restricted and Repetitive Behaviors significantly predicted friendships at Time 6. Participants with higher scores on the Social/Communication domain and higher scores on the Restricted and Repetitive Behaviours domain were more likely to have no friendships in adulthood.

Table 8.7. Multinomial logistic regression analyses of association between Time 6 autism symptom variables and Time 6 outcomes (relative risk ratios or odds ratios)

	Overall Outcome [a]	Living arrangements [b]		Daytime activity [c]		Friendships [d]	
	Poor/Very Poor (OR)	Supported (RRR)	Independent (RRR)	No activity (RRR)	Mainstream (RRR)	One or more relationships (RRR)	Some peer relationships (RRR)
ADI-R Social/Communication	21.39**	5.06**	0.19*	0.23**	0.08**	0.09**	0.31**
ADI-R Restricted and Repetitive Behaviors	7.23	-	-	-	-	0.59	0.08*

Note: only ADI-R domains with significant correlations with the outcome variable was included in regression analysis

ADI-R = Autism Diagnostic Interview – Revised; *OR* = odds ratio; *RRR* = relative risk ratio

[a] comparison is *Very Good/Good;* n=63

[b] reference category is *with family;* n=69

[c] reference category is *disability specific activity*; n=69

[d] reference category is *no peer relationships;* n=69

* $p < .05$ ** $p < .01$

8.6 DISCUSSION

This study aimed to explore the childhood and adulthood factors that are associated with social and community inclusion outcomes for adults with autism. Childhood factors included degree of intellectual disability, age, socioeconomic disadvantage, autism symptoms, behaviour and emotional problems. Adulthood factors included functional skills, current age, socioeconomic disadvantage, behaviour and emotional problems, mental health disorder diagnosis, and autism symptoms.

8.6.1 Childhood Predictors of Adult Outcome

Childhood degree of intellectual disability was consistently associated with adult outcomes, with significant associations between degree of intellectual disability and overall outcome, living arrangements, daytime activities, and friendships. It was evident that individuals with a severe degree of intellectual disability in childhood were more likely to have poorer outcomes in adulthood. All participants with severe intellectual disability, except one, were living in supported accommodation, all were in disability specific daytime activities, and all had a *poor* overall outcome rating. Participants without intellectual disability, however, had a much more varied outcome. They predominantly lived either with family (52%) or independently (43%) and were mostly in mainstream employment or education (52%), although some were in disability-specific activities (26%), and others with no daytime activity (22%). Overall outcomes for adults without intellectual disability ranged from *Very Good* (35%) to *Poor* (22%). These results are consistent with previous studies for adults with autism and no intellectual disability, with a wide range of outcomes reported in adulthood (Zimmerman et al., 2018).

While overall behaviour and emotional problems in childhood were not significantly associated with outcomes in adulthood, more specific problems as measured by the DBC2-P

subscales, were. Higher rates of childhood Self-Absorbed behaviours as measured by the DBC2-P were related to poorer overall adult outcome ratings, more supported living arrangements, and poorer friendships. Interestingly, greater childhood Communication Disturbance problems as measured by the DBC2-P were associated with better overall outcomes. As the items on this subscale require verbal communication skills, and child language skills have been shown to be associated with better outcomes in adulthood (Gillespie-Lynch et al., 2012; Magiati et al., 2014), this may explain the relationship between higher scores on this subscale and better overall outcomes.

Further, while there was no relationship between childhood DBC2-P Communication Disturbance scores and DBC2-P Anxiety scores and type of daytime activity in adulthood, there was a relationship between higher scores on these subscales in childhood and less time spent in daytime activities in adulthood. This replicates the finding of an earlier timepoint of this study, where childhood behaviour and emotional problems predicted time spent in daytime activities in adulthood (Gray et al., 2014), although the current study points specifically to Communication Disturbance and Anxiety behaviour problems, rather than behaviour and emotional problems more generally. This finding suggests that it is important to consider the time spent in daytime activities as well as whether there is *any* participation in daytime activities.

Regression analyses revealed the predictive value of childhood degree of intellectual disability on adult outcomes, even when all other significant variables were controlled for, consistent with previous research (Howlin & Magiati, 2017). However, as seen in previous studies, not all participants with moderate to severe intellectual disability had *Poor/Very Poor* outcomes, and not all participants without intellectual disability had *Very Good/Good* outcomes (Mason et al., 2021; Steinhausen et al., 2016), and while degree of intellectual disability is important, other factors also play a role (Lord et al., 2020).

8.6.2   Adult Correlates of Outcomes

The impact of functional skills (such as self-care, home-living, and leisure skills) in adulthood on outcome was clear – participants with more impaired functional skills were consistently more likely to have a *Poor/Very Poor* overall outcome, less likely to be living independently, less likely to be in mainstream employment or education, and less likely to have developed friendships or peer relationships. These results are consistent with previous studies (K. A. Anderson et al., 2014; Roux et al., 2013). Future research should continue to explore the relationship between functional skills and outcome but should also evaluate the impact of interventions and supports to improve functional skills. Improvement in particular functional skill areas may be more important for some adults than others, and will depend on their own goals. For example, increasing self-care and home living skills may be important for an adult whose goal is to live independently, while developing communication and social skills may be important for someone who aims to find regular employment.

Difficulties with behaviour and emotional problems as adults were correlated with all outcome areas, except for hours spent in daytime activity. It was clear in the current study that higher scores on any of the DBC2-A subscales were associated with poorer outcomes, highlighting this as an area that is critical to address in order to improve outcomes. Presence of a mental health disorder was only correlated with overall outcome rating and daytime activity, however, the direction of the relationship between mental health disorder diagnoses and outcomes such as daytime activity was not able to be considered in the current study. It may be that additional mental health concerns increase the difficulty of engaging in regular daytime activities, or perhaps lack of activity perpetuates mental health problems.

Autism symptoms in adulthood were correlated with adulthood outcomes, with ADI-R scores on the combined Social/Communication domain showing strong correlations with overall outcome rating, living arrangements, daytime activity, and friendships, consistent with

previous research (Howlin et al., 2013), while scores on the Restricted and Repetitive Behavior domain were only related to overall outcome rating and friendships. Regression analyses suggest that overall outcomes were better explained by the Social/Communication domain, highlighting that stereotyped patterns of behaviour are not necessarily associated with outcome. This, however, was in contrast to the findings of Howlin et al. (2013), where the reciprocal social interaction and restricted and repetitive behaviour domains had the strongest influence on overall outcome. This discrepancy may be due to the differing samples; thus, participants in the Howlin et al. (2013) study were all of average nonverbal IQ as children, in contrast to the current sample where the majority of the sample had a moderate to severe degree of intellectual disability. These findings suggest that further research is needed to explore the impact of various autism traits and symptoms for all adults, irrespective of intellectual disability, although it is clear that a relationship between autism symptoms in adulthood and adult outcomes exists.

8.6.3 Limitations

While a number of childhood and concurrent factors were correlated with adult outcome in the current study, there were factors that were not able to be considered that may contribute to adult outcomes. For example, the types of interventions and programmes that participants had already engaged in was not recorded, and these may have influenced outcomes. Thus, although it was clear that a range of current personal factors influenced outcome, including functional skills and behaviour and emotional problems, the impact of support services on adult outcomes remains unclear and more research is needed to investigate what supports and services are being utilised by adults, how effective these services are and how access to more appropriate services can be improved.

The potential impact of missing data in this study is important to consider. While significant relationships were found between current functional skills, autism symptoms and behaviour

and emotional problems with adult outcomes, there were some missing ABAS data ($n = 6$), DBC2-A data ($n = 9$), and current ADI-R data ($n = 9$). Importantly, most participants for whom this information was unavailable were living independently, were without intellectual disability, and generally functioning quite independently. This may mean that the results of this study are slightly biased towards individuals who are still living with family or in supported accommodation, and those with more severe intellectual disability.

8.6.4 Conclusion

The influence of internal and external factors on adult outcome for individuals with autism is complex. No individual factor can comprehensively predict outcome as measured by the constructs of independent living, employment or daytime activity, and friendships, however, the importance of looking specifically at modifiable factors, such as functional skills, social and communication skills, and addressing behaviour and emotional problems, is crucial.

Importantly, future research must continue to work directly with adults to determine what they consider to be a *good* outcome and find out what goals they would like to achieve. The current study is important in identifying a number of childhood and adulthood factors that may contribute to outcome, at least as defined by specific constructs of independent living, employment, and friendships. Adult autism research now needs to expand to explore a wider range of potential outcomes, and, in particular to take much greater account of the views of people with autism themselves with respect to what constitutes a "good outcome" (Howlin, 2021). Further, future research should explore the social and environmental factors that may be barriers for adults with autism in accessing community and social inclusion opportunities, for example, community perceptions and biases towards people with autism. In addition, interventions targeting factors that appear to be related to outcome (i.e., functional skills, social and communication skills, and behaviour and emotional problems) should be provided in order to address individuals' needs and wishes and their goals for community and social

inclusion. This should be supported by improvements to community programs and resources to ensure accessibility for adults with autism. It is particularly evident in this study that intellectual disability and fewer functional skills impact on community and social inclusion. Therefore, adaptations to community programs and facilities should also ensure the needs of adults with intellectual disability are understood and considered.

REFERENCES

American Psychiatric Association. (1987). *Diagnostic and Statistical Manual for Mental Disorders* (3rd ed.). Washington, DC: American Psychiatric Association.

American Psychiatric Association. (1994). *Diagnostic and Statistical Manual for Mental Disorders* (4th ed.). Washington, DC: American Psychiatric Association.

American Psychiatric Association. (2013). *Diagnostic and Statistical Manual for Mental Disorders* (5th ed.). Washington, DC: American Psychiatric Association.

Anderson, D. K., Liang, J. W., & Lord, C. (2014). Predicting young adult outcome among more and less cognitively able individuals with autism spectrum disorders. *The Journal of Child Psychology and Psychiatry, 55*(5), 484-494. doi:10.1111/jcpp.12178

Anderson, K. A., Shattuck, P. T., Cooper, B. P., Roux, A. M., & Wagner, M. (2014). Prevalence and correlates of postsecondary residential status among young adults with an autism spectrum disorder. *Autism, 18*(5), 562-570. doi:10.1177/1362361313481860

Australian Bureau of Statistics. (2016). Census of Population and Housing: Socio-Economic Indexes for Areas (SEIFA). Retrieved from https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/2033.0.55.001~2016~Main%20Features~SOCIO-ECONOMIC%20INDEXES%20FOR%20AREAS%20(SEIFA)%202016~1

Billstedt, E., Gillberg, C., & Gillberg, C. (2005). Autism after adolescence: Population-based 13- to 22-year follow-up study of 120 individuals with autism diagnosed in childhood. *Journal of Autism and Developmental Disorders, 35*(3), 351-360. doi:10.1007/s10803-005-3302-5

Billstedt, E., Gillberg, I. C., & Gillberg, C. (2011). Aspects of quality of life in adults
diagnosed with autism in childhood. *Autism, 15*, 7-20.
doi:10.1177/1362361309346066

Brereton, A. V., Tonge, B. J., Mackinnon, A. J., & Einfeld, S. L. (2002). Screening young
people for autism with the Developmental Behavior Checklist. *Journal of the
American Academy of Child & Adolescent Psychiatry, 41*(11), 1369-1374.
doi:10.1097/01.CHI.0000024838.94814.A5Cameron, L. A., Tonge, B. J., Howlin, P.,
Einfeld, S. L., Stancliffe, R. J., & Gray, K. M. (2021). *Social and community
inclusion outcomes for adults with autism with and without intellectual disability in
Australia*. Manuscript submitted for publication.

Cohen, J. W. (1988). *Statistical Power Analysis for the Behavioral Sciences* (2nd edition ed.).
Hillsdale, NJ: Lawrence Erlbaum Associates.

Eaves, L. C., & Ho, H. H. (2008). Young adult outcome of autism spectrum disorders.
Journal of Autism and Developmental Disorders, 38, 739-747. doi:10.1007/s10803-
007-0441-x

Ee, D., Hwang, Y. I., Reppermund, S., Srasuebkul, P., Troller, J. N., Foley, K., & Arnold, S.
R. C. (2019). Loneliness in adults on the autism spectrum. *Autism in Adulthood, 1*(3),
182-193. doi:10.1089/aut.2018.0038

Einfeld, S., & Tonge, B. J. (1996a). Population prevalence of psychopathology in children
and adolescents with intellectual disability: I rationale and methods. *Journal of
Intellectual Disability Research, 40*(2), 91-98. doi:10.1046/j.1365-
2788.1996.767767.x.

Einfeld, S., & Tonge, B. J. (1996b). Population prevalence of psychopathology in children
and adolescents with intellectual disability: II epidemiological findings. *Journal of

Intellectual Disability Research, 40(2), 99-109. doi:10.1046/j.1365-2788.1996.768768.x.

Esbensen, A. J., Bishop, S. L., Seltzer, M. M., Greenerg, J. S., & Taylor, J. L. (2010). Comparisons between individuals with autism spectrum disorders and individuals with Down Syndrome in adulthood. *American Journal of Intellectual and Developmental Disabilities, 115*(4), 277-291. doi:10.1352/1944-7558-115.4.277

First, M. B., Williams, J. B. W., Karg, R. S., & Spitzer, R. L. (2015). *User's Guide for the Structured Clinical Interview for DSM-5 Disorders, Research Version (SCID-5-RV)*. Arlington, VA: American Psychiatric Association.

Fusar-Poli, L., Brondino, N., Orsi, P., Provenzani, U., De Micheli, A., Ucelli de Nemi, S., . . . Politi, P. (2017). Long-term outcome of a cohort of adults with autism and intellectual disability: A pilot prospective study. *Research in Developmental Disabilities, 60*, 223-231. doi:10.1016/j.ridd.2016.10.014

Gillespie-Lynch, K., Sepeta, L., Wang, Y., Marshall, S., Gomez, L., Sigman, M., & Hutman, T. (2012). Early childhood predictors of the social competence of adults with autism. *Journal of Autism and Developmental Disorders, 42*, 161-174. doi:10.1007/s10803-011-1222-0

Gray, K. M., Keating, C. M., Taffe, J., Brereton, A. V., Einfeld, S., & Tonge, B. J. (2012). Trajectory of behavior and emotional problems in autism. *American Journal of Intellectual and Developmental Disabilities, 117*(2), 121-133. doi:10.1352/1944-7588-117-2.121

Gray, K. M., Keating, C. M., Taffe, J. R., Brereton, A. V., Einfeld, S. L., Reardon, T. C., & Tonge, B. J. (2014). Adult outcomes in autism: Community inclusion and living skills. *Journal of Autism and Developmental Disorders, 44*, 3006-3015. doi:10.1007/s10803-014-2159-x

Gray, K. M., Tonge, B. J., Einfeld, S., Gruber, C., & Klein, A. (2018). *Developmental Behavior Checklist 2 (DBC2) (Manual)*. Torrance, CA: Western Psychological Services.

Harrison, P. L., & Oakland, T. (2015). *Adaptive Behavior Assessment System, Third Edition*. Torrance, CA: Western Psychological Services.

Helles, A., Gillberg, I. C., Gillberg, C., & Billstedt, E. (2017). Asperger syndrome in males over two decades: Quality of life in relation to diagnostic stability and psychiatric comorbidity. *Autism, 21*(4), 458-469. doi:10.1177/1362361316650090

Howlin, P. (2021). Adults with autism: Changes in understanding since DSM-111. *Journal of Autism and Developmental Disorders*. Advance online publication. doi:10.1007/s10803-020-04847-z

Howlin, P., Goode, S., Hutton, J., & Rutter, M. (2004). Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry, 45*(2), 212-229. doi:10.1111/j.1469-7610.2004.00215.x

Howlin, P., & Magiati, I. (2017). Autism spectrum disorder: Outcomes in adulthood. *Current Opinion in Psychiatry, 30*, 69-76. doi:10.1097/YCO.0000000000000308

Howlin, P., Moss, P., Savage, S., & Rutter, M. (2013). Social outcomes in mid- to later adulthood among individuals diagnosed with autism and average nonverbal IQ as children. *Journal of the American Academy of Child & Adolescent Psychiatry, 52*(6), 572-581. doi:10.1016/j.jaac.2013.02.017

Kirby, A. V., Baranek, G. T., & Fox, L. (2016). Longitudinal predictors of outcomes for adults with autism spectrum disorder: Systematic review. *Occupation, Participation and Health, 36*(2), 55-64. doi:10.1177/1539449216650182

Kraper, C. K., Kenworthy, L., Popal, H., Martin, A., & Wallace, G. L. (2017). The gap between adaptive behavior and intelligence in autism persists into young adulthood

and is linked to psychiatric comorbidities. *Journal of Autism and Developmental Disorders, 47*, 3007-3017. doi:10.1007/s10803-017-3213-2

Lai, M., & Baron-Cohen, S. (2015). Identifying the lost generation of adults with autism spectrum conditions. *Lancet Psychiatry, 2*, 1013-1027. doi:10.1016/S2215-0366(15)00277-1.

Lord, C., McCauley, J. B., Pepa, L. A., Huerta, M., & Pickles, A. (2020). Work, living, and the pursuit of happiness: Vocational and psyschosocial outcomes for young adults with autism. *Autism, 24*(7), 1691-1703. doi:10.1177/1362361320919246

Magiati, I., Wei Tay, X., & Howlin, P. (2014). Cognitive, language, social and behavioural outcomes in adults with autism spectrum disorders: A systematic review of longitudinal follow-up studies. *Clinical Psychology Review, 34*, 73-86. doi:10.1016/j.cpr.2013.11.002

Mason, D., Capp, S. J., Stewart, G. R., Kempton, M. J., Glaser, K., Howlin, P., & Happe, F. (2021). A meta-analysis of outcomes studies of autistic adults: Quantifying effect size, quality, and meta-regression. *Journal of Autism and Developmental Disorders, 51*, 3165-3179. doi:10.1007/s10803-020-04763-2

McCauley, J. B., Elias, R., & Lord, C. (2020). Trajectories of co-occurring psychopathology symptoms in autism from late childhood to adulthood. *Development and Psychopathology, 32*(4), 1287-1302. doi:10.1017/S0954579420000826

McCauley, J. B., Pickles, A., Huerta, M., & Lord, C. (2020). Defining positive outcomes in more and less cognitively able autistic adults. *Autism Research, 13*, 1548-1580. doi:10.1002/aur.2359

McConkey, R., & Walsh, J. (1982). An index of social competence for use in determining the service needs of mentally handicapped adults. *Journal of Mental Deficiency Research, 26*, 47-61. doi:10.1111/j.1365-2788.1982.tb00128.x

Pallant, P. (2011). *SPSS Survival Manual* (4th ed.). Crows Nest, NSW: Allen & Unwin.

Roux, A. M., T., S. P., Cooper, B. P., Anderson, K. A., Wagner, M., & Narendorf, S. C.
(2013). Postsecondary employment experiences among young adults with an autism
spectrum disorder. *Journal of the American Academy of Child & Adolescent
Psychiatry, 52*(9), 931-939. doi:10.1016/j.jaac.2013.05.019

Rutter, M., Le Couteur, A., & Lord, C. (2003). *Autism Diagnostic Interview-Revised*. Los
Angeles, CA: Western Psychological Services.

Sonido, M., Arnold, S., Higgins, J., & Hwang, Y. (2020). Autism in later life: What is known
and what is needed? *Current Developmental Disorders Reports, 7*, 69-77.
doi:10.1007/s40474-020-00192-z

Sparrow, S. S., Balla, D. A., Cicchetti, D. V., Harrison, P. L., & Doll, E. A. (1984). *Vineland
Adaptive Behavior Scales*. Circle Pines, MN: American Guidance Service.

Steinhausen, H. C., Mohr Jensen, C., & Lauritsen, M. B. (2016). A systematic review and
meta-analysis of the long-term overall outcomes of autism spectrum disorders on
adolescence and adulthood. *Acta Psychiatrica Scandinavica, 133*, 445-452.
doi:10.1111/acps.12559

Taffe, J. R., Tonge, B. J., Gray, K. M., & Einfeld, S. L. (2008). Extracting more infomation
from behaviour checkists by using components of mean based scores. *International
Journal of Methods in Psychiatric Research, 17*(4), 232-240. doi:10.1002/mpr.260

Tonge, B. J., & Einfeld, S. (2003). Psychopathology and intellectual disability: the Australian
Child to Adult longitudinal study. In L. M. Glidden (Ed.), *International Review of
Research in Mental Retardation, Volume 26* (pp. 61-91). San Diego, CA: Academic
Press.

Wechsler, D. (2011). *Manual for the Wechsler Abbreviated Scale of Intelligence-Second
Edition*. Bloomington, MN: Pearson.

Zimmerman, D., Ownsworth, T., O'Donovan, A., Roberts, J., & Gullo, M. J. (2018). High-functioning autism spectrum disorder in adulthood: A systematic review of factors related to psychosocial outcomes. *Journal of Intellectual and Developmental Disability, 43*, 2-19. doi:10.3109/13668250.2016.1262010

CHAPTER 9: STUDY 3 – "CHILDHOOD AND ADULTHOOD PREDICTORS OF COMMUNITY PARTICIPATION BY ADULTS WITH AUTISM"

9.1   PAPER COMMENTARY

This chapter presents a paper submitted for publication to the Journal of Autism and Developmental Disabilities. This paper has been formatted to the specific requirements of the journal. Headings and page numbers have been reformatted to allow for consistency within the thesis.

This study addressed a number of the gaps in the literature identified by the systematic review conducted and reported in Chapter 4. In particular, the study included adults with co-occurring intellectual disability, a significant limitation of existing literature identified in Chapter 4, as well as a focus on a sample in mid-adulthood, with most of the existing community participation research involving younger adults. Further, the consistent use of established measures of community participation were a core recommendation in Chapter 4. The current study uses the Index of Community Involvement to assess the frequency and variety of community participation, consistent with other studies of adults with autism and intellectual disability, allowing for a comparison with other samples. The first aim of this study was to explore how adults with autism participate in the community, in particular, how often, and in how many different activities. The second aim was to investigate the childhood and adulthood factors associated with community participation in adulthood. This study found that, while there are adults who do participate in the community regularly, there are many adults who do not. The impact of childhood and adulthood degree of intellectual disability, autism symptoms, and behaviour and emotional problems, as well as adulthood

living arrangements and daytime activity on community participation was evident. The implications for future research, and for the development of interventions and programmes to support adults with autism to participate in the community, are discussed.

Associations between Time 1 and Time 6 predictor variables and Time 6 community participation frequency and variety are discussed in the results of the manuscript. Tables A.4 and A.5 summarise this information but were not included in the manuscript for publication. They can be found in Appendices J and K of this thesis.

Cameron, L. A., Tonge, B. J., Howlin, P., Einfeld, S. L., Stancliffe, R. J., and Gray, K. M. (submitted). Childhood and adulthood predictors of community participation by adults with autism. *Journal of Autism and Developmental Disabilities.*

9.2 ABSTRACT

Few studies have explored community participation for adults with autism. This study aims to investigate how adults with autism participate in the community, and the childhood and adulthood factors that predict community participation in adulthood. Eighty-four adults with autism (mean age 34 years) recruited as children and adolescents, participated in the current study. Community participation frequency and variety was measured in adulthood. Childhood and adulthood predictors of community participation were investigated. Participants engaged in the community an average of 18.21 times (range 0-49) over the previous 30-day period, in an average of 6.33 different activities (range 0-13). Childhood and adulthood factors (autism symptoms, intellectual disability, living arrangements) were associated with community participation. Areas for additional support and resources were identified.

9.3 INTRODUCTION

Community participation, including participation in informal groups, social clubs, common interest groups, and recreational and leisure activities, has been identified by the World Health Organisation as important to the health and functioning of all people (World Health Organisation, 2001). Further, the benefits of community participation for children, adolescents, and adults with varying intellectual, developmental, and physical disabilities have been well documented, including greater social inclusion and friendships, independence, and improved physical and mental wellbeing (Andrews, Falkmer, & Girdler, 2015). Despite the known benefits, community participation for individuals with intellectual and developmental disabilities, including Autism Spectrum Disorder (hereafter referred to as autism), can be limited and challenging. Systematic reviews have highlighted that children with autism (Askari et al., 2015) and adults with intellectual disability (Verdonschot, de Witte, Reichrath, Buntinx, & Curfs, 2009) participate in their communities less than their typically developing peers. In addition, rates of community participation decline over time

from adolescence to adulthood (Myers, Davis, Stobbe, & Bjornson, 2015), with adults participating in significantly fewer community activities and at a significantly lower frequency than the general population (Shea, Verstreate, Nonnemacher, Song, & Salzer, 2021).

While participation overall is more limited, the type of participation in community, recreation, and leisure activities for individuals with autism is important to consider. For example, adolescents and young adults with autism may participate significantly more in solo leisure activities (e,g. going for a walk, engaging in a hobby) and organised group activities (e.g. special interest groups) than their typically developing peers, while participation in community activities (e.g. going to a café, attending sports events) may be more limited (Gray et al., 2014; Orsmond, Krauss, & Seltzer, 2004). More recently, research has demonstrated that adults with autism often participate in online social activities, such as solo videogames or online multi-player role playing games (Cameron, Tonge, Borland, & Gray, 2021), suggesting that, while engagement in the wider community might be limited, adults are finding ways of engaging and participating in activities with like-minded people, building their relationships and sharing interests with others. One recent study found that adults reported engaging in activities that support their daily living, such as shopping and running errands, as well as more social activities, such as going out to restaurants, or visiting with family and friends, to be important to them (Shea et al., 2021).

A number of factors are likely to influence participation in the community, although few studies have explored these. Personal factors, such as anxiety and mental health problems, communication and social skill difficulties, and lack of necessary planning skills, as well as environmental factors, such as living arrangements, household income, and access to services, have been identified as potential barriers to community participation (Cameron et al., 2021; Myers et al., 2015; Shea et al., 2021). Further, better functional skills, and access to

resources and opportunities have been associated with higher rates of community participation in some studies (Cameron et al., 2021). However, research to date has largely focused on younger adults and individuals without intellectual disability. Additional research is needed to understand how these factors may impact a broader range of adults.

Particularly lacking in the research literature to date is the inclusion of adults with autism with co-occurring intellectual disability. A recent systematic review reported that only a third of research studies exploring community participation included adults with co-occurring intellectual disability (Cameron et al., 2021). This is particularly concerning, as individuals with co-occurring intellectual disability will have different needs and support requirements, as well as different goals in relation to community participation, than individuals with autism alone. It is important for research to ensure that all adults with autism are represented when seeking to understand community participation support experiences, needs, and resources.

This study aimed to explore how adults with autism in Australia participate in the community, in particular, how often, and in how many different activities. This study also aimed to evaluate the childhood and adulthood factors associated with community participation outcomes in adulthood. Childhood factors included degree of intellectual disability, behaviour and emotional problems, autism symptoms, and socioeconomic disadvantage. Factors in adulthood included degree of intellectual disability, behaviour and emotional problems, autism symptoms, socioeconomic disadvantage, living arrangements, and daytime activities. It was predicted that adults with autism would have low rates of community participation (frequency) and participate in a small range of community activities (variety). It was hypothesised that greater community participation frequency and variety would be predicted by younger age, less severe intellectual disability in childhood and adulthood, less severe autism symptoms in childhood and adulthood, fewer behaviour and emotional problems in childhood and adulthood, and less socioeconomic disadvantage in

childhood and adulthood. It was hypothesised that adults living independently, and adults engaged in regular daytime activities (employment, education, or disability specific day program) would participate in the community more than those living with family or in supported accommodation, or those with no regular daytime activity. It was predicted that gender would not impact community participation frequency or variety.

9.4 METHOD

9.4.1 Sample

Participants were part of the Australian Child to Adult Development (ACAD) Study and were recruited from metropolitan and regional areas of Victoria and New South Wales, Australia in 1991 through health and education agencies (Einfeld & Tonge, 1996a, 1996b). Data were collected at six time points: Time 1 (1991-1993), Time 2 (1995-1996), Time 3 (1999), Time 4 (2002-2003), Time 5 (2007-2009), and Time 6 (2016-2019).

At entry to the study, participants were likely to be representative of children in the community who had an autism diagnosis and were receiving services (Tonge & Einfeld, 2003). All participants met criteria for DSM-III-R Autistic Disorder (American Psychiatric Association, 1987) following clinical assessment by a multidisciplinary team at study entry. Participants were reassessed at Time 2 to confirm diagnosis against DSM-IV criteria (American Psychiatric Association, 1994; Gray et al., 2012). At Time 6, diagnoses were reviewed again, using all clinical information gathered in the study, including the Autism Diagnostic Interview-Revised (Rutter, Le Couteur, & Lord, 2003). All Time 6 participants met current DSM-5 criteria for Autism Spectrum Disorder (American Psychiatric Association, 2013).

9.4.2 Measures

Demographic information, including age, gender, socioeconomic disadvantage, current living arrangements, and daytime activity were collected via parent/carer and/or self-report questionnaire at Time 6 of this study. Living arrangements were categorised as: living independently, living with family, or living in supported accommodation. Daytime activity was categorised as: no activity, disability specific activity, or mainstream employment or education.

9.4.2.1 Degree of intellectual disability

At Time 1, participants were grouped according to their degree of intellectual disability: no intellectual disability, mild, moderate, or severe degree of intellectual disability (Gray et al., 2014). At Time 6, current degree of intellectual disability was reviewed and classified by two authors (L.A.C and K.M.G) following DSM-IV (American Psychiatric Association, 1994) and DSM-5 (American Psychiatric Association, 2013) criteria. Classification was based on a range of assessment information, including adaptive behaviour (Adaptive Behavior Assessment System; Harrison & Oakland, 2015), daily living skills (Index of Social Competence; McConkey & Walsh, 1982), and cognitive assessment (Wechsler Abbreviated Scale of Intelligence; Wechsler, 2011).

9.4.2.2 Behaviour and emotional problems

The Developmental Behavior Checklist 2 (DBC2) is an informant-report measure of behaviour and emotional problems in individuals with intellectual and developmental disabilities (Gray, Tonge, Einfeld, Gruber, & Klein, 2018). Respondents are asked to rate each item on a three-point scale ranging from 0 (not true as far as you know) to 2 (very true or often true), based on the previous six months. The DBC2 produces a Total Behaviour Problem Score (TBPS) as well as scores across five subscales. Two versions of the DBC2

have been used across the duration of this study, the DBC-Parent/carer report (DBC2-P) and the DBC-Adult (DBC2-A). Subscales for the DBC2-P include *Disruptive, Communication Disturbance, Anxiety, Self-Absorbed,* and *Social Relating.* For the DBC2-A, subscales include *Disruptive, Communication and Anxiety Disturbance, Depressive, Self-Absorbed,* and *Social Relating.* Mean Item Scores (MIS) were calculated for all subscales at Time 1 and Time 6 (Taffe, Tonge, Gray, & Einfeld, 2008). The DBC2-P was completed by parents/carers at Time 1 and the DBC2-A completed by parents or carers at Time 6. The DBC2 has well established psychometric properties (Einfeld & Tonge, 2002; Gray et al., 2018; Mohr, Tonge, & Einfeld, 2005; Mohr, Tonge, Einfeld, & Taffe, 2011).

9.4.2.3 Autism symptoms

The Developmental Behaviour Checklist 2 Autism Screening Algorithm (DBC2 ASA; Brereton, Tonge, Mackinnon, & Einfeld, 2002) was used as a measure of childhood (Time 1) autism symptoms. It is calculated from the DBC2-P, and has established validity as a screening tool for autism (Brereton et al., 2002; Steinhausen & Metzke, 2004).

Autism symptoms at Time 6 were assessed using the Autism Diagnostic Interview-Revised (ADI-R; Rutter et al., 2003), completed with parents or carers. For this study, only the current algorithm ADI-R domain scores were used as a measure of current autism symptoms. Due to challenges of recall, and as a number of interviews were completed with professional carers and not parents, only current item codes were used in analysis. The ADI-R algorithm produces scores on three domains: Qualitative Abnormalities in Reciprocal Social Interaction (hereafter referred to as the Social domain), Qualitative Abnormalities in Communication (hereafter referred to as the Communication domain), and Restricted, Repetitive, and Stereotyped Patterns of Behaviour (hereafter referred to as the Restricted and Repetitive Behavior domain). For the purposes of this study, mean algorithm scores were calculated for each of the ADI-R domains, due to different numbers of items contributing to

the Communication domain algorithm score depending on the verbal ability of the individual. Mean scores, therefore, allowed for a more consistent approach across analyses. The Social and Communication domains were also highly correlated ($r = .72$), and were therefore combined to create an overall Social/Communication domain score. Current ADI-R interviews were missing for $n = 9$ participants, and current domain algorithm scores were unable to be calculated for $n = 6$ participants due to missing information.

9.4.2.4 Mental health

Interviews were conducted with parents or carers, as well as the participant themselves where possible, to determine presence of any mental health problems at Time 6. Symptom level information was gathered using the Structured Clinical Interview for DSM-5, Research version (SCID-5; First, Williams, Karg, & Spitzer, 2015). Mental health diagnoses were determined by clinical case reviews with a panel of the authors (K.M.G, B.J.T, P.H, S.L.E), experts in the field of intellectual and developmental disabilities and mental health. Participants were categorised according to whether they had a current mental health disorder diagnosis or not.

9.4.2.5 Socioeconomic disadvantage

The Socio-Economic Index for Areas (SEIFA; Australian Bureau of Statistics, 2016) was used as a measure of socioeconomic disadvantage. SEIFA produces a ranking of areas in Australia based on relative socioeconomic advantage and disadvantage. The Index of Relative Socioeconomic Disadvantage (IRSD) was calculated for each participant based on where they were living at Time 1 and at Time 6. A lower score indicates relatively greater disadvantage.

9.4.2.6 Community participation

The Index of Community Involvement-Revised (ICI; Raynes, Sumpton, & Pettipher, 1989) is a 16-item scale that assesses the frequency and variety of participation in social, community, and leisure activities over the previous month, completed as an informant or self-report measure. At Time 6, the ICI was completed by parents or carers, as well as by the participant themselves where possible. Self-report responses were used in the first instance where they were available. Each item was rated based on how often each activity was participated in over the previous month on a 6-point scale, ranging from 0 (no participation) to 5 (5 or more times). Respondents are also asked to indicate whether the activity was usually undertaken independently, or with parents or professional carers. *Frequency* was scored by summing the total of all items (range 0 to 80), indicating how often or how many times the participant has engaged in community activities. *Variety* was scored by calculating the number of activities that have been participated in at least once over the previous month (range 0 to 16), indicating the range and variety of activities the participant engages in.

9.4.3 Procedure

All participants were invited to participate at each time point and were sent a questionnaire to be completed by a parent or carer, and, at Time 6, the adult themselves where possible. At Time 6, interviews were also conducted with parents/carers and the adult participant. Ethics approval was obtained from Monash University Human Research Ethics Committee (CF15/1045-2015000486). Informed consent was provided by parents/carers, and where possible, the adult themselves.

9.4.4 Statistical Analysis

Descriptive statistics were calculated for all variables. Associations between predictor variables and community participation outcomes were assessed using Pearson's correlations,

independent samples t-test, or one-way analysis of variance as appropriate, in order to determine variables to enter into regression models (see Table A.4; Appendix J, and Table A.5; Appendix K). The strength of the association, as well as statistical significance, was considered in this determination. Strength of correlations were interpreted as per Cohen (1988). Regression analyses were performed with the determined predictor variables. Correlational analyses were conducted between all predictor variables to identify multicollinearity (see Table A.1; Appendix G, and Table A.3; Appendix I). Using a correlation coefficient cut-off of 0.90 (Pallant, 2011), no multicollinearity was detected between predictor variables entered into each regression model. For interpretation of regression models, significance was set at $p < .05..$

At Time 6, there were missing data across a number of predictor variables (ABAS ($n = 5$ missing), ADI-R ($n = 9$ missing), DBC2-A ($n = 9$ missing)). To maximise sample size and reduce overfitting in regression models, mean algorithm scores for each of the ADI-R domains (Social, Communication, and Restricted and Repetitive Behaviors) were assessed in a separate regression model.

9.5 RESULTS

A total of 84 adults with autism participated at Time 6 (response rate 75%). Participants were aged between 26.75 and 44.15 years (M = 34.21, SD = 4.49) and 81% ($n = 68$) were male. Further details of the sample, including, age, gender, and degree of intellectual disability at Time 1 and Time 6 is provided in Table 9.1. There were no significant differences between those who participated at Time 6 and those who did not in terms of degree of intellectual disability, χ^2 (4, n = 119) = .05, $p = .97$, or behaviour and emotional problems at Time 1 (DBC2 Mean Item Score), $t(117) = 1.50$, $p = .14$.

Table 9.1. Sample demographics and descriptive statistics (M, SD) of behaviour and emotional problems and autism symptoms at Time 1 and Time 6

	Time 1 $n = 119$	Time 6 $n = 84$
Male (%)	98 (82%)	68 (81%)
Mean age (SD)	8.7 (4.3)	34.2 (4.5)
Age range (years)	2.8 – 19.8	26.8 – 44.2
Degree of intellectual disability (n, %)		
Average	11 (9%)	14 (17%)
Borderline	16 (13%)	13 (16%)
Mild	29 (24%)	13 (16%)
Moderate	46 (39%)	21 (25%)
Severe/profound	17 (14%)	23 (27%)
Socioeconomic disadvantage		
Mean IRSD (SD)	1025 (58.9)	998.25 (68.7)
IRSD range	902 – 1179	817 – 1126
DBC2 TBPS MIS [a]	0.64 (0.26)	0.47 (0.27)
Mental health disorder diagnosis [b] (n, %)	-	54 (68%)
Autism symptoms (M, SD)		
DBC2-P Autism Screening Algorithm	27.45 (10.87)	-
ADI-R Social/Communication [c]	-	2.39 (1.02)
ADI-R-Restricted and Repetitive Behaviors [c]	-	0.64 (0.39)

IRSD = Index of Relative Socioeconomic Disadvantage; *DBC2 TBPS* = Developmental Behavior Checklist 2 Total Behavior Problem Score; *DBC2-P* = Developmental Behavior Checklist 2 – Parent; *MIS* = mean item score; *ADI-R* = Autism Diagnostic Interview-Revised
[a] Time 6: *n* = 75
[b] *n* = 79
[c] *n* = 69

9.5.1 Community participation at Time 6

The ICI was completed for 82 participants at Time 6 (n = 52 parent/carer report, n = 30 self-report). Over the previous 30-day period, participants engaged in community activities an average of 18.21 times (SD = 9.59), range 0 to 49. An average of 6.33 (SD = 2.78) different types of activities were participated in, ranging from 0 to 13. Two participants had not participated in any activities over the past 30 days. There was a large correlation between frequency and variety (r = 0.85, p < .001), demonstrating that a greater variety of activities was associated with increased frequency of participation.

The number of participants that had engaged in each ICI activity over the previous month is provided in Table 9.2. Only four activities were participated in by more than half of the sample; shopping, café/restaurant, trips out with family/friends, and going on a bus. Less than a quarter of participants had been to more structured community events, such as sports events, cinemas, concert/play, or church services.

Table 9.2. Frequency of participation in each Index of Community Involvement activity (N = 82)

Index of Community Involvement items	*n* (%)
Been shopping	70 (85%)
Been to a café/restaurant	63 (77%)
Had trips out with family/friends	61 (74%)
Been on a bus	43 (52%)
Been on a holiday (past 12 months)	41 (50%)
Been to a hairdresser	36 (44%)
Been to a hotel/pub/bar	32 (39%)
Been to a bank	32 (39%)
Been to a social club	28 (34%)
Been on an overnight stay to family/friends	25 (30%)
Had family or friends in for a meal	23 (28%)
Been to a sports event	20 (24%)
Been to a cinema	20 (24%)
Been to a concert/play	10 (12%)
Been to church	8 (10%)
Had guests to stay	8 (10%)

For each activity participated in, respondents were asked whether the activity was usually undertaken independently or with parents/carers. For all activities, except for *had guests to stay*, and *been to a church*, participants overwhelmingly participated with a parent or carer rather than independently. Overall, 14 participants (17.5%) participated in all activities independently, 26 (32.5%) participated in a combination of activities both independently and with a parent/carer, and 40 (50%) always participated in activities with the support of a parent/carer.

9.5.2 Associations between Time 1 (childhood) predictor variables and Time 6 community participation frequency and variety

Pearson's correlations revealed small to medium associations between Time 6 community participation frequency and childhood autism symptoms (DBC2-P ASA) (r = -0.36, p < .001) and Time 1 Self-Absorbed behaviour problems (DBC2-P) (r = -0.27, p < .05). Significant differences were found between Time 1 levels of degree of intellectual disability and community participation frequency [$F(3,78)$ = 2.84, p < .05), however, post-hoc analyses revealed no significant bivariate relationships. Only childhood autism symptoms and Time 1 Self-Absorbed behaviour problems were associated with Time 6 variety of community participation activities (r = -0.28 and -0.24 respectively, both p < .05), although these correlations were small.

Multiple regression analyses were conducted to further explore the relative contribution of the significantly associated Time 1 variables on Time 6 community participation frequency and variety outcome (see Table 9.3). Time 1 degree of intellectual disability, autism symptoms (DBC2-P ASA), and Self-Absorbed behaviour (DBC2-P) explained 13% of the variance in Time 6 community participation frequency. For Time 6 community participation variety, Time 1 autism symptoms and Self-Absorbed behaviours explained 6% of the variance. Although both of the overall models were significant, none of the predictors contributed significantly to the outcome variable.

Table 9.3. Multiple regression analyses for the association between Time 1 degree of intellectual disability, behaviour and emotional problems, and autism symptoms, and Time 6 community participation frequency and variety

Variable	B	$SE\ B$	β	p value
Model 1: Community Participation Frequency (*n*=82)				
Degree of intellectual disability [a]				
Severe/profound	-4.56	3.18	0.17	0.16
Mild	3.56	2.88	0.14	0.22
Average/borderline	0.69	2.49	0.03	0.78
Autism symptoms [b]	-0.37	0.20	-0.38	0.07
DBC2-P Self-Absorbed	2.89	6.19	0.10	0.64
Adjusted R^2	0.13			
F	3.34**			
Model 2: Community Participation Variety (*n*=82)				
Autism symptoms [b]	-0.06	0.06	-0.20	0.36
DBC2-P Self-Absorbed MIS	-0.83	1.75	-0.10	0.64
Adjusted R^2	0.06			
F	3.52*			

DBC2-P = Developmental Behavior Checklist 2 – Parent
[a] reference category is *moderate intellectual disability*
[b] autism symptoms is measured using the DBC2-P Autism Screening Algorithm
Note: adjusted R squared values are reported due to the small sample size
* $p < .05$ ** $p < .01$

9.5.3 Associations between Time 6 (adulthood) predictor variables and Time 6 community participation frequency and variety

Correlations revealed significant, moderate associations between Time 6 community participation frequency and Time 6 socioeconomic disadvantage ($r = 0.30$), autism symptoms, specifically ADI-R Social/Communication domain ($r = -0.40$)and behaviour and emotional problems, specifically Self-Absorbed ($r = -0.37$) and Social Relating ($r = -0.30$) behaviour problems (DBC2-A) (all $p < .01$). There was a significant difference between levels of Time 6 degree of intellectual disability on community participation frequency score [F(3, 78) = 7.34, $p < .001$]. Participants with severe/profound intellectual disability (M =

11.87, SD = 7.44) participated significantly less frequently than those with moderate intellectual disability (M = 20.70, SD = 10.83) and no intellectual disability (M = 22.81, SD = 8.65). There was a significant difference between different living arrangements [F(2,79) = 10.57, *p* < .001], where participants living in supported accommodation (M = 13.22, SD = 6.64) participated significantly less than both those living with family (M = 19.89, SD = 10.38) and those living independently (M = 24.93, SD = 7.79). There was also a significant difference between daytime activities [F(2,79) = 5.10, *p* < .01), with adults in mainstream activities (M = 23.14, SD = 9.09) participating significantly more than both those in no activity (M = 13.00, SD = 8.54) or disability specific activities (M = 17.00, SD = 9.25). There was no significant difference on community participation frequency for those with or without additional mental health disorder diagnoses [*t*(75) = 1.12, *p* = .266], and no significant relationship between community participation frequency and age (*r* = -0.14, *p* = .221) or gender [*t*(80)=1.10, *p* = .275).

There were small to moderate significant correlations between Time 6 community participation variety and Time 6 socioeconomic disadvantage (*r* = 0.31, *p* < .01), autism symptoms, specifically ADI-R Social/Communication domain (*r* = -0.38, *p* < .01), and ADI-R Restricted and Repetitive Behaviors domain (*r* = -0.27, *p* < .05), and behaviour and emotional problems, specifically Self-Absorbed and Social Relating behaviour (DBC2-A) (*r* = -0.40 and *r* = -0.34 respectively, both *p*'s < .01). There was a significant difference between levels of adulthood degree of intellectual disability on community participation variety score [F(3, 78) = 4.71, *p* < .01]. Participants with severe/profound intellectual disability (M = 4.61, SD = 2.29) participated in significantly fewer activities than those with moderate intellectual disability (M = 7.00, SD = 3.43) and no intellectual disability (M = 7.12, SD = 2.39). There was also a significant difference between Time 6 living arrangements [F(2,79) = 5.11, *p* < .01), with those living in supported accommodation (M = 5.22, SD = 2.30) participating in

fewer activities than those living independently (M = 7.60, SD = 2.41). There was no significant difference in terms of community participation frequency for those in different daytime activities at Time 6 [$F_{(2,79)}$ = 2.49, p = 0.09), with or without additional mental health disorder diagnoses [$t_{(75)}$ = 0.42, p = .68], and no significant relationship between community participation frequency and age (r = -0.10, p = .37) or gender [$t_{(80)}$=-0.83, p = .41].

Multiple regression was used to explore the contribution of each of the associated Time 6 variables on community participation outcome. When considering community participation frequency, 30% of the variance was explained by Time 6 degree of intellectual disability, socioeconomic disadvantage, Self-Absorbed behaviour problems, Social Relating behaviour problems, living arrangements, and daytime activities (see Table 9.4). In the model, living in supported accommodation was the only significant predictor when the other variables were controlled for. Living in supported accommodation was associated with a decrease of participation in community activities. When assessing the variety of community participation at Time 6, 20% of the variance was explained by Time 6 degree of intellectual disability, socioeconomic disadvantage, Self-Absorbed behaviour problems, Social Relating problems, and living arrangements (see Table 9.4). None of the predictor variables were significant in the regression model.

Table 9.4. Multiple regression analyses for the association between Time 6 degree of intellectual disability, behaviour and emotional problems, socioeconomic disadvantage, living arrangements, and daytime activity, and Time 6 community participation frequency and variety

Variable	*B*	*SE B*	β	*p* value
Model 1: Community Participation Frequency (*n*=74)				
Degree of intellectual disability [a]				
Severe/profound	-0.61	3.92	-0.03	0.88
Moderate	3.32	3.51	0.15	0.35
Mild	-3.84	3.21	-0.15	0.24
Socioeconomic disadvantage	0.02	0.02	0.16	0.16
DBC2-A Self-Absorbed MIS	-0.22	0.15	-0.21	0.15
DBC2-A Social Relating MIS	0.04	0.27	0.02	0.89
Living arrangements [b]				
Supported	-6.11	2.63	-0.31	0.02*
Independently	2.85	3.02	0.12	0.35
Daytime activity [c]				
None	-6.89	3.52	-0.22	0.06
Mainstream	0.64	3.16	0.03	0.84
Adjusted R^2	0.30			
F	4.12**			
Model 2: Community Participation Variety (*n*=74)				
Degree of intellectual disability [a]				
Severe/profound	-0.22	1.17	-0.04	0.85
Moderate	1.08	0.96	0.17	0.27
Mild	0.27	0.99	0.04	0.79
Socioeconomic disadvantage	0.01	0.01	0.20	0.09
DBC2-A Self-Absorbed MIS	-0.05	0.05	-0.17	0.29
DBC2-A Social Relating MIS	-0.11	0.08	-0.16	0.19
Living arrangements [b]				
Supported	-1.09	0.79	-0.19	0.17
Independently	0.08	0.92	0.01	0.93
Adjusted R^2	0.20			
F	3.25**			

DBC2-A = Developmental Behavior Checklist 2 – Adult; *MIS* = mean item score
[a] reference category is *average/borderline*
[b] reference category is *living with family*
[c] reference category is *disability specific activity*
Note: adjusted R squared values are reported due to the small sample size
* $p < .05$ ** $p < .01$

The association between current adult autism symptoms (Time 6) and Time 6 community participation frequency and variety was assessed in separate regression models (Table 9.5). For community participation frequency, 15% of the variance was explained by the combined ADI-R Social/Communication domain mean algorithm scores. A negative beta value indicated that greater difficulty with reciprocal social interaction and communication (i.e. higher scores on the Social/Communication domain) was associated with a decreased frequency of community participation. For community participation variety, 15% of the variance was explained by the mean algorithm scores of the ADI-R Social/Communication and Restricted and Repetitive Behavior domains (Table 9.5). The ADI-R Social/Communication domain was the strongest predictor of community participation variety, with a negative beta value indicating that greater difficulty with reciprocal social interaction and communication was associated with decreased variety of community activities.

Table 9.5. Multiple regression demonstrating the association between Time 6 autism symptoms and Time 6 community participation frequency and variety

Variable	B	SE B	β	p value
Model 1: Community Participation Frequency (*n*=69) [a]				
ADI-R Social/Communication	-3.78	1.06	-0.40	0.001
R^2	0.15			
F	12.65**			
Model 2: Community Participation Variety (*n*=69)				
ADI-R Social/Communication	-0.92	0.33	-0.33	0.01
ADI-R Restricted and Repetitive Behavior	-1.31	0.85	-0.18	0.13
R^2	0.15			
F	6.82**			

[a] ADI-R Restricted and Repetitive Behavior is not included in the 'frequency' regression model as there was no significant correlation between community participation and mean ADI-R Restricted and Repetitive Behavior domain algorithm score
Note: adjusted R squared values are reported due to the small sample size
* $p < .05$ ** $p < .01$

9.6   DISCUSSION

This study aimed to explore how adults with autism were participating in their communities, and the childhood and adulthood factors that predicted frequency and variety of participation. Results suggested that adults in the study were participating in some areas of the community, and much less in others. For example, participation in essential activities, such as shopping, and more social activities, such as going out to a café or restaurant, or taking trips out with family or friends, was higher than participation in more structured community events, such as going to sports events, the cinema, or a concert or play. It may be that these kinds of activities require more planning and are more expensive, for example, purchasing tickets and planning transport, and are therefore more complicated for adults to attend. These results were

consistent with a recent study, reporting that shopping, errands, going to a restaurant or café, and time with family and friends were the most commonly attended activities (Shea et al., 2021).

The current study did not compare participation with other samples or populations. However, the overall ICI frequency and variety scores were comparable to studies including adults with autism and co-occurring intellectual disability (Felce, Perry, Lowe, & Jones, 2011; Totsika, Felce, Kerr, & Hastings, 2010), and variety scores reported by Ager, Myers, Kerr, Myles, and Green (2001) in a group of adults with intellectual disability moving into community-based homes. These studies were all conducted in the UK, and with a wider age range than the current study, and all living in community-based housing with at least some staff support. When looking more closely at individuals in the current study who were living in similar supported housing or accommodation, and individuals with a severe/profound intellectual disability, participation rates were lower for both frequency and variety than others in the current study and the UK studies. This may point to a lack of services or appropriate activities for adults with autism and more severe/profound intellectual disability as well as for adults living in supported accommodation in Australia.

When asked whether adults usually participated in each activity independently or with support, it was evident that few participants engaged in the community on their own. Over half of the participants were reported to have attended all community activities with a parent or carer, highlighting the ongoing support required. This study did not, however, ask whether the individual would be able to participate in the activity without support, or whether there were additional barriers, such as access to transport or financial limitations, that were prohibiting more independent participation. It may be the case that many of the adults who reported always attending events or activities with a parent or carer may desire to do this independently yet lacked the required skills or resources to do so. Future research should

ensure adults are asked what they want to do in the community and focus on what skills or resources they need to be able to do this.

Childhood autism symptoms and Self-Absorbed behaviour problems were significantly associated with both community participation frequency and variety, and childhood degree of intellectual disability was significantly associated with community participation frequency. Self-Absorbed behaviour problems as measured by the DBC2-P includes a high proportion of autism symptom-like behaviours (for example, *likes to play with unusual objects, stares at lights/spinning objects*). It is therefore likely that the relationship between this subscale and overall community participation outcomes is broadly reflective of autism symptoms. Few studies have considered the influence of childhood autism symptoms on community participation in adulthood however, this study suggests that children with a greater number of autism symptoms may be at greater risk for reduced time in community activities as adults, and this should be further investigated.

A number of adulthood factors, including degree of intellectual disability, socioeconomic disadvantage, autism symptoms, Self-Absorbed and Social Relating behaviour problems, living arrangements, and current daytime activity, had significant, small to moderate relationships with community participation frequency and variety. However, regression analyses revealed only living arrangement to be significant when including other variables in the model. In particular, adults living in supported accommodation had much lower frequency of community participation when compared to adults living with family. This may be attributed to difficulties for staff working in supported accommodation in having the necessary time and resources to support each adult in their care to participate regularly in the community. Further, while daytime activity did not remain significant when controlling for living situation, it was clear that adults who attend disability specific daytime activities have significantly less frequency of participation when compared to adults in mainstream

employment or education. While disability-specific day programmes often involve going out into the community to attend events or participate in other community activities, this may be the only time that these adults are engaging in community-based activities. Access to support outside of day programmes to attend activities in the community may be limited, particularly for adults who are also living in supported accommodation.

Further, there was a significant association between adult autism symptoms and community participation, with scores on the combined Social/Communication domain of the ADI-R correlated with community participation frequency and variety. Scores on the Restricted and Repetitive Behaviors domain were only correlated with variety of activities, and variance in the community participation variety outcome was better explained by scores on the Social/Communication domain. Together, these results demonstrate the impact of difficulties with social interaction and communication on regular engagement in the community. It may be that adults with poorer social interaction and communication skills choose to engage in other recreation and leisure activities that involve less interaction with other people, such as playing video games or participating in other solo hobbies. This experience of social isolation has been demonstrated in other studies, where young adults with autism engage in fewer social activities than young adults with other developmental disabilities (Orsmond, Shattuck, Cooper, Sterzing, & Anderson, 2013). This is often considered to be due to difficulties with social interaction as a core feature of autism, and some qualitative studies have highlighted difficulty with social skills as a barrier to community participation (Cameron et al., 2021). However, the barriers created by the community are also important to consider. For example, misperceptions of adults with autism may mean that activities within the wider community are less inclusive (Mitchell, Sheppard, & Cassidy, 2021). Further, limited accessibility of resources, such as transport or funding, may also prevent adults with autism from participating in the community. These environmental barriers are important for future

research to explore. Song et al. (2021) reported that community participation activities that involve social interaction are a low priority for adults with autism, however, they did not look at whether this was due to a lack of social interaction skills. The current study is the first to look specifically at the impact of difficulty with social interaction on community participation. This is an important area for research to continue to explore, as social skills interventions may be an important step in increasing community participation.

Diagnosis of a mental health disorder in adulthood was not associated with community participation, in contrast to a recent study by Shea et al. (2021). However, more specific behavioural problems, including Self-Absorbed and Social Relating behaviours, were. The impact of behaviour and emotional problems on community participation warrants further investigation. While there does appear to be some relationship between behaviour and emotional problems and community participation, the direction of the relationship is not clear. Do higher rates of behaviour and emotional problems, and additional mental health difficulties, result in decreased community participation, or does restricted community participation impact behaviour and emotional problems? While there is evidence that increasing time spent in community or leisure activities can support improvement of symptoms of depression for adults with intellectual disability (Jahoda et al., 2017), similar outcomes have not been established for adults with autism, with or without intellectual disability (Cameron et al., 2021).

The current study had a number of limitations. First, the sample size (n = 82) was quite small, which should be considered when interpreting results from regression analyses. Despite the small sample size, all assumptions of analyses conducted were met. Secondly, this study did not ask participants whether there were other activities they would like to participate in, and what kinds of supports or resources would allow them to do this. Further, while the results of this study demonstrate that nearly all adults with autism participated in at least some kind of

community activity over the previous month, whether this participation was meaningful for the individual was not assessed. Adults may be attending certain community activities as they have been organised for them, or they are attending as part of a group, but these activities may not necessarily be important to them. Recent research has started to identify what kinds of activities are important for adults with autism (Shea et al., 2021), and it is important for future research to continue to ask these questions to ensure adults are being supported to participate in activities that are meaningful to them.

The study had a number of strengths. Firstly, as a longitudinal study, the childhood factors that may impact on community participation were able to be investigated, something few studies have explored. Secondly, the study included participants with and without intellectual disability, resulting in information being available for individuals with a wide range of abilities. This is particularly important as so few studies include adults with co-occurring intellectual disability, or when they do, fail to report on how degree of intellectual disability was determined (Cameron et al., 2021). Finally, the current study made use of both parent/carer and self-report data, maximising the information available. Using self-report data where possible is important in allowing adults to contribute their own thoughts and responses.

Overall, this study demonstrated that, while some adults with autism are quite active in participating in the community, many experience much more limited participation. Further, it was evident that difficulties with social interaction, both in childhood and in adulthood, was an important factor in limiting community participation for the adults in this study. This points to a need for increasing social skill development and support in childhood and adulthood. Further, it is necessary to create opportunities and programmes for adults with more severe intellectual disability to increase their participation in the community, particularly for individuals also living in supported accommodation. While there is a need for research to continue to explore the overall mental health benefits of community participation,

removing barriers and increasing community participation for adults with autism is a critical step in promoting greater wellbeing. The wider environmental and societal factors impacting community participation, including accessibility of transport, funding, and programmes, as well as the attitudes and perceptions towards people with autism from the wider community, are important for future research to explore. Further understanding of these factors will enable programmes and resources to best target ways to support and facilitate community participation. This may be through improving social skills for adults with autism in addition to increasing education within the community of ways to be more inclusive of people with autism, making community participation more accessible and inviting. Most importantly, it is essential that any interventions, programmes, or resources, work directly with adults to ensure that their own community participation goals are being met.

REFERENCES

Ager, A., Myers, F., Kerr, P., Myles, S., & Green, A. (2001). Moving home: Social integration for adults with intellectual disabilities resettling into community provision. *Journal of Applied Research in Intellectual Disabilities, 14*, 392-400. doi:10.1046/j.1468-3148.2001.00082.x

American Psychiatric Association. (1987). *Diagnostic and Statistical Manual for Mental Disorders* (3rd ed.). Washington, DC: American Psychiatric Association.

American Psychiatric Association. (1994). *Diagnostic and Statistical Manual for Mental Disorders* (4th ed.). Washington, DC: American Psychiatric Association.

American Psychiatric Association. (2013). *Diagnostic and Statistical Manual for Mental Disorders* (5th ed.). Washington, DC: American Psychiatric Association.

Andrews, J., Falkmer, M., & Girdler, S. (2015). Community participation interventions for children and adolescents with neurodevelopmental intellectual disability: A systematic review. *Disability and Rehabilitation, 37*(10), 825-833. doi:10.3109/09638288.2014.944625

Askari, S., Anaby, D., Bergthorson, M., Majnemer, A., Elsabbagh, M., & Zwaigenbaum, L. (2015). Participation of children and youth with autism spectrum disorder: A scoping review. *Review Journal of Autism and Developmental Disorders, 2*, 103-114. doi:10.1007/s40489-014-0040-7

Australian Bureau of Statistics. (2016). Census of Population and Housing: Socio-Economic Indexes for Areas (SEIFA). Retrieved from https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/2033.0.55.001~2016~Main%20Features~SOCIO-ECONOMIC%20INDEXES%20FOR%20AREAS%20(SEIFA)%202016~1

Brereton, A. V., Tonge, B. J., Mackinnon, A. J., & Einfeld, S. L. (2002). Screening young

    people for autism with the Developmental Behavior Checklist. *Journal of the*

    American Academy of Child & Adolescent Psychiatry, 41(11), 1369-1374.

    doi:10.1097/01.CHI.0000024838.94814.A5

Cameron, L. A., Tonge, B. J., Borland, R. L., & Gray, K. M. (2021). *Community*

    participation for adults with autism: A systematic review. Manuscript submitted for

    publication.

Cohen, J. W. (1988). *Statistical Power Analysis for the Behavioral Sciences* (2nd edition ed.).

    Hillsdale, NJ: Lawrence Erlbaum Associates.

Einfeld, S., & Tonge, B. J. (1996a). Population prevalence of psychopathology in children

    and adolescents with intellectual disability: I rationale and methods. *Journal of*

    Intellectual Disability Research, 40(2), 91-98. doi:10.1046/j.1365-

    2788.1996.767767.x.

Einfeld, S., & Tonge, B. J. (1996b). Population prevalence of psychopathology in children

    and adolescents with intellectual disability: II epidemiological findings. *Journal of*

    Intellectual Disability Research, 40(2), 99-109. doi:10.1046/j.1365-

    2788.1996.768768.x.

Einfeld, S., & Tonge, B. J. (2002). *Manual for the Developmental Behaviour Checklist*

    Second Edition. Melbourne: Monash University.

Felce, D., Perry, J., Lowe, K., & Jones, E. (2011). The impact of autism or severe challenging

    behaviour on lifestyle outcome in community housing. *Journal of Applied Research*

    in Intellectual Disabilities, 24, 95-104. doi:10.1111/j.1468-3148.2010.00571.x

First, M. B., Williams, J. B. W., Karg, R. S., & Spitzer, R. L. (2015). *User's Guide for the*

    Structured Clinical Interview for DSM-5 Disorders, Research Version (SCID-5-RV).

    Arlington, VA: American Psychiatric Association.

Gray, K. M., Keating, C. M., Taffe, J., Brereton, A. V., Einfeld, S., & Tonge, B. J. (2012). Trajectory of behavior and emotional problems in autism. *American Journal of Intellectual and Developmental Disabilities, 117*(2), 121-133. doi:10.1352/1944-7588-117-2.121

Gray, K. M., Keating, C. M., Taffe, J. R., Brereton, A. V., Einfeld, S. L., Reardon, T. C., & Tonge, B. J. (2014). Adult outcomes in autism: Community inclusion and living skills. *Journal of Autism and Developmental Disorders, 44*, 3006-3015. doi:10.1007/s10803-014-2159-x

Gray, K. M., Tonge, B. J., Einfeld, S., Gruber, C., & Klein, A. (2018). *Developmental Behavior Checklist 2 (DBC2) (Manual)*. Torrance, CA: Western Psychological Services.

Harrison, P. L., & Oakland, T. (2015). *Adaptive Behavior Assessment System, Third Edition*. Torrance, CA: Western Psychological Services.

Jahoda, A., Hastings, R. P., Hatton, C., Cooper, S., Dagnan, D. J., Zhang, Y., . . . Melville, C. (2017). Comparison of behavioural activation with guided self-help for treatment of depression in adults with intellectual disabilities: A randomised controlled trial. *Lancet Psychiatry, 4*, 909-919. doi:10.1016/S2215-0366(17)30426-1

McConkey, R., & Walsh, J. (1982). An index of social competence for use in determining the service needs of mentally handicapped adults. *Journal of Mental Deficiency Research, 26*, 47-61. doi:10.1111/j.1365-2788.1982.tb00128.x

Mitchell, P., Sheppard, E., & Cassidy, S. (2021). Autism and the double empathy problem: Implications for development and mental health. British Journal of Developmental Psychology, 39, 1-18. doi: 10.1111/bjdp.12350

Mohr, C., Tonge, B. J., & Einfeld, S. (2005). The development of a new measure for the assessment of psychopathology in adults with intellectual disability. *Journal of Intellectual Disability Research, 49*, 469-480. doi:10.1111/j.1365-2788.2005.00701.x

Mohr, C., Tonge, B. J., Einfeld, S., & Taffe, J. (2011). *Manual for the Developmental Behaviour Checklist for Adults (DBC-A)*. Australia: The University of Sydney and Monash University.

Myers, E., Davis, B. E., Stobbe, G., & Bjornson, K. (2015). Community and social participation among individuals with autism spectrum disorder transitioning to adulthood. *Journal of Autism and Developmental Disorders, 45*, 2373-2381. doi:10.1007/s10803-015-2403-z

Orsmond, G. I., Krauss, M. W., & Seltzer, M. M. (2004). Peer relationships and social and recreational activities among adolescents and adults with autism. *Journal of Autism and Developmental Disorders, 34*(3), 245-256.

Orsmond, G. I., Shattuck, P. T., Cooper, B. P., Sterzing, P. R., & Anderson, K. A. (2013). Social participation among young adults with an autism spectrum disorder. *Journal of Autism and Developmental Disorders, 43*, 2710-2719. doi:10.1007/s10803-013-1833-8

Pallant, P. (2011). *SPSS Survival Manual* (4th ed.). Crows Nest, NSW: Allen & Unwin.

Raynes, N., Sumpton, R., & Pettipher, C. (1989). *The Index of Community Involvement - Revised*. Manchester, UK: University Department of Social Policy and Social Work.

Rutter, M., Le Couteur, A., & Lord, C. (2003). *Autism Diagnostic Interview-Revised*. Los Angeles, CA: Western Psychological Services.

Shea, L., Verstreate, K., Nonnemacher, S. L., Song, W., & Salzer, M. S. (2021). Self-reported community participation experiences and preferences of autistic adults. *Autism, 25*(5), 1295-1306. doi:10.1177/1362361320987682

Song, W., Shea, L., Nonnemacher, S. L., Brusilovskiy, E., Townley, G., & Salzer, M. S. (2021). Community participation comparison between adults on the autism spectrum and adults in the general population. *Journal of Autism and Developmental Disorders*. Advance online publication. doi:10.1007/s10803-021-05059-9

Steinhausen, H. C., & Metzke, C. W. (2004). Differntiating the behavioural profile in autism and mental retardation and testing of a screener. *European Child & Adolescent Psychiatry, 13*(4), 214-220. doi:10.1007/s00787-004-0400-4

Taffe, J. R., Tonge, B. J., Gray, K. M., & Einfeld, S. L. (2008). Extracting more infomation from behaviour checkists by using components of mean based scores. *International Journal of Methods in Psychiatric Research, 17*(4), 232-240. doi:10.1002/mpr.260

Tonge, B. J., & Einfeld, S. (2003). Psychopathology and intellectual disability: the Australian Child to Adult longitudinal study. In L. M. Glidden (Ed.), *International Review of Research in Mental Retardation, Volume 26* (pp. 61-91). San Diego, CA: Academic Press.

Totsika, V., Felce, D., Kerr, M., & Hastings, R. P. (2010). Behavior problems, psychiatric symptoms, and quality of life for older adults with intellectual disability with and without autism. *Journal of Autism and Developmental Disorders, 40*, 1171-1178. doi:10.1007/s10803-010-0975-1

Verdonschot, M. M. L., de Witte, L. P., Reichrath, E., Buntinx, W. H. E., & Curfs, L. M. G. (2009). Community participation of people with an intellectual disability: A review of empirical findings. *Journal of Intellectual Disability Research, 53*(4), 303-318. doi:10.1111/j.1365-2788.2008.01144.x

Wechsler, D. (2011). *Manual for the Wechsler Abbreviated Scale of Intelligence-Second Edition*. Bloomington, MN: Pearson.

World Health Organisation. (2001). International Classification of Functioning, Disability,

and Health: ICF. World Health Organisation, Geneva.

https://apps.who.int/iris/handle/10665/42407

CHAPTER 10: GENERAL DISCUSSION

This thesis aimed to further understand the social and community inclusion outcomes for adults with autism, as well as the childhood and adulthood factors that predict adult outcomes. Social and community inclusion, including overall outcomes, living arrangements, education, and employment or daytime activity, was explored in two empirical studies (Study 1; Chapter 7, and Study 2; Chapter 8). Community participation, a particularly understudied area in the adult outcome literature, was explored by first undertaking a systematic review (Chapter 4), followed by a study looking more closely at community participation outcomes for adults (Study 3; Chapter 9). Overall, the results from the studies included in this thesis further understanding of social and community inclusion outcomes for adults with autism and the childhood and adulthood factors associated with adult outcome. Importantly, the studies in this thesis identified a number of areas where interventions and supports, both in childhood and in adulthood, could be developed to improve outcomes. In particular, this study addressed the need for research to examine outcomes for adults with autism and co-occurring intellectual disability.

10.1   SUMMARY OF KEY RESEARCH FINDINGS

10.1.1 Social and Community Inclusion Outcomes (Study 1)

Study 1 aimed to: (1) determine the overall outcome rating in population of adults with autism; (2) explore community inclusion outcomes (living, education, and daytime activity) and determine whether these outcomes differ from the general Australian population; (3) explore social inclusion outcomes (friendships and social satisfaction); and (3) compare overall, community, and social inclusion outcomes for those with and without intellectual disability.

This study found that a third (33.8%) of participants had *Very Good/Good* overall outcomes, comparatively better than that reported in previous studies conducted in other countries, such as the USA (20%; Farley et al., 2017) and the UK (18-24%; Howlin, Goode, Hutton, & Rutter, 2004; Howlin, Moss, Savage, & Rutter, 2013). While similar rates of *Poor/Very Poor* outcomes were reported (58%), it is encouraging to see that higher rates of adults in Australia are doing comparatively better. More specifically, higher rates of independent living and lower rates of unemployment were found in the current study than reported previously (Billstedt, Gillberg, & Gillberg, 2011; Farley et al., 2017; Howlin et al., 2013). Differences in outcomes seen in the current study and other studies may be attributed to sample differences, such as inclusion of participants with intellectual disability and adults of varying ages. For example, both the Billstedt et al. (2005) and Farley et al. (2017) studies had higher proportions of participants with severe intellectual disability, and participants in the Howlin et al. (2013) study were older than participants in the current study and without co-occurring intellectual disability. Both intellectual disability and older age have been associated with poorer outcomes in the literature. Further, although the current study found lower rates of unemployment, there was evidence that engagement in regular daytime activities (whether that was employment or attending a disability-specific day programme) was often limited, with approximately 20% of participants engaged for fewer than 20 hours per week. As a result, while these adults were not considered to be unemployed in the same way as previous studies (Billstedt et al., 2011; Farley et al., 2017; Howlin et al., 2013), they still had considerable periods of time in their week when they were not engaged in any activity.

When looking at community inclusion outcomes more specifically, however, and comparing these to outcomes in the general Australian population, it was apparent that adults with autism have lower rates of independent living, employment, and educational attainment. The majority of participants were living with family or in supported accommodation, and over

half were engaged in a regular disability-specific day programme, with less than 20% living independently, and only a quarter (26%) working in the mainstream workforce. Adults with co-occurring intellectual disability reported even lower levels of independent living, engagement in employment, or pursuit of higher education. A particularly concerning finding was the number of adults who had no regular daytime activity (11%), including those with and without intellectual disability.

Social outcomes were also explored in regard to friendships and experiences of loneliness and social satisfaction. The current study demonstrated that most participants had no, or limited peer relationships, when reported by parents or carers. However, self-reported responses to a social satisfaction questionnaire were available for a smaller number of participants (n = 28). For these participants, nearly all (86%) reported that they did have some friendships, and 54% reported that they had lots of friends. While the adults who self-reported were predominantly without intellectual disability, the results give some insight into the experiences of friendships, and how the individuals own view may differ from that of their parent or carer. This outcome highlights the need for research to gather both parent/carer and self-report data wherever possible, to ensure that all experiences are captured and understood. Overall, the adults in this study who were able to self-report indicated that they were largely satisfied with their social experiences, with low levels of loneliness reported. This finding is limited to the sub-sample of adults who completed this questionnaire, however, it suggests that so-called normative outcomes of achieving independent living, employment, and higher education do not necessarily equate to overall satisfaction, and warrants further investigation. This is an important area for future research to explore, as understanding the individual experiences and desires of adults with autism is essential in ensuring the most appropriate supports and resources are made available to them.

The limited community and social inclusion outcomes experienced by adults with autism warrants further investigation as to what factors are driving these limitations. Are there individual factors that seem to be impacting on ability to live and work independently, or is there a lack of access to supports, services, and appropriate programmes for adults that allow them to develop the skills and have the necessary support to do so? The second study of this thesis sought to address one aspect of this by exploring the childhood and adulthood factors that may influence overall, community, and social inclusion outcomes.

10.1.2 Childhood and Adulthood Predictors of Social and Community Inclusion Outcomes (Study 2)

Study 2 aimed to explore the childhood and adulthood factors that predict overall, community, and social inclusion outcomes for adults with autism. Childhood factors included gender, age, socioeconomic disadvantage, degree of intellectual disability, autism symptoms, and behaviour and emotional problems. Concurrent adulthood factors included age, socioeconomic disadvantage, functional skills, autism symptoms, behaviour and emotional problems, and mental health disorder diagnosis.

Childhood degree of intellectual disability was consistently found to predict outcome in adulthood, with more severe intellectual disability being associated with poorer overall, living, employment, and social outcomes, consistent with existing research (Howlin, 2021; Kirby, Baranek, & Fox, 2016; Lord, McCauley, Pepa, Huerta, & Pickles, 2020; Mason et al., 2020). Similarly, the impact of functional skills in adulthood was overwhelmingly associated with all adult outcomes. Greater impairments in functional skills predicted poorer overall outcome, less independent living, less involvement in mainstream employment or education, and fewer friendships. The impact of functional skills was consistent in predicting outcome over and above other factors. This is an important finding, as functional skills are modifiable

and can be taught, making them a perfect candidate for intervention in both childhood and adulthood. The development of interventions and support services for adults with autism should focus on teaching functional skills to support adults to increase their ability to live and work more independently if they choose.

While degree of intellectual disability and functional skills were important factors in relation to adult outcomes, higher rates of behaviour and emotional problems, as well as more severe autism symptoms, particularly difficulty with social skills, were also associated with outcomes. This relationship was evident for both childhood and adulthood behaviour and emotional problems and autism symptoms severity. As a result, early interventions as well as interventions in adulthood should address these areas, with the aim to then improve social and community inclusion in adulthood in addition to benefits in childhood.

Overall, this study highlighted that there is no individual factor that can predict outcomes in adulthood for individuals with autism. While childhood degree of intellectual disability and adulthood functional skills clearly play a prominent role, they did not account for outcomes on their own. Difficulties with behaviour and emotional problems, both in childhood and adulthood, were also clearly associated with outcomes, as was severity of autism symptoms. Future research should continue to understand these relationships in order to determine where interventions and support should be directed. In addition to further understanding the relationships between person-specific factors and community inclusion outcomes, the impact of the wider community and environment must be considered in future research. As previously described, the social model of disability posits that a person's experience of disability is limited by the environment, such as lack of access to transport, lack of relevant resources or programs, and difficulty accessing funding (Burchardt, 2004), in addition to the perceptions of people with autism by the wider community and the difficulty of communication between people with and without autism (Crompton et al., 2021; Mitchell et

al., 2021). These factors, external to the individual, and the impact they have on meaningful inclusion for adults with autism, is critical to understand further.

10.1.3 Community Participation (Systematic Review and Study 3)

A systematic review was first undertaken to synthesise the available research and information surrounding community participation for adults with autism. The systematic review had three aims: (1) to synthesise the available information on how, and how often, adults with autism participate in the community; (2) identify the benefits of community participation on wellbeing; and (3) identify barriers and facilitators to engagement in the community. The systematic review found 63 articles (58 unique studies) meeting inclusion criteria. Overall, the review highlighted the significant bias evident in the literature relating to adults with co-occurring intellectual disability. Specifically, only a third of studies meeting inclusion criteria included participants with co-occurring intellectual disability. Further, the review highlighted the predominantly moderate to high risk of bias of studies looking at community participation, limiting the ability to be able to draw comprehensive conclusions.

The review found that, overall, adults with autism participate in some types of community participation more than others. For example, participation in both solitary and organised group activities was more prominent that more general community activities. Further, the increasing use of online platforms to facilitate social and community engagement was evident. Few studies explored the relationship between community participation and overall wellbeing and mental health. While there was some evidence of greater community participation supporting better wellbeing and mental health, more research is needed to understand the nature of this relationship and what the implications for interventions might be. A number of factors were identified throughout the review as possibly hindering and facilitating community participation, however, the evidence was limited and inconsistent. Some studies identified personal factors, such as mental health concerns, and difficulties with

communication and social skills, as well as environmental factors, such as lack of access to appropriate resources and programmes, as barriers to community participation (e.g. Haertl et al., 2013; Nichols et al., 2019; Taylor, Adams, & Bishop, 2017; Wang & Berg, 2014). Conversely, greater daily living skills, motivation to engage with like-minded people, higher family income and socioeconomic status, as well as access to support resources and structured programmes, were reported in some studies to facilitate community participation (e.g. Nichols et al., 2019; McCollum, LaVesser, & Berg, 2016; Myers et al., 2015). This is an important area for future research to continue to explore and understand as identifying barriers and facilitators to community participation will point to where improvements to supports and services need to be directed to overcome barriers.

In response to the systematic review, the third empirical study of this thesis looked at community participation for adults with autism. This study aimed to explore how, and how often, adults with autism participated in the community. Further, the study aimed to evaluate the childhood and adulthood predictors of community participation frequency and variety. Overall, Study 3 found that community participation for the participants in our study was extremely varied – some adults were regularly engaged in the community, while others did not participate in any community-based activities. While a range of factors were again found to be associated with adulthood community participation, the impact of degree of intellectual disability, adulthood living arrangements, and social interaction skills was clear. Adults with moderate to severe intellectual disability, and adults living in supported accommodation, were at greater risk for limited community participation. This may mean that there are not enough appropriate programmes and resources in the community to support adults with more severe intellectual disability to engage in their community, and limited abilities for professional carers in supported accommodation settings to be able to engage adults in the community outside of their regular daytime programmes. Further development of these kinds

of programmes and resources is critical to ensuring all adults with autism have access to participation in the community. In addition, greater difficulty with social skills was related to less participation in the community, highlighting this as another area where adults need support as well as early intervention in skill development.

Together, the systematic review and study of community participation for adults with autism contributed to the existing literature by highlighting gaps in the existing knowledge base and addressing these. Specifically, the current study furthered understanding of community participation for adults with and without co-occurring intellectual disability, demonstrating that adults with severe/profound intellectual disability were at greater risk for reduced community participation. Further, the current study looked at the effect of specific behaviour and emotional problems, as well as autism symptoms, both in childhood and in adulthood, which few studies have considered. This approach found that autism symptoms, in particular, difficulties with reciprocal social interaction, was a strong predictor of more limited community participation in adulthood. The difficulties experienced with social interaction are likely compounded by the misperceptions and misunderstandings of autism from the typically developing population, as explained by the double empathy problem discussed earlier in this thesis, making social and community inclusion more difficult for adults with autism. As a result, interventions that aim to target development of social skills and social interaction should be considered to support increased community participation, in addition to educational and inclusive programs targeted to the general population about autism. Changing community understanding and attitudes is an important step in facilitating inclusion, where all individuals are afforded the ability to participate meaningfully and feel a sense of belonging (Weaver et al., 2021).

10.1.4 Overarching Findings

The current study added support to the general findings in the literature that, when considering a general overall outcome rating, adults with autism tend to have *poor* outcomes, and was the first study to evaluate this in an Australian cohort. However, this study also highlighted the flaws in using this type of rating, whereby broad overall outcome ratings often miss the nuance in the range of outcomes for adults. While objectively, this participant would be considered to have a *poor* outcome, this was not able to be demonstrated when following pre-determined rating criteria. Future research should instead focus on the specific outcomes adults may be experiencing, rather than a broad rating, to ensure that the breadth of life experiences and outcomes is captured.

When exploring the impact of mental health on outcomes in adulthood, the literature broadly suggests that poor mental health will lead to poorer outcomes for adults with autism. This, however, was not demonstrated in the current study. Following a comprehensive mental health disorder diagnosis process, participants who met criteria for a current mental health disorder did not fare any worse in terms of independent living, employment, or social and community inclusion outcomes. However, having greater behaviour and emotional problems more broadly did influence outcome. Few studies have explored the impact of behaviour and emotional problems outside of specific mental health problems, and the studies in this thesis suggest that this is an area that warrants further attention.

Further, the studies within this thesis supported existing knowledge that adults with co-occurring intellectual disability often have more restricted outcomes that those without intellectual disability, however, this was not the sole contributing factor. Difficulties with reciprocal social interaction and communication were consistently highlighted throughout this thesis as being associated with a range of adult social and community inclusion outcomes, including lower rates of employment, independent living, and community

participation. These findings point to a need for further exploration of how difficulties with social interaction and communication may impact opportunities for adults with autism to engage and participate in the community, and what resources are needed to remove this barrier. The need for development of skills in these areas is also highlighted, providing a potential target for intervention that could further improve social and community inclusion and participation outcomes.

10.2 IMPLICATIONS

This study highlights a number of factors, both in childhood and in adulthood, that are likely to influence outcome in adulthood, as well as identifying a number of areas where adults with autism experience greater difficulty than other adults. The role of functional skills, behaviour and emotional problems, and autism symptoms, particularly social interaction skills, on a range of adult outcomes suggests these are important areas for interventions to target. By improving these skills and addressing behaviour and emotional problems both in childhood and in adulthood, adults will be more likely to achieve the goals they have for their lives, in terms of independence and community participation.

The findings of this research also have important implications for adults with co-occurring intellectual disability. The current studies involved adults with a wide range of degree of intellectual disability, something that has been lacking in the research literature to date, particularly surrounding community participation. As a result, this thesis provides further evidence that *poorer* outcomes are more likely amongst adults with both autism and co-occurring intellectual disability. As adults with intellectual disability will require different approaches to interventions and supports than those without intellectual disability, it is important to understand what outcomes look like for this population, in order to inform interventions.

Importantly, the findings of this thesis highlighted the need to continue to work with adults with autism to understand what a *good* outcome means for them. While this thesis demonstrated that adults with autism were more likely to experience poorer outcomes in some areas than the general population (for example, lower rates of independent living, lower levels of education, and greater unemployment), the research literature highlights that these outcomes might not be desirable for all adults with autism (Howlin, 2021), and that it is important to consider what a *good* outcome looks like for the individual (Taylor, 2017). Adults may have different ideas of what social and community inclusion means for them, and any measurement of a *good* outcome should take this into account.

10.3   LIMITATIONS

This body of research has limitations that should be considered. First, the ACAD study is made up of a community sample of individuals with autism who were recruited as children and adolescents in 1991, and therefore reflects the diagnostic practices and understanding of autism at that time. This may mean that the adults in the ACAD sample have more severe symptoms than children and adults who may be diagnosed today with greater recognition and understanding of what autism looks like. Further, the gender ratio in the ACAD sample (81% male) is reflective of the gender ratios at the time of recruitment. Females tend to present with different characteristics than males, for example, females are less likely to show unusual or restricted interests, and therefore often fail to be diagnosed (Howlin, 2021; Loomes, Hull, & Mandy, 2017). As a result, the females in the ACAD study are not likely to be representative of all females with autism. Despite this, the ACAD sample includes a wide variety of individuals, ranging from severe/profound intellectual disability to no intellectual disability, as well as adults with a wide range of autism symptoms.

Inherent in a longitudinal study are the inevitable drop-out rates, reducing sample size over time. The current sample is small (n = 84), however, retention has remained quite high throughout the course of the study (75% at Time 6). Attrition over a long period of time in a longitudinal study will limit the sample size, however, the strengths of this longitudinal study in being able to identify childhood characteristics and how they relate to adult outcome is important. Further, there were no significant differences between those who participated at the most recent time point and those who did not in terms of intellectual disability or behaviour and emotional problems, suggesting that the current research is not necessarily biased towards a particular group of people.

While the current study made use of both parent/carer as well as self-report data, there were some instances where appropriate data was unable to be collected. For example, current autism symptoms and behaviour and emotional problems were not able to be determined for a small number of participants (n = 6), as they were living independently with only sporadic contact with their parents, and therefore parents were not considered an appropriate respondent for current behaviours. As a result, those with missing data in these areas are generally more independent with less severe symptoms, and this should be considered when interpreting results where these measures are used.

10.4 DIRECTIONS FOR FUTURE RESEARCH

One of the most important outcomes of this thesis is the need for future research to focus on developing appropriate supports and interventions for individuals with autism, including early interventions in childhood, as well as interventions to support skill development in adulthood. It was apparent throughout this study that, despite a small number of adults having quite positive outcomes, the majority of individuals in this study experience challenges with social and community inclusion and participation. This is consistent with the literature,

reporting that outcomes in adulthood have remained *poor* over time, despite increased awareness and understanding of autism (Mason et al., 2020). It is clear that more work is needed to change this trajectory and improve overall outcomes and quality of life for adults with autism. The results of this thesis pointed to a number of areas that are necessary to target for intervention in addition to identifying individuals who might be at the greatest risk for limited independence and community engagement in adulthood. Degree of intellectual disability in childhood was a consistent predictor of adult outcomes, and therefore suggests children with autism and co-occurring intellectual disability are particularly in need of early intervention to ensure they and their families have the tools to support social and community inclusion as they enter adulthood. Further to this, the impact of lower functional skills in adulthood on social and community inclusion and participation was evident in this thesis, again pointing to functional skill development as critical to improving outcomes and supporting community engagement as adults.

As discussed by Howlin (2021), while there is some evidence of development and evaluation of interventions for adults with autism in the research literature, they are largely focused on reduction of autism symptoms, particularly restricted and repetitive behaviours, rather than supporting improvements in wellbeing and quality of life. As demonstrated through the studies in this thesis, when controlling for a range of autism symptoms, including social interaction skills, communication skills, and restricted and repetitive behaviours, limited social and communication skills were a stronger predictor of *poorer* social and community inclusion outcomes than restricted and repetitive behaviours. This suggests targeting social skills is an important area for interventions to focus on for improving social and community inclusion outcomes. There is already some evidence that social skills intervention programmes for individuals with autism are effective and may lead to improvements in social and community engagement, although these studies have generally been of poor quality (lack

of control groups, recruitment biases often towards university students), and mostly include adolescents and younger adults, and participants without intellectual disability (Cameron, Tonge, Borland, & Gray, 2021; Howlin, 2021). Future research should focus on the development and evaluation of interventions in older adults and adults with co-occurring intellectual disability, and with greater methodological rigour (for example, including control groups, and recruiting from the general community). Moreover, as per the social model of disability, the barriers experienced within society are particularly important to consider in future research. Burchardt (2004) highlights the economic, social, and physical barriers often experienced by individuals with disability – factors which are crucial for future research to consider. Studies exploring social and community inclusion and participation should consider whether accessibility to transport, relevant programs, and funding, impact the ability for adults with autism to participate in their community. Research should also aim to adapt interventions and programmes to address the needs of all adults with autism, ensuring all adults have access to effective intervention programmes that will support their inclusion in the wider community.

Further, the studies within this thesis highlighted the ongoing impact of intellectual disability and the added challenges faced by adults with both autism and intellectual disability. It is essential that future research continues to further understand the differing experiences for adults with co-occurring intellectual disability, and how their support needs differ from adults without intellectual disability. As highlighted in the systematic review undertaken in this thesis (Chapter 4), existing intervention studies for adults with autism rarely include adults with co-occurring intellectual disability. Conclusions can therefore not be made about the effectiveness of these interventions for adults with co-occurring intellectual disability. Future research should aim to develop and evaluate interventions and programmes that target the

particular needs for adults with autism and intellectual disability, also taking into consideration the different goals that this group of adults may have.

The need for future research to continue to work with adults with autism directly to further understand their experiences and what supports and resources they feel would best allow them to live they life they choose was also evident throughout the studies in this thesis. The current study highlighted the many areas in which adults with autism experience difficulty, particularly in relation to living and working in the community, developing friendships, and participating in community activities. The current study, however, did not ask participants whether their current situation in terms of living, daytime activity, socialisation, or community participation, differed from what they desire. While high rates of living with family, and low rates of engagement in mainstream employment or education were found, it may be that adults and their families were happy with these arrangements and were not seeking to change them. Future research should speak directly with adults and their families to determine what their desires are for living in adulthood, and what is prohibiting them from making changes if in fact they do want to live in a different way.

10.5 CONCLUDING REMARKS

Overall, this thesis highlighted not only areas in which adults with autism experience greater difficulty, but also highlighted that many individuals do well in adulthood. A number of participants were living independently, engaged in regular employment, had friendships and a sense of social satisfaction, and regularly participated in the community. This is an important finding, as it suggests that the overall *poor* outcomes that have been consistently highlighted in the literature are not concrete and there are opportunities for adults with autism to live their life in a way that is positive for them and their families. The importance of ensuring the appropriate supports and resources are available to adults was a consistent finding of the

current research. Importantly, interventions, supports, and community programmes should be tailored for the individual, as it was evident throughout this thesis that a range of factors can influence outcome and the opportunities available. Further, future research should continue to work directly with adults to determine where they need support, develop and evaluate appropriate interventions and support programmes, and critically, to determine what their own goals for their lives are.

REFERENCES

Billstedt, E., Gillberg, I. C., & Gillberg, C. (2011). Aspects of quality of life in adults
diagnosed with autism in childhood. *Autism, 15*, 7-20.
doi:10.1177/1362361309346066

Burchardt, T. (2004). Capabilities and disability: The capabilities framework and the social
model of disability. *Disability & Society, 19*(7), 735-751. doi:
10.1080/0968759042000284213

Cameron, L. A., Tonge, B. J., Borland, R. L., & Gray, K. M. (2021). *Community
participation for adults with autism: A systematic review.* Manuscript submitted for
publication.

Crompton, C. J., DeBrander, K., Heasman, B., Milton, D., and Sasson, N. J. (2021). Double
empathy: Why autistic people are often misunderstood. *Frontiers for Young Minds, 9,*
554875. doi: 10.3389/frym.2021.554875

Farley, M. A., Cottle, K. J., Bilder, D., Viskochil, J., Coon, H., & McMahon, W. M. (2017).
Mid-life social outcomes for a population-based sample of adults with ASD. *Autism
Research, 11*, 142-152. doi:10.1002/aur.1897

Haertl, K., Callahan, D., Markovics, J., & Sheppard, S. S. (2013). Perspectives of adults
living with autism spectrum disorder: Psychosocial and occupational implications.
Occupational Therapy in Mental Health, 29(1), 27-41.
doi:10.1080/0164212X.2012.760303

Howlin, P. (2021). Adults with autism: Changes in understanding since DSM-111. *Journal of
Autism and Developmental Disorders*. Advance online publication.
doi:10.1007/s10803-020-04847-z

Howlin, P., Goode, S., Hutton, J., & Rutter, M. (2004). Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry, 45*(2), 212-229. doi:10.1111/j.1469-7610.2004.00215.x

Howlin, P., Moss, P., Savage, S., & Rutter, M. (2013). Social outcomes in mid- to later adulthood among individuals diagnosed with autism and average nonverbal IQ as children. *Journal of the American Academy of Child & Adolescent Psychiatry, 52*(6), 572-581. doi:10.1016/j.jaac.2013.02.017

Kirby, A. V., Baranek, G. T., & Fox, L. (2016). Longitudinal predictors of outcomes for adults with autism spectrum disorder: Systematic review. *Occupation, Participation and Health, 36*(2), 55-64. doi:10.1177/1539449216650182

Loomes, R., Hull, L., & Mandy, W. (2017). What is the male-to-female ratio in Autism Spectrum Disorder? A systematic review and meta-analysis. *Journal of the American Academy of Child & Adolescent Psychiatry, 56*(6), 466-474. doi:10.1016/j.jaac.2017.03.013

Lord, C., McCauley, J. B., Pepa, L. A., Huerta, M., & Pickles, A. (2020). Work, living, and the pursuit of happiness: Vocational and psyschosocial outcomes for young adults with autism. *Autism, 24*(7), 1691-1703. doi:10.1177/1362361320919246

Mason, D., Capp, S. J., Stewart, G. R., Kempton, M. J., Glaser, K., Howlin, P., & Happe, F. (2021). A meta-analysis of outcomes studies of autistic adults: Quantifying effect size, quality, and meta-regression. *Journal of Autism and Developmental Disorders, 51*, 3165-3179. doi:10.1007/s10803-020-04763-2

McCollum, M., LaVesser, P., & Berg, C. (2016). Participation in daily activities of young adults with high functioning autism spectrum disorder. Journal of Autism and Developmental Disorders, 46(3), 987-997. doi:10.1007/s10803-015-2642-z

Mitchell, P., Sheppard, E., & Cassidy, S. (2021). Autism and the double empathy problem: Implications for development and mental health. *British Journal of Developmental Psychology, 39*, 1-18. doi: 10.1111/bjdp.12350

Myers, E., Davis, B. E., Stobbe, G., & Bjornson, K. (2015). Community and social participation among individuals with autism spectrum disorder transitioning to adulthood. Journal of Autism and Developmental Disorders, 45(8), 2373-2381. doi:10.1007/s10803-015-2403-z

Nichols, C., Block, M. E., Bishop, J. C., & McIntire, B. (2019). Physical activity in young adults with autism spectrum disorder: Parental perceptions of barriers and facilitators. Autism, 23(6), 1398-1407. doi:10.1177/1362361318810221

Taylor, J. L. (2017). When is a good outcome actually good? *Autism, 21*(8), 918-919. doi:10.1177/1362361317728821

Taylor, J. L., Adams, R. E., & Bishop, S. L. (2017). Social participation and its relation to internalizing symptoms among youth with autism spectrum disorder as they transition from high school. Autism Research, 10(4), 663-672. doi:10.1002/aur.1709

Wang, H. Y., & Berg, C. (2014). Participation of young adults with high-functioning autism in Taiwan: A pilot study. OTJR: Occupation, Participation and Health, 34(1), 41-51. doi:10.3928/15394492-20131209-01

Weaver, L. A., Bingham, E., Luo, K., Juarez, A. P., & Taylor, J. L. (2021). What do we really mean by "inclusion?": The importance of terminology when discussing approaches to community engagement. *Autism, 25*(8), 2149-2151. doi: 10.1177/13623613211046688

APPENDICES

APPENDIX A – ETHICS APPROVAL

MONASH University

Monash University Human Research Ethics Committee (MUHREC)
Research Office

Human Ethics Certificate of Approval

This is to certify that the project below was considered by the Monash University Human Research Ethics Committee. The Committee was satisfied that the proposal meets the requirements of the *National Statement on Ethical Conduct in Human Research* and has granted approval.

Project Number:	CF15/1045 - 2015000486
Project Title:	Social outcomes and the emotional and behavioural well-being of adults with autism
Chief Investigator:	Assoc Prof Kylie Gray
Approved:	From: 22 May 2015 To: 22 May 2020

Terms of approval - Failure to comply with the terms below is in breach of your approval and the Australian Code for the Responsible Conduct of Research.

1. The Chief investigator is responsible for ensuring that permission letters are obtained, <u>if relevant</u>, before any data collection can occur at the specified organisation.
2. Approval is only valid whilst you hold a position at Monash University.
3. It is the responsibility of the Chief Investigator to ensure that all investigators are aware of the terms of approval and to ensure the project is conducted as approved by MUHREC.
4. You should notify MUHREC immediately of any serious or unexpected adverse effects on participants or unforeseen events affecting the ethical acceptability of the project.
5. The Explanatory Statement must be on Monash University letterhead and the Monash University complaints clause must include your project number.
6. Amendments to the approved project (including changes in personnel): Require the submission of a Request for Amendment form to MUHREC and must not begin without written approval from MUHREC. Substantial variations may require a new application.
7. Future correspondence: Please quote the project number and project title above in any further correspondence.
8. Annual reports: Continued approval of this project is dependent on the submission of an Annual Report. This is determined by the date of your letter of approval.
9. Final report: A Final Report should be provided at the conclusion of the project. MUHREC should be notified if the project is discontinued before the expected date of completion.
10. Monitoring: Projects may be subject to an audit or any other form of monitoring by MUHREC at any time.
11. Retention and storage of data: The Chief Investigator is responsible for the storage and retention of original data pertaining to a project for a minimum period of five years.

Professor Nip Thomson
Chair, MUHREC

cc: Prof Bruce Tonge, Prof Stewart Einfeld, Prof Patricia Howlin, Prof Roger Stancliffe

Appendix B – Participant Explanatory Statement and Consent Form (Parent/Carer)

MONASH University

EXPLANATORY STATEMENT

PARENT/CARER

Project: Social outcomes and the emotional and behavioural wellbeing of adults with autism (CF15/1045 – 2015000486)

Researchers: **Associate Professor Kylie Gray (Chief Investigator), Emeritus Professor Bruce Tonge, Ms Kate Phillips and Ms Lauren Cameron (PhD Candidate)** Centre for Development Psychiatry & Psychology, Monash University
Phone: (03) 9902 4563 or (03) 9594 1354
Email: kylie.gray@monash.edu
Professor Stewart Einfeld & Professor Roger Stancliffe, The University of Sydney
Emeritus Professor Patricia Howlin, Kings College London & The University of Sydney

You are invited to take part in this study. Please read this Explanatory Statement in full before deciding whether or not to participate in this research. If you would like further information regarding any aspect of this project, you are encouraged to contact the researchers via the phone numbers or email addresses listed above.

What does the research involve?

Individuals with autism are particularly vulnerable to poor social outcomes and serious emotional and behavioural problems in adulthood. Such problems often prevent adults from gaining or sustaining employment, independent living and social inclusion. This study will provide information on the pathways of these problems across the lifespan. The study will identify what factors impact outcomes in adulthood. Information on these factors can assist health professionals and families make decisions on appropriate treatments and supports during childhood/adolescence in order to increase independence and well-being during adulthood.

Should you consent to continue your participation in the study, we will send you a questionnaire to complete and you will meet with a member of the research team at a time and place convenient to you. The questionnaire will include questions in relation to your son/daughter's daily living skills, behaviours, emotional well-being, employment status, living arrangements, and social activities. This questionnaire will take approximately 40-60 minutes to complete. When we meet with you, we will ask you questions about your son/daughter's current behaviours and difficulties, including questions on behaviours associated with autism, emotional and behavioural difficulties, and mental health. This interview will take 1-1.5 hours to complete. We may also meet with your son/daughter to complete an assessment of their intellectual functioning, and ask them some questions, including

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questions about their social satisfaction and supports, and loneliness. This assessment will take 1-1.5 hours to complete.

You will be provided with a report on the results of the assessment. These results may be of use to professionals involved in the care of your son/daughter.

To assist us with the assessment, we may ask for your permission to make an audiovisual recording of your child's assessment. This recording will only be viewed by the project team and will be deleted after six months. You can say no to the audiovisual recording and still participate in the study.

Why were you chosen for this research?

You have been sent this information as you have participated in previous stages of the project (since the early 1990's). You may also have participated in follow-ups over the subsequent 20 years. We are inviting you and your son/daughter/person in your care to participate in a follow-up study, focussing on the experiences of adults with autism.

Source of funding

The project has been funded by the Australian Research Council (DP150104369).

Consenting to participate in the project and withdrawing from the research

If you agree to be a part of this project, please complete the attached consent form and return it to us in the reply-paid envelope provided. No stamp is necessary. Once we have received your consent form, a member of our research team will then contact you to organise a meeting.

Please note that participation in this project is voluntary and you can withdraw from the study. However, you can only withdraw your data up to four months after collection as the results will be pooled together and it will not be possible to identify your data after it has been analysed for publication.

Whether you take part or not, it will not make any difference to the medical care or other professional services which your son/daughter or your family currently receive.

Possible benefits and risks to participants

There is no likely risk of physical or psychological harm in the study. If any specific difficulties or problems are identified, a referral to appropriate services can be arranged. If you have any concerns, questions, or need any help please feel free to directly contact the Chief Investigator, A/Prof Kylie Gray (contact details above), who will assist with arranging help for you if needed.

Confidentiality

Data on computers will be securely stored and deidentified (names are not used). There will be nothing in any reports of the study that could identify individuals or families, as only aggregate data will be reported. Reports on the study will be submitted for publication to journals and conferences, but individual participants will not be identifiable in such reports.

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Storage of data

In compliance with Monash University regulations, storage of hardcopy data collected will be kept on University premises in a locked filing cabinet for 25 years after which time data may be destroyed pending researchers' review. Electronic data (including video footage) will be securely stored on password protected computers and deleted after six months from collection date. Only the research staff directly involved with the study will have access to these files.

Use of data for other purposes

Due to the project looking at factors across the lifespan, it may be necessary to use this data in future stages of the project. There will be nothing in any reports of the study that could identify individuals or families. Reports on the study will be submitted for publication, but individual participants will not be identifiable in such reports.

Results

If you would like to be informed of the research findings, please contact A/Prof Kylie Gray (see above).

Complaints

Should you have any concerns or complaints about the conduct of the project, you are welcome to contact the Executive Officer, Monash University Human Research Ethics (MUHREC):

Executive Officer
Monash University Human Research Ethics Committee (MUHREC)
Room 111, Building 3e
Research Office
Monash University Vic 3800
Tel: +61 3 9905 2052   Email: muhrec@monash.edu   Fax: +61 3 9905 3831

Thank you for taking the time to assist us with our project.

A/Prof Kylie Gray   **E/Prof Bruce Tonge**

Prof Stewart Einfeld   **Prof Patricia Howlin**   **Prof Roger Stancliffe**

MONASH University

Centre for Developmental Psychiatry & Psychology, Monash University
Centre for Disability Research & Policy, University of Sydney
Kings College, London

Conducted by: A/Prof. Kylie Gray, E/Prof. Bruce Tonge,
Prof. Stewart Einfeld, E/Prof. Patricia Howlin, & Prof. Roger Stancliffe

PARENT / CARER CONSENT FORM

I,

Name (print):

Address:

Daytime telephone:

Email:

have been asked to participate in the research project entitled *Social outcomes, emotional and behavioural well-being of adults with autism* being conducted by Associate Professor Kylie Gray, Professor Bruce Tonge, Professor Stewart Einfeld, Professor Patricia Howlin and Professor Robert Stancliffe involving myself and my child/charge,

Name of person in care:	Date of birth:

I give voluntary consent for my son/daughter/charge for whom I am the guardian to participate in the above project. I have had the project explained to me and I have read the Explanatory Statement, which I can keep for my records. I understand that the research study will be carried out in a manner conforming with the principles set out by the National Statement on Ethical Conduct in Research Involving Humans, and further that:

1. I understand the general purposes, methods, demands and benefits and possible risks, inconveniences and discomforts of the study as outlined in the 'Parent/Guardian Explanatory Statement' that has been given to me.

2. Although I understand that the purpose of this research project is to improve the quality of care, it has also been explained that my involvement may not be of any direct personal benefit to me or my son/daughter/person for whom I am the guardian.

3. My participation in the research study is voluntary, and I am free to withdraw my data up to four months after collection at any time, and to continue receiving appropriate treatment for my son/daughter/person for whom I am the guardian, as will be the case if I do not volunteer to enter the study.

293

MONASH University

4. I have been given the opportunity to have a member of my family or a friend present while the project was explained.

5. I have been given the opportunity to ask questions in relation to the research study, and I have received all the information and explanations I have requested.

6. I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party.

7. I understand that any data provided will be de-identified and collated with other participant's data, and analysed as a group. This collated data may also be used in future research or analyses undertaken by A/Prof Gray, Prof Tonge, Prof Einfeld, Prof Howlin or Prof Stancliffe. The results of this group data may also be used for publication in scientific journals and at conferences.

☐ **Please tick this box if you would NOT like to find out about future research studies. Receiving this information does not mean you have to take part in future studies.**

Parent / Carer signature :

Signature [   ]   **Date** [   ]

Investigator: I, ... have fully explained the aims, risks, and procedures of the abovenamed study to the person named therein.

Signature: .... **Date:** ....

MONASH University

Social outcomes and well-being of adults with autism

Centre for Developmental Psychiatry & Psychology, Monash University
Centre for Disability Research & Policy, University of Sydney,
Kings College London

PARTICIPANT INFORMATION SHEET

Everybody can have problems with how they feel and behave sometimes. This can make them and their families very sad and upset.
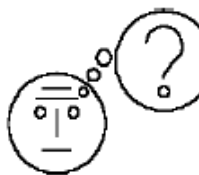
People with these problems can find it hard to learn new things, go to school or work or do the fun things they would like to do. We are working on a way to make it easier for staff and doctors to help people with their problems.

We have some questions that we want to ask the person who helps you about what you do and how you feel. We will not ask the person who helps you any questions if you do not want us to. We would also like to ask your doctor some questions about your worries and concerns, and your daily life. The answers we get from the person who helps you, will then help us to work out how many people are having problems, what kind of problems they are having and how we might help

We would really like to talk to you again about how you have been getting on recently and how things are going for you and your family. We would like to invite you to meet with us. Your mum or dad or a support person can also be there if you like. We will talk to you and do some activities and ask some questions. This should take about 1.5 hours. You will be able to have breaks when you need them.

We also have some questions that we want to ask your mum or dad, carer about what you do and how you feel.

The answers we get from you and your parents will then help us to work out how many people are having problems, what kind of problems they are having and how we might help.

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Sometimes the things we find out get written in a book or magazine. If this happens, we will take your name out so that it remains PRIVATE. No one will know that the answers to the questions were about you.

What we find out about you is PRIVATE. It is just between you, us and your parents. What your parents tell us will not be given to or seen by anyone else but the people working on the project. After 25 years we will throw away all of this information.
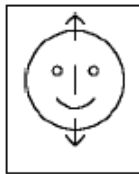
If you change your mind and no longer want your parents to answer questions about how you feel and what you do, this is OK and you will still get help with what you need.
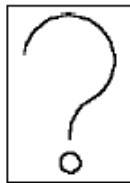
If you have any questions, please call Dr Kylie Gray on (03) 9902 4563 OR 9594 1354, who will be happy to answer them. You can keep this form for yourself.

Complaints: if you don't like something about what we do or say you can complain. You or your parent or guardian can phone (03) 9905 2052.

Ask to speak to the secretary of the Human Ethics Committee and tell him or her that the number of the project is CF15/1045-20156000486.

You could also write to the secretary. That person's address is:

Executive Officer
Monash University Human Research Ethics Committee (MUHREC)
Research Office
Monash University VIC 3800
Tel: +61 3 9905 2052
Email: muhrec@monash.edu
Fax: +61 3 9905 3831

Thank you!

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Social outcomes and the emotional and behavioural

well-being of adults with autism

Centre for Developmental Psychiatry & Psychology, Monash University

Centre for Disability Research & Policy, University of Sydney

Kings College, London

Conducted by: Dr Kylie Gray, Dr Bruce Tonge, Dr Stewart Einfeld,

Dr Patricia Howlin & Dr Roger Stancliffe

PARTICIPANT CONSENT FORM

I have been told that my mum or dad will be asked some questions. I have been told that I will do some activities and answer some questions I have read the information sheet about this and I agree to take part. This means that:

I understand that what my mum or dad says is PRIVATE. It is just between me, my parents, and the people working on the project. What my mum or dad says will not be given to or seen by anyone else but the people working on this project.
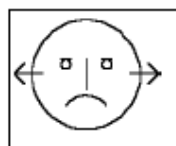
If I do not want to help with this project, that is OK.

If I change my mind and no longer want my mum or dad to answer questions about how I feel and what I do, this is OK too and I will still get help with what I need.

297

You are choosing if you want to take part. Your signature means that you are happy to take part in this project and that you have read the information sheet about this project.

_____

Name: _____

Signature: _____

Witness: I, _____

       of, _____

as an independent witness, confirm that the aims and procedures of the study and any risks involved have been explained to the person consenting, whose signatures I witness. In opinion, he/she is acting rationally and voluntarily.

**Witness
Signature:** _____   Date: _____

APPENDIX D – QUESTIONNAIRE: EDUCATION, EMPLOYMENT/DAYTIME ACTIVITY, AND LIVING ARRANGEMENTS

1. EDUCATION

1.1 What is the highest level of education s/he has completed?

Year 9 or below	☐ 1	
Year 10	☐ 2	
Year 11	☐ 3	
Year 12	☐ 4	

Completed in a special school? ☐ No ☐ Yes

→ Was it an autism specific school?
Yes ☐
No ☐

Certificate I/II ☐ 5

Certificate III/IV ☐ 6

Advanced Diploma ☐ 7

Bachelor degree ☐ 8

Grad. Diploma/Grad. Certificate ☐ 9

Postgraduate degree ☐ 10

Other ☐ 11 → Please describe:

1.2 If the person is currently undertaking an education course, please give the name of the course and institution:

Name of course:
....

Institution:
....

2. EMPLOYMENT

The following questions relate to the person's participation in the workforce over the PAST MONTH.

2.1 What is their current working arrangement? (Tick all that apply)

Unemployed [ ] 1

Volunteer (unpaid) [ ] 2 → [ ] Hours per week

Organised day activity program [ ] 3 → [ ] Hours per week

Go to Question 2.4 (Pg.9)

Paid job in mainstream workforce **WITH SUPPORT** [ ] 4 → [ ] Hours per week → [ ] Hours of support per week

Paid job in mainstream workforce **WITHOUT SUPPORT** [ ] 5 → [ ] Hours per week

Sheltered workshop / Disability enterprise [ ] 6 → [ ] Hours per week

What is their employment status?

Permanent [ ] 1

Casual [ ] 2

Fixed-term contract [ ] 3

Other (please describe) [ ] 4

Describe person's current main job:

Job title & main tasks/duties:

300

3. LIVING ARRANGEMENTS

3.1 What is their current living arrangement?

Supported accommodation for people with disability	☐ 1	At home with both parents	☐ 2
With other relatives	☐ 3	At home with sole parent	☐ 4
With spouse/partner	☐ 5	With foster parents	☐ 6
Living alone	☐ 7	With friend(s)	☐ 8
Other (please describe)	☐ 9		

....

3.2 How many people live there?

☐ with a disability   ☐ without a disability

3.3 How much paid disability support does s/he receive in their living setting?

☐ Average hours per week

3.4 Are the living arrangements in... (Tick <u>one</u> response)

Property/mortgage in **own** name	☐ 1	Rented/leased in **own** name	☐ 2
Property/mortgage in **family's** name	☐ 3	Rented/leased in **family's** name	☐ 4
Disability Services own property/lease	☐ 5	Other	☐ 6

APPENDIX E – MODIFIED WORKER LONELINESS QUESTIONNAIRE

Chadsey-Rusch, J., DeStefano, L., O'Reilly, M., Gonzalez, P., & Collet-Klingenberg, L. (1992). Assessing the loneliness of workers with mental retardation. *Mental Retardation, 30*(2), 85-92.

The following questions relate to your social interactions.

Please tick one response for each question.

	NO (0)	SOMETIMES (1)	YES (2)
1. Is it easy for you to make friends?	☐	☐	☐
2. Do you have people to talk to?	☐	☐	☐
3. Is it hard for you to make friends?	☐	☐	☐
4. Do you have lots of friends?	☐	☐	☐
5. Do you feel alone?	☐	☐	☐
6. Can you find a friend when you need one?	☐	☐	☐
7. Is it hard to get people to like you?	☐	☐	☐
8. Do you feel left out of things?	☐	☐	☐
9. Are there people you can go to when you need help?	☐	☐	☐
10. Are you lonely?	☐	☐	☐
11. Do people like you?	☐	☐	☐
12. Do you have friends?	☐	☐	☐

The following questions relate to your child/guardian's community involvement over the past month. Please tick one answer for each question. In the past month, has s/he undertaken any of these activities? For each activity undertaken, note how many times and whether the activity is usually undertaken independently or with either a parent or with a residential care or other staff member.

Activity in the past month	No	Yes - How many times?						Usually independently?		
	0	1	2	3	4	5+		Yes	With parent	With staff
1. Had guests to stay (nbr. of nights)	0	1	2	3	4	5		1	2	3
2. Had family or friends in for a meal.	0	1	2	3	4	5		1	2	3
3. Been to a social club	0	1	2	3	4	5		1	2	3
4. Been on an overnight stay to family or friends (nbr. of nights)	0	1	2	3	4	5		1	2	3
5. Had trips out with family or friends	0	1	2	3	4	5		1	2	3
6. Been to a café / restaurant	0	1	2	3	4	5		1	2	3
7. Been to a hotel (incl. RSL, Leagues etc.)	0	1	2	3	4	5		1	2	3
8. Been to a hairdresser	0	1	2	3	4	5		1	2	3
9. Been shopping	0	1	2	3	4	5		1	2	3
10. Been to a church	0	1	2	3	4	5		1	2	3
11. Been to a sports events	0	1	2	3	4	5		1	2	3
12. Been to a cinema	0	1	2	3	4	5		1	2	3
13. Been to a concert or play	0	1	2	3	4	5		1	2	3
14. Been on a bus	0	1	2	3	4	5		1	2	3
15. Been to a bank	0	1	2	3	4	5		1	2	3
16. Been on holiday in the past 12 months	0	1	2	3	4	5		1	2	3

APPENDIX G – TIME 1 PREDICTOR VARIABLES INTERCORRELATION MATRIX

Table A.1 below presents correlations between each of the Time 1 predictor variables (degree of intellectual disability, socioeconomic disadvantage, sex, age, behaviour and emotional problems (DBC2-P total score and subscales), and autism symptoms (DBC2-P Autism Screening Algorithm)), to assess for multicollinearity. The same Time 1 predictor variables were used in analyses in both Study 2 and Study 3.

Table A.1. Time 1 predictor variables intercorrelation matrix (Studies 2 and 3)

	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.
1. Degree of intellectual disability	-	-	-	-	-	-	-	-	-	-	-
2. Socioecon. disad,	0.11	-	-	-	-	-	-	-	-	-	-
3. Sex	-0.07	-0.10	-	-	-	-	-	-	-	-	-
4. Age	-0.31**	0.03	0.18*	-	-	-	-	-	-	-	-
5. DBC2-P TBPS MIS	-0.08	-0.07	-0.06	0.07	-	-	-	-	-	-	-
6. DBC2-P Disruptive MIS	0.08	-0.07	-0.10	0.09	0.86**	-	-	-	-	-	-
7. DBC2-P Self Absorbed MIS	-0.33**	-0.04	-0.09	0.01	0.80**	0.50**	-	-	-	-	-
8. DBC2-P Comm. Dist. MIS	0.24*	-0.11	0.03	0.01	0.64**	0.55**	0.28**	-	-	-	-
9. DBC2-P Anxiety MIS	0.07	0.01	-0.13	-0.04	0.63**	0.59**	0.27**	0.38**	-	-	-
10. DBC2-P Social Relating MIS	-0.24*	-0.08	0.08	0.19*	0.66**	0.43**	0.57**	0.37**	0.29**	-	-
11. DBC2-P ASA	-0.26*	-0.08	-0.05	0.02	0.89**	0.65**	0.89**	0.47**	0.41**	0.73**	-

Correlation coefficients: Pearson's r or Spearman's rho
Socioecon. disad. = socioeconomic disadvantage (Index of Relative Socioeconomic Disadvantage); DBC2-P = Developmental Behavior Checklist 2 – Parent; TBPS = Total Behavior Problem Score, Comm. Dist. = Communication Disturbance; ASA = Autism Screening Algorithm; MIS = Mean Item Score
* $p < .05$ **$p < .01$

APPENDIX H – TIME 6 PREDICTOR VARIABLES INTERCORRELATION MATRIX (STUDY 2)

Table A.2 below provides correlations between Time 6 predictor variables used in Study 2 to assess for multicollinearity. Time 6 predictor variables included functional skills (ABAS), socioeconomic disadvantage, sex, age, autism symptoms (ADI-R mean domain algorithm scores), behaviour and emotional problems (DBC2-A total score and subscale scores), and diagnosis of a mental health disorder.

Table A.2. Time 6 predictor variables intercorrelation matrix (Study 2)

	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.	13.	14.
1. Functional skills	-	-	-	-	-	-	-	-	-	-	-	-	-	-
2. Socioecon. disad.	0.23*	-	-	-	-	-	-	-	-	-	-	-	-	-
3. Sex	-0.00	0.07	-	-	-	-	-	-	-	-	-	-	-	-
4. Age	-0.32**	-0.08	0.24*	-	-	-	-	-	-	-	-	-	-	-
5. ADI-R: Social^	-0.78**	-0.12	0.07	0.24	-	-	-	-	-	-	-	-	-	-
6. ADI-R: Communication	-0.83**	-0.14	0.01	0.21	0.70**	-	-	-	-	-	-	-	-	-
7. ADI-R: RRB	-0.28*	-0.15	-0.10	-0.01	0.28*	0.23	-	-	-	-	-	-	-	-
8. DBC2-A TBPS MIS	-0.51**	-0.21*	0.04	-0.08	0.39**	0.43**	0.46**	-	-	-	-	-	-	-
9. DBC2-A Disr. MIS	-0.30*	-0.27*	0.13	-0.10	0.15	0.27*	0.23	0.87**	-	-	-	-	-	-
10. DBC2-A C&A MIS	-0.29*	-0.22	-0.03	-0.09	0.16	0.16	0.47**	0.86**	0.71**	-	-	-	-	-
11. DBC2-A SA MIS	-0.72**	-0.21	0.00	0.05	0.60**	0.70**	0.34**	0.80**	0.61**	0.51**	-	-	-	-
12. DBC2-A Dep. MIS	-0.19	-0.16	0.09	-0.19	0.16	0.03	0.40**	0.74**	0.59**	0.72**	0.39**	-	-	-
13. DBC2-A SR MIS	-0.32**	-0.30*	-0.08	0.06	0.45**	0.34**	0.45**	0.59**	0.36**	0.42**	0.42*	0.40**	-	-
14. Mental health disorder	-0.27*	-0.03	-0.13	-0.01	0.22	0.09	0.25*	0.20	0.08	0.16	0.15	0.26*	0.14	-

Correlation coefficients: Pearson's *r* or Spearman's rho
Socioecon. disad. = socioeconomic disadvantage (Index of Relative Socioeconomic Disadvantage); ADI-R = Autism Diagnostic Interview-Revised; RRB = Restricted and Repetitive Behaviours; DBC2-A = Developmental Behavior Checklist 2 – Adult; TBPS = Total Behavior Problem Score, Disr. = Disruptive; C&A = Communication and Anxiety Disturbance; SA = Self-Absorbed; Dep. = Depressive; SR = Social Relating; MIS = Mean Item Score
^calculated with item 65 (friendships) removed
* *p* < .05   **p* < .01

APPENDIX I – TIME 6 PREDICTORS INTERCORRELATION MATRIX (STUDY 3)

Table A.3 below provides correlations between Time 6 predictor variables used in Study 3 to assess for multicollinearity. Time 6 predictor variables included degree of intellectual disability, socioeconomic disadvantage, sex, age, living arrangements, daytime activity, autism symptoms (ADI-R domain algorithm scores), behaviour and emotional problems (DBC2-A total score and subscale scores), and mental health disorder diagnosis.

Table A.3. Time 6 predictor variables intercorrelation matrix (Study 3)

	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.	13.	14.	15.	16.
1. Degree of ID	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
2. Socioecon. disad.	0.24*	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
3. Sex	-0.03	0.07	-	-	-	-	-	-	-	-	-	-	-	-	-	-
4. Age	-0.38**	-0.08	0.24*	-	-	-	-	-	-	-	-	-	-	-	-	-
5. Living arrangement	0.69**	0.22*	-0.12	-0.29**	-	-	-	-	-	-	-	-	-	-	-	-
6. Daytime activity	0.43**	0.13	-0.04	-0.13	-0.35**	-	-	-	-	-	-	-	-	-	-	-
7. ADI-R Social	-0.69**	-0.13	0.08	0.25*	-0.54**	-0.33**	-	-	-	-	-	-	-	-	-	-
8. ADI-R Communication	-0.79**	-0.14	0.01	0.21	-0.68**	-0.30*	0.72**	-	-	-	-	-	-	-	-	-
9. ADI-R RRB	-0.26*	-0.15	-0.10	-0.01	-0.16	-0.13	0.28*	0.23	-	-	-	-	-	-	-	-
10. DBC2-A TBPS MIS	-0.46**	-0.21*	0.06	-0.08	-0.38**	-0.43**	0.40**	0.43**	0.46**	-	-	-	-	-	-	-
11. DBC2-A Disr. MIS	-0.32**	-0.27*	0.13	-0.10	-0.33**	0.22	0.14	0.27*	0.23	0.87**	-	-	-	-	-	-
12. DBC2-A C&A MIS	-0.30**	-0.22	-0.03	-0.09	-0.19	-0.42**	0.17	0.16	0.47**	0.86**	0.71**	-	-	-	-	-
13. DBC2-A SA MIS	-0.69**	-0.21	0.00	0.05	-0.52**	-0.46**	0.60**	0.70**	0.34**	0.80**	0.61**	0.51**	-	-	-	-
14. DBC2-A Dep. MIS	-0.16	-0.16	0.09	-0.19	-0.09	-0.31**	0.16	0.03	0.40**	0.74**	0.59**	0.72**	0.39**	-	-	-
15. DBC2-A SR MIS	-0.26*	-0.30*	-0.08	0.06	-0.27*	-0.21	0.46**	0.34**	0.45**	0.60**	0.36**	0.42**	0.42**	0.40**	-	-
16. Mental health disorder	-0.19	-0.03	-0.13	-0.01	-0.09	-0.30*	0.21	0.09	0.25*	0.20	0.08	0.16	0.15	0.26*	0.14	-

Correlation coefficients: Pearson's r or Spearman's rho
ID = intellectual disability; socioecon. disad. = socioeconomic disadvantage (Index of Relative Socioeconomic disadvantage); ADI-R = Autism Diagnostic Interview-Revised; RRB = Restricted and Repetitive Behavior; DBC2-A = Developmental Behavior Checklist 2 – Adult; TBPS = Total Behavior Problem Score; Disr. = Disruptive; C&A = Communication and Anxiety Disturbance; SA = Self-Absorbed; Dep. = Depressive; SR = Social Relating; MIS = Mean Item Score
* $p < .05$ ** $p < .01$

Table A.4. Associations between Time 1 predictor variables and Time 6 community participation frequency and variety (Study 3)

Time 1 Variables		Index of Community Involvement			
		Frequency		Variety	
Categorical variables	N	M (SD)	Test statistic	M (SD)	Test statistic
Sex					
Male	67	17.66 (10.04)	$t(80) = -1.10$	6.21 (2.87)	$t(80) = -0.83$
Female	15	20.67 (7.01)		6.87 (2.30)	
Degree of ID					
Severe/profound	12	11.75 (7.39)		4.92 (2.07)	
Moderate	32	18.13 (10.87)	$F(3,78) = 2.84*$	6.16 (3.39)	$F(3,78) = 1.70$
Mild	15	21.93 (7.82)		6.87 (1.73)	
Borderline/Average	23	19.26 (8.53)		6.96 (2.53)	
Continuous variables	N	r		r	
Age	84	-0.11		-0.10	
Socioeconomic disadvantage	84	-0.01		-0.04	
DBC2-P ASA	82	-0.36**		-0.28*	
DBC2-P TBPS MIS	82	-0.07		-0.09	
DBC2-P Disruptive MIS	82	0.12		0.08	
DBC2-P Comm. Dist MIS	82	-0.03		-0.03	
DBC2-P Self-Absorbed MIS	82	-0.27*		-0.24*	
DBC2-P Anxiety MIS	82	-0.06		-0.11	
DBC2-P Social Relating MIS	82	0.13		-0.12	

Pearson's r correlation for continuous variables; independent samples t-test for binary predictor variables (sex); one way ANOVA for categorical predictors (degree of intellectual disability)

ID = intellectual disability; DBC2-P = Developmental Behavior Checklist 2 – Parent; ASA = Autism Screening Algorithm; TBPS = Total Behavior Problem Score; Comm. Dist = Communication Disturbance; MIS = mean item score

* $p < .05$ ** $p < .01$

Table A.5. Associations between Time 6 predictor variables and Time 6 community participation and frequency (Study 3)

Time 6 Variables		Index of Community Involvement			
		Frequency		Variety	
Categorical variables	N	M (SD)	Test statistic	M (SD)	Test statistic
Sex					
Male	67	17.66 (10.04)	$t(80)= -1.10$	6.21 (2.87)	$t(80)= -0.83$
Female	15	20.67 (7.01)		6.87 (2.30)	
Degree of ID					
Severe/profound	21	11.87 (7.44)		4.61 (2.29)	
Moderate	20	20.70 (10.83)	$F(3,78)=7.34**$	7.00 (3.43)	$F(3,78) = 4.71**$
Mild	13	16.38 (6.41)		6.77 (1.96)	
Borderline/Average	26	22.81 (8.65)		7.12 (2.39)	
Mental health disorder diagnosis					
Yes	52	17.31 (10.65)	$t(75)=1.12$	6.23 (3.09)	$t(75)=0.42$
No	25	19.60 (7.05)		6.52 (2.22)	
Living arrangement					
Supported accommodation	33	13.22 (6.64)		5.22 (2.30)	
With family	35	19.89 (10.38)	$F(2,79)=10.57**$	6.80 (3.01)	$F(2,79)=5.11**$
Independently	16	24.93 (7.79)		7.60 (2.41)	
Daytime activity					
No activity	9	13.00 (8.54)		5.00 (2.65)	
Disability specific	51	17.00 (9.25)	$F(2,79)=5.10**$	6.16 (2.77)	$F(2,79)=2.49$
Mainstream	22	23.14 (9.09)		7.27 (2.64)	
Continuous variables	N	r		r	
Age	84	-0.14		-0.10	
Socioeconomic disadvantage	84	0.30**		0.31**	
ADI-R Social/Communication	69	-0.40**		-0.38**	
ADI-R RRB	69	-0.20		-0.27*	
DBC2-A TBPS MIS	79	-0.31**		-0.32**	
DBC2-A Disruptive MIS	79	-0.20		-0.19	
DBC2-A Comm. Anx. MIS	79	-0.18		-0.16	
DBC2-A Self-Absorbed MIS	79	-0.39**		-0.39**	
DBC2-A Depressive MIS	79	-0.19		-0.22	
DBC2-A Social Relating MIS	79	-0.30*		-0.33**	

Pearson's r correlation for continuous variables; independent samples t-test for binary predictor variables (mental health, sex); one way ANOVA for categorical predictors (degree of intellectual disability, living arrangements, daytime activity)

ID = intellectual disability; ADI-R = Autism Diagnostic Interview-Revised; RRB = Restricted and Repetitiv Behaviors, DBC2-A = Developmental Behavior Checklist 2 – Adult; TBPS = Total Behavior Problem Score; *Comm. Anx.* = Communication and Anxiety Disturbance; MIS = mean item score

*p < .05   **p < .01