

**Parent-observed thematic data on quality of life in children with autism spectrum disorder**

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## **Abstract**

Domains of quality of life in children with autism spectrum disorder have not previously been explored and there has been no quality of life measure developed for this population. Our study investigated parent observations to identify the domains important to children with autism spectrum disorder who also had an intellectual disability. Twenty-one parents (19 mothers, 2 fathers) of children with autism spectrum disorder (aged 6-17 years) participated in a qualitative study to discuss their child's quality of life. Thematic analysis using a grounded theory framework was conducted and ten domains emerged in relation to health and wellbeing, capacity to perform and develop skills in daily life, and connections with the community and environment. Unique aspects of quality of life included varying levels of social desire, consistency of routines, and time spent in nature and the outdoors, which are not comprehensively captured in existing measures. Parent observations provide an initial framework for understanding quality of life in autism spectrum disorder and support the development of a new measure for this population.

## **Keywords**

Autism spectrum disorders, neurodevelopmental disability, quality of life, qualitative research, wellbeing, intellectual disability

## **Introduction**

Population-based estimates of the prevalence of autism spectrum disorder (ASD) range from 5.1 to 15.5 per 1000 births (Bourke et al., 2016; Van Naarden Braun et al., 2015). The prevalence is increasing in part due to changing diagnostic criteria and assessment practices (Hansen et al., 2015), but the ability to predict and improve individual outcomes has become increasingly vital. Despite advancements in early detection, therapy and intervention, individuals with ASD remain at risk for developing significant physical and psychiatric problems (Gabis et al., 2005; Mazurek et al., 2013; Salazar et al., 2015). Assessments of quality of life (QoL) are therefore important not only to paint an authentic picture of a child's life, but also to identify areas where support is needed and for evaluating treatment and intervention efficacy to promote successful outcomes.

QoL refers to how an individual perceives and evaluates his or her life experiences (Felce and Perry, 1995) and can be conceptualized by domains that are universal (e.g. emotional and physical wellbeing) or specific to particular populations (e.g. in relation to symptoms associated with a condition) (Stoppelbein et al., 2016). Having a good QoL is important because it is indicative of positive perceptions of overall health and wellbeing as well as satisfaction with life experiences (e.g. having meaningful social relationships). Whilst there are no instruments capturing the areas of life quality that are specific to ASD, QoL has been measured using generic instruments. Children and youth

with ASD without intellectual disability (aged 8-17 years;  $IQ \geq 80$ ) and their parents have reported poorer QoL than their typically developing peers using the generic KIDSCREEN questionnaire (Egilson et al., 2017). KIDSCREEN assesses child QoL across five dimensions: physical wellbeing; psychological wellbeing; parent relations and autonomy; social support and peers; and school (Ravens-Sieberer et al., 2007). Studies using the generic Pediatric Quality of Life Inventory (PedsQL) (Varni et al., 2003) also report lower scores for children with ASD, particularly those with more severe behavioral problems, more depression and anxiety, and lower self-esteem, than aged-matched normative samples (Ikeda et al., 2014). The PedsQL measures health-related QoL in healthy children and adolescents and those with acute and chronic health conditions across four domains of functioning: physical, emotional, social, and school (Varni et al., 2003). However, there may be additional domains of life that are specific to children with ASD, with a recent qualitative study of four children with ASD and ten parents describing that important themes such as preferring to be alone or feelings of anxiety were not represented in the current tools (Tavernor et al., 2013). A condition-specific QoL instrument may therefore be useful for understanding in which areas these children, including those with concomitant intellectual disability, would benefit from additional support.

Qualitative methods have previously been used to articulate a framework of QoL domains for children with Rett syndrome (Epstein et al., 2016) and Down syndrome (Murphy et al., 2017), as observed by their parents. Parent observations enabled coding of the experiences of a wide range of children, including those who were unable to speak or with more severe intellectual disability, and novel domains not previously reported in the literature were identified. The QoL domains for children with ASD have not been explored and parent observations could provide a preliminary framework for understanding a child's QoL. This is important because parent-report informs much clinical decision-making, particularly if age or disability precludes self-report (Davis et al., 2007).

The current study therefore explored parental observations to identify QoL domains important to children with ASD with co-occurring intellectual disability. We also investigated whether different domains would be observed in childhood and adolescence. Findings aimed to support the development of a new measure of QoL for children with ASD.

## **Methods**

### *Participants*

Twenty-three families of children with ASD (aged 6-17 years) who were registered with the Western Australian Autism Biological Registry (WAABR) were invited to participate (Taylor et al., 2013). Two additional families residing in rural communities were recruited through network sampling and were included in our final sample. We were unable to include families who were not fluent in English. Twenty-two parents (two fathers) who were the primary caregivers were interviewed and spoke on behalf of their child with an ASD diagnosis. Three families declined participation due to other commitments and one family withdrew from the study after the interview and did not cite a reason. The remaining 21 interviews were used for analyses.

Recruitment was purposive and theoretically directed until data saturation was reached in order to capture variability within the sample for gender, age, social communication ability, intellectual ability, health comorbidities, other neurodevelopmental problems, and residence by urban or rural location (Table 1). The children (13 males, 8 females) were aged 6 to 17 years and the mean (SD) age of the child at the time of the interview was 10.4 (3.7) years. Each child's clinical diagnosis had been previously verified using the Autism Diagnostic Observation Schedule-Generic (ADOS-G) (Lord et al., 2000). The majority of children in our sample were administered ADOS-G modules 1 or 2 indicating substantial communication and social limitations for their age, and one child with a diagnosis of

intellectual disability was administered the ADOS-G module 3 (Table 1). Co-occurring neurodevelopmental and physical health problems were previously identified on recruitment to the WAABR (Taylor et al., 2013). The mean (SD) age of parent respondents at the time of the interview was 31.3 (4.9) years and slightly fewer than half were born in Australia (48%). All were Caucasian aside from one respondent who was Asian and one who self-reported as “Other” and was born in Argentina, and approximately half had tertiary education (Table 1).

### *Procedure*

A grounded theory approach allowed for the assessment and comparison of different themes in order for domains to spontaneously evolve (Strauss and Corbin, 1990). Parents participated in individual semi-structured stem and leaf phone interviews (Table 2), which explored how their child indicated by any means (e.g. facial expressions, verbalizations) that they were pleased with or challenged by various aspects of their daily lives. At the outset of every interview, parents were provided with a definition of QoL and were told that the study was investigating the domains that were important to their child’s QoL. Consistent with the interview schedule for Rett syndrome, parents were asked probing questions (e.g. ‘How do you know?’) (Epstein et al., 2016) to ensure the child was demonstrating observable evidence of their feelings and to reduce

parents' inaccurate inferences of what experiences their children found enjoyable or otherwise.

Interviews were 30-90 minutes in length and were undertaken, recorded, and transcribed by one researcher with psychology training (AE) who had considerable experience in conducting similar interviews for other groups of parents whose child had an intellectual disability (Epstein et al., 2016; Murphy et al., 2017). Transcripts were sent to participants for first-level member checking (completed by 13/21 (62%)), which gave parents an opportunity to review and edit their responses to confirm accuracy and validate their narratives (Brantlinger et al., 2005). A Consumer Reference Group (CRG) comprising parents whose children with ASD were aged 10 to 41 years met with the research team to review the domains and engage in second-level member checking, whereby parents were presented with interpretations of the interview data to validate researchers' conclusions (Brantlinger et al., 2005). Parents offered further examples of their children's experiences that enriched our understanding of QoL and provided new dimensions to our data (e.g. the importance of their child receiving recognition in day-to-day life: 'Being recognised as being good at something'). This feedback enhanced how we had conceptualized some of the concepts, and parents confirmed our overall pattern of domains as important components of QoL for their children. Ethical approval of this study was provided by the Human Research Ethics Committee at the University

of Western Australia (RA/4/1/6931) and parent caregivers provided informed consent to participate in this study.

### *Analyses*

Interview transcripts were explored for qualitative themes using a grounded theory methodology (Liamputtong, 2009). Data coding was performed by AE using NVivo (QSE International Pty Ltd, 2014). The identification of primary domains as well as elements within those domains was achieved by placing similar codes together under a common theme, continuously comparing these codes, and then re-evaluating themes with new data as it became available. All descriptions of observable behaviors were coded and all codes were classified as equally relevant and important. Interviews and analyses were therefore ongoing until no new themes or “domains” were identified, at which point data saturation was reached and data collection ceased.

Domains were then examined by two researchers (AE, JD), who discussed the interpretation of each domain as well as checked the coding of text from the transcripts. Consensus of the interpretation of primary domains and domain elements was reached through joint discussion. The domains and domain elements were compared for children and adolescents aged 6 to 11 years and 12 to 17 years. Domains were then compared with those in the PedsQL parent-report measure (Table 3) (Varni et al., 2003).

## **Results**

### *Quality of life domains*

*Physical health* included body pain and discomfort; sleep and energy levels; health comorbidities (e.g. epilepsy); and physical fitness. Issues related to gastrointestinal wellbeing such as stomach pain and constipation were frequently reported to affect physical comfort.

Being healthy makes a huge difference to his overall outward mental health. Even disability aside, this is across the board for everyone and it's just more important I think with autistic children ... to recognise how much is down to what's going on with their body first, and then work on what's going on mentally. (Mother of a 7-year-old male, ADOS-G module 1)

She has constipation and problems with her diet. So we need to make sure that we're on top of that and ... that needs to be closely watched every day. And if that's in tune then she's generally happy. (Mother of a 12-year-old female, ADOS-G module 1)

*Behavior and emotional wellbeing* included observable changes in body language and expression which indicated a variety of emotions. Elevated levels of aggression, destruction, or self-injury showed that the child was distressed.

... the last time he got an ice cream ... he runs over to the ice cream fridge and he sort of hits it and just squeals. And he runs really fast to the counter and he expresses everything with his movements and his body language. Then he can't wait to open it and gives me lots of eye contact and he just looks ecstatic. (Mother of an 8-year-old male, ADOS-G module 1)

... last year his best friend left the school. That caused him so much anxiety that he started having incontinence problems. And we were also moving house so he had a lot of anxiety surrounding that ... we learnt that incontinence for him is the way that he expresses his fears and when he's anxious. (Mother of an 11-year-old male, ADOS-G module 2)

Some children also exhibited sensitivities to sensory aspects of their environment (e.g. noise from vacuum cleaners, security alarms) by covering their ears or avoiding areas with known triggers. One parent stated, '... if it's a noisy environment and there is a large group of people, he might get a bit overwhelmed and extra aroused and less likely to become responsive' (Mother of a 9-year-old male, ADOS-G module 1).

Repetitive behaviors including flapping, jumping, rocking, and echolalia were a common way for children to exhibit emotions ranging from 'ultra-excited' to 'anxious or annoyed'.

Lots of smiling and giggling. She tends to jump around a little bit and throw herself down on the mat ... like she'll bounce around because she likes the stimulation, the feedback on her limbs – on her hands and her legs and things. So she'll sometimes join in with some of the songs or as

soon as a song finishes then she'll sing it and I know that she enjoyed it then. (Mother of a 6-year-old female, ADOS-G module 1)

*Relaxation and reassurance* included calming or comforting activities, settings, and strategies to soothe the child which generated feelings of safety and reduced distress.

... the classroom has 30 kids, it might be noisy... so then he's motivated to get that task done and then ... he goes to the break room and he gets sensory time. So they will sandwich him between two large cushions and press on him. They might read a book to him while they do that. They might roll a fit ball on top of him. (Mother of a 6-year-old male, ADOS-G module 1)

Some children sought physical contact from parents (e.g. hugs, massage) to decrease their stress or anxiety. A parent explained, 'We have special time watching [television] at home, we have family time. He likes sitting on the couch between me and his dad, the deep pressure cuddles' (Mother of a 6-year-old male, ADOS-G module 1).

Other children chose solitary activities to reduce outside stimulation and self-manage their responses to stress (e.g. listening to music, retreating to their bedroom for 'downtime'). One parent shared, '... we've got a swing that she can go and take herself on whenever she's feeling stressed out, the vestibular stimulation on the swing helps a lot to calm her down' (Mother of a 12-year-old female, ADOS-G module 1).

*Communication and expression* included the pleasure or frustration in expressing wants and needs or sharing feelings and narratives.

He still has frustrations about his speech and not being able to comprehend and understand things socially. I think he's got it up in his head, he just sometimes can't verbally, it's hard for him to express certain things. And the way that he expresses it, certain ways of explaining things, and you never thought of it that way ... he just makes you smile and think, 'Well that's right!'

(Mother of an 11-year-old male, ADOS-G module 2)

Several parents discussed their child's ability to select a preferred object or activity through verbal exchanges.

So it's a very simple request ... so she would say, 'I want to go swinging', 'I want to go swimming in the pool', 'Can I have the iPad?' or 'Can I have the iPod?'. She will request. And they're pretty much the main ones she sticks with. (Mother of a 12-year-old female, ADOS-G module 1)

Other children utilized non-verbal communication such as gestures or eye gaze. A parent stated, 'If he gets shy, if there's someone else around, he'll pull faces, he'll stick his tongue out, he'll roll his eyes, he'll look all over the place' (Mother of a 6-year-old male, ADOS-G module 1).

*Flexibility and routines* included the familiar and predictable aspects of the children's activities, schedules, and environment. Children differed in their ability to adapt to change. Some children felt safe and thrived on routine, such that sudden changes triggered non-compliance or aggression.

I think for her it's a feeling of stability and regularity. She probably feels the most happiness when she's in control of herself and her environment. Once she's done something a couple of times she's comfortable with it. But if you try to throw a new activity at her it can be very challenging. If it's something totally out of routine, she doesn't deal well without lots of warning.  
(Mother of a 6-year-old female, ADOS-G module 1)

Generally, children were able to better adjust to change when parents prepared them in advance in order to make the experience more predictable.

So when things are going good, he knows what's happening next because he's following a schedule or a routine and it is staying consistent ... not just at home but at school as well... he absolutely functions best when he knows what's happening. So for example if it's a Monday, he knows what time he's got to get up. He knows when he gets up that the first thing he has to do is get dressed. And then after ... it's breakfast. And then after ... it's brushing teeth and combing hair ... then he gets his own bag ready to go to school. It's just trying to eliminate change because change does affect him greatly. (Mother of a 7-year-old male, ADOS-G module 1)

Parents also discussed the challenges associated with their child's ability to stop a preferred activity (e.g. computer games) or to shift their focus away from a topic of intense interest (e.g. their favorite show).

... at the moment we have a laptop that has become broken through use ... it's gone in for repair. And she's got a different laptop now and the screen doesn't look the same and her favourites aren't in the same positions on screen as they were on her own laptop ... that has been such a bugbear for the last five weeks, it's just this constant, 'Black puter, black puter, black puter'. And we say ... 'I'm sorry, the black computer is broken. This computer is working, this is your computer now'. That would go on for hours ... and it's still going on because the black computer isn't back yet. (Mother of a 16-year-old female, ADOS-G module 1)

*Independence and autonomy* included deriving pleasure from learning new things, accomplishing tasks, and achieving goals. Children also appeared satisfied with having some control over aspects of their daily lives (e.g. getting themselves dressed, riding their bike home from school alone).

... his thing that he enjoys more than anything else is if you give him some white goods – a washing machine, a stereo, something – anything with screws and he can just be left alone to take it apart. So that's when he's happiest. No verbal input, no social pressure – just doing his thing and taking things apart. (Mother of a 6-year-old male, ADOS-G module 1)

... achievements that make him feel good about himself ... because he likes achieving at the end of an activity, I think that's also why he picks things like Lego and puzzles and crafts. And I think that's why he enjoys math and spelling and stuff at school as well. Because if he gets it right ... and he gets 30 out of 30, he's pretty chuffed with himself. (Mother of a 7-year-old male, ADOS-G module 1)

Some parents discussed how their children developed independent computer skills, which enabled them to play online games or to search for information about topics of interest. Receiving recognition from others for being skillful and achieving tasks was recognized as an important part of children feeling confident, self-sufficient, and accomplished.

... we'll give her the iPad and she goes in her room and plays with her iPad ... doing YouTube and iTunes and we never taught her that, she went straight into it herself. (Mother of a 7-year-old female, ADOS-G module 1)

... he's not too keen on physically doing sports. But he likes to help, he's good at helping or getting things set up. His voice gets excited and he talks a little louder. And he wants to take over .... (Mother of a 13-year-old male, ADOS-G module 2)

*Social desire* included occasions when the children were happier being left alone to

engage in activities of their choosing. Despite their desire to be included, some children were bullied or actively excluded from social activities with their peers.

I don't really see kids not wanting to play with him ... so he's not being excluded at all. If anyone's excluding him, he's doing it himself by choice, not because he's feeling left out, because he just doesn't know. He feels better being on his own and playing his own games or just watching or whatever he wants to do. (Mother of a 7-year-old male, ADOS-G module 1)

[Things are not good] ... if he's being bullied at the school. I know that there's something wrong because he talks to himself a lot. He needs to be by himself and he sort of talks through in his head what's happened through the day. And he needs time out .... (Mother of a 17-year-old male, ADOS-G module unknown)

Participatory social activities included interactions with family and friends, expressing anticipation of an upcoming event, and the excitement felt when sharing news or achievements with others. Parents discussed how satisfied their children were with the social exchanges they had with other people.

So he really does have this ability to engage with people. Wherever I go in the school everybody knows him. He's just genuinely curious about people ... he's not inhibited in any way. He thinks that the world is full of interesting things and he's just happy to go bowling up to anybody and talk to them about what they're up to ... he's genuinely interested and he will ask questions:

‘What are you doing?’, ‘Why are you doing that?’. (Mother of a 6-year-old male, ADOS-G module 1)

... he has a very close friend that he plays with on the internet. They just laugh all the time and he looks forward to that socialisation. Basically any sort of socialisation where he feels that he’s a part of the group, and it’s all normal stuff really. I think he finds most of his interaction is through games because it’s non-judgemental. People can’t see the way he looks. He does have ... oral dyspraxia. So some people do pick up on that over the net. But I just feel he has a wicked sense of humour, so once people get to know him they like him. (Mother of a 17-year-old male, ADOS-G module unknown)

For many children, feeling included by others (e.g. receiving birthday party invitations) as well as the attention others paid to them (e.g. peers listening to what they have to say) were seen as meaningful social connections.

He loves it if we’ve got family coming around for a barbeque. He gets everybody organised and where they need to be, and he has just got the biggest smile on his face when that’s happening. I think it’s just because he’s got everybody that’s most important in his life in the one room. So I think that’s what’s important about it because obviously he has myself and my wife and his brothers here all the time, but he doesn’t have Nana and Grandad at home all the time ... so when they come around for whatever reason, he gets very excited. (Father of a 16-year-old male, ADOS-G module unknown)

Some children also empathized and supported their peers by defending them during a conflict or by offering understanding and encouragement.

... yesterday apparently, there was a child who has autism in his school. And the teacher was yelling at her to hurry up with her work, literally yelling. And he just said, 'Yelling at her isn't going to make her work faster. She's working as fast as she can'. He stands up for people. And he spoke about that several times last night .... (Mother of a 17-year-old male, ADOS-G module unknown)

*Leisure and recreation* included participation in free-time activities at home and within the community.

I think those activities where she's out and about ... she's gotten great enjoyment from the basketball, going there. And what's been lovely to see is the degree of relaxation she has, which I really was surprised at because it's a very vibrant, busy, noisy environment that she's gone into. It's non-stop, it's coming at her from the ceiling, the people coming down on guy ropes. There's cheerleaders, there's music, there's canons throwing paper out, it's crazy stuff. And she's sitting there with an arm around each carer twirling her hair with her finger and just very happy.

(Mother of a 16-year-old female, ADOS-G module 1)

Children enjoyed physical activities (e.g. swimming, bowling); singing, dancing or listening to music; reading books; screen-time (e.g. computers, television); or creative

and innovative pursuits (e.g. building blocks, drawing).

... she has always been a fantastic swimmer. She used to do lots of swimming; they're addicted to the ocean. But yes, she loves being under water. Maybe the pressure of the water, the blocking out maybe of certain sounds. (Father of a 9-year-old female, ADOS-G module 2)

Some children preferred home-based activities with fewer social interactions and less social pressure.

... if people are putting too much pressure or demands on him or in his space. Or if kids are coming into his space and trying to play with something he wants to play with he can quite often lash out ... when he has no pressure or expectations being put on him and he's just free to roam and do whatever he wants, that's when he's happiest. (Mother of a 6-year-old male, ADOS-G module 1)

*The natural environment* included a demonstrated interest in nature and animals.

Children enjoyed time spent with pets, walking or biking around their neighborhood, and visiting the beach or the zoo.

I have noticed that he's engaging more with her as an animal than I've ever seen before. He's actually looking into her face and he goes, 'Cat meow'. And he puts out his hand to stroke her a bit, even though he may not stroke her, he looks like he's about to ... I've never seen him so

engaged with an animal like that before. Or sometimes if he's just upset and he's not really coming out of it, I've gone and taken him for a walk ... and after we've started walking for a while, the fresh air ... gets to him and he's happy. (Mother of an 11-year-old male, ADOS-G module 1)

These opportunities allowed for contact with various natural elements (e.g. water, grass, sunshine). As one parent described, 'Going out on the boat and seeing the dolphins with the family makes her incredibly relaxed and happy. Anything with the wind in her face makes her very happy' (Mother of a 12-year-old female, ADOS-G module 1).

For some, being outdoors in the fresh air appeared to promote feelings of independence, as the children were able to navigate the world with fewer restrictions.

... we have a property down south and there's nowhere where he's happier than down there. It's the space. I just think he has a sense of freedom down there, which he really enjoys. (Mother of a 6-year-old male, ADOS-G module 1)

*Services and associated outcomes* included support, advocacy, and financial assistance.

Receiving adequate support in school and within the community were identified as important factors promoting the children's skill development.

[His school has] employed an aide for his allocated aide time. His confidence in reading is increasing because he's had this time. His confidence at going to school has increased. And I've got a confident, happy child that seems to be less anxious at school. And no refusal to go to school so it's massive – 'I'm ready to go to school'. (Mother of a 6-year-old male, ADOS-G module 1)

With proper support services and funds in place, parents felt that their children could more comfortably engage in a range of social and recreational opportunities (e.g. provision of one-on-one support for a child wanting to attend school excursions).

... a lot of the schools haven't been so understanding of why [she] does things and so they've been quite tough on her. And that approach has just never worked. Whereas the school that she's at now, they're better at understanding why she does things and understanding her needs. They try harder to communicate with her. (Mother of a 12-year-old female, ADOS-G module 1)

#### *Comparison of domains for age*

All domains were described in interviews with parents of children (6-11 years) and adolescents (12-17 years), suggesting that the domains were applicable across these age groups. Our CRG families, whose children ranged in age, corroborated these findings through discussion of their child's experiences within each domain.

#### *Comparison of domains to PedsQL*

Table 3 lists our ten QoL domains and domain elements mapped against the four PedsQL domains (Physical functioning, Emotional functioning, Social functioning, School functioning) (Varni et al., 2003). Each of the PedsQL domains were represented in our domains, however our findings included additional domains and elements (e.g. relaxation and reassurance, flexibility and routines) not represented in the PedsQL measure.

## **Discussion**

In this qualitative study, we have used empirical means to identify QoL domains observed to be important to children with ASD. As with other children (Solans et al., 2008), health and wellbeing, capacity to perform and develop skills in daily life, and connections with the community and environment were important components of life quality. Similar to children with Down syndrome (Murphy et al., 2017) and Rett syndrome (Epstein et al., 2016), predictable routines and immersion into the natural environment also contributed to the QoL of children with ASD.

The domains that emerged from our data represented the different aspects of disability as articulated in the International Classification of Functioning, Disability and Health (ICF) (World Health Organization, 2001). From the ICF domain of “Body Functions and Structures”, aspects of physical health, emotion and behavior were important

components of QoL for children with ASD. For example, children with poor sleep quality found daytime functioning to be a greater challenge (Cohen et al., 2014; Schreck et al., 2004). Expressions of frustration or anxiety including destructive or self-injurious behaviors were observed, although effective use of communication (Goldstein, 2002) and routines (Sytsma et al., 2001) were able to resolve these to some extent. Being in good health and appearing relaxed were associated with better quality and frequency of the child's social interactions, irrespective of verbal abilities. The themes of communication and routines linked with the ICF domains of "Activities" and "Participation".

Community, activities, routines and the outdoors were also important, linking to the "Environmental Factors" domain of the ICF. Children with ASD often prefer solitary activities and many children favored time spent alone, to unwind and pursue their own interests. However, our data indicated that many children also desired social connections in which they felt understood and included by the people around them. Some children had experienced bullying or exclusion from their peer group, which appeared to hinder their development of social confidence and encouraged social withdrawal. Immersion into community programs (e.g. swimming, bowling) allowed the children to feel more accepted, and provided opportunities to develop new social connections. As for Rett syndrome (Epstein et al., 2016) and Down syndrome (Murphy

et al., 2017), the children were observed to enjoy the various sensory experiences that the outdoors provided and it was often an avenue for them to break away from screen-time with freedom to ‘explore and wander’. The natural environment has the potential to promote mental health and wellbeing in the general population (Mitchell, 2013), yet research is limited on how exposure to nature and the outdoors specifically impacts individuals with ASD.

In previous investigations in cerebral palsy, some domains emerged only for adolescents but not for children, such as those relating to relationships and transitioning to adulthood (Davis et al., 2009; Waters et al., 2005). However, very few children in the cerebral palsy sample were affected by intellectual disability, which may account for the differences between the two age groups. As corroborated by our CRG and also found for Down syndrome (Murphy et al., 2017), the domains and domain elements we identified for those with ASD were similar for both children and adolescents. Based on the current findings, separate measures of QoL for children and adolescents with ASD and intellectual disability do not appear to be indicated.

The PedsQL (Varni et al., 2003) is one of the most commonly used measures in ASD clinical practice and research (Ikeda et al., 2014). Although designed to assess functioning, this instrument captures some of the domains and elements that emerged in

our interviews, such as the absence of pain, adequate sleep, opportunities for learning and activity, and social acceptance. Social connectedness was represented in both the PedsQL and our interview data, although our data revealed more nuances such as the desire to engage in solitary activities. Other domains and domain elements were not included in the PedsQL, including challenging behaviors, the need for routines, pleasure in achievements, sharing enjoyment with others, and participating in activities within the natural environment. Consistent with other qualitative work (Tavernor et al., 2013) and review of available measures for children with ASD (McConachie et al., 2015), our findings suggest the need for a more relevant measure to capture these components of QoL.

Recruitment of families whose children with ASD varied by age, gender, communication and intellectual ability enabled us to achieve thematic saturation of our dataset. The importance of providing families with a platform on which to discuss their children's QoL was evident, given our high recruitment (84%) and member checking (62%) fractions. Parents' levels of comfort and confidence in the interview were made evident by their willingness to discuss sensitive subjects in great depth with the interviewer, whereby parents spoke at length in interviews that often lasted longer than an hour. This preliminary study sought to firstly establish the primary domains of QoL important for children who are characterized by their social communication challenges,

irrespective of their communication abilities. We acknowledge that an important goal of future research would be to capture the QoL views of children with ASD, including those with communication and intellectual impairments, through appropriate accommodations such as the use of AAC (augmentative and alternative communication) devices. Importantly, our data will inform future protocols to systematically investigate child perspectives including those who cannot communicate verbally.

We acknowledge some limitations to our study. Since data was collected solely from parents, including other informants (e.g. siblings, teachers, paid carers) may offer further insight into the child's QoL. The interviews were also conducted by telephone, which may have been a limitation but enabled us to capture rural families. We were unable to include families who were not fluent in English. A higher proportion of parent respondents had tertiary education, which we would expect given that socioeconomic status is generally higher for parents of children with ASD (Leonard et al., 2011).

Although this research was conducted in one state in Australia, the children represented different aspects of ASD and both children and parents came from different settings. Our domains would likely be relevant to other settings, and replicating the study in different areas would be an important task for the future.

Children with ASD are vulnerable to communication, behavioral and learning difficulties with suboptimal participation in our society. Our study provides an empirical preliminary framework as observed by parents for understanding the QoL domains important for children with ASD and intellectual disability, many of whom were unable to speak. We have identified unique aspects of QoL including varying levels of social desire, consistency of routines, and time spent in nature and the outdoors, which are not comprehensively captured in existing measures. There is increasing awareness of the importance of understanding the lived experiences of individuals with ASD. Better understanding of QoL will enable us to capture important elements beyond abilities and functioning. This information will assist clinicians in thinking about how to improve QoL for the children and young people they see. For example, this could include suggestions to encourage outdoor experiences rather than continuing to focus on specific skill sets that are unlikely to improve. Our data contributes to our larger study on QoL in children with intellectual disability. Findings will inform the development of a specific QoL measure that provides an evidence-base from which to plan day-to-day supports for the breadth of QoL issues impacting children with ASD.

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**Table 1.** Characteristics of the children with autism spectrum disorder and their parents.

| <b>Children</b>                                    | <b>N(%)</b> |
|--|-------------|
| Age  |             |
| Middle childhood (6 to 11 years)                   | 13(62)      |
| Adolescence (12 to 17 years)                       | 8(38)       |
| Gender   |             |
| Male   | 13(62)      |
| Female   | 8(38)       |
| ADOS-G module at assessment <sup>a</sup>           |             |
| Module 1   | 14(67)      |
| Module 2   | 4(19)       |
| Module 3   | 1(5)        |
| Module 4   | --          |
| Unknown  | 2(9)        |
| Intellectual disability/Global developmental delay | 14(67)      |
| Health comorbidities <sup>b</sup>                  | 7(33)       |
| Other neurodevelopmental problems <sup>c</sup>     | 4(19)       |
| Family stratification                              |             |
| Simplex  | 16(76)      |
| Multiplex  | 5(24)       |
| Location of residence                              |             |
| Urban  | 18(86)      |
| Rural  | 3(14)       |
| <b>Parent respondents</b>                          |             |
| Country of birth                                   |             |
| Australia  | 10(48)      |
| Other <sup>d</sup>                                 | 11(52)      |
| Education/qualification                            |             |
| No higher than secondary school                    | 4(19)       |
| TAFE/technical certificate                         | 6(29)       |
| University degree                                  | 11(52)      |

<sup>a</sup> Autism Diagnostic Observation Schedule-Generic (ADOS-G) module (Lord et al., 2000) not known for two children, but both were verbal and had received a diagnosis of intellectual disability.

<sup>b</sup> Conditions included obstructive sleep apnea, epilepsy and otitis media.

<sup>c</sup> Conditions included dyspraxia, attention deficit disorder and dyslexia.

<sup>d</sup> Other countries of birth included Argentina, England, Germany, Ireland, New Zealand, Poland, Scotland and Singapore.

**Table 2.** Semi-structured stem and leaf telephone interview questions.

|  |
|--|
| <i>Open-ended questions on the child's quality of life – how you feel that they feel?</i>  |
| <ol style="list-style-type: none"><li>1. What areas of your child's life are important to his/her happiness?</li><li>2. When everything is going great for your child, what sorts of things are happening in his/her life?</li><li>3. When things are not so good, what sorts of things are happening?</li><li>4. What sorts of activities make your child feel good about him/herself?</li><li>5. What challenges him/her?</li><li>6. What is a good quality of life for your child?</li><li>7. What should we do to nurture his/her quality of life?</li></ol> |
| <i>Probing questions for each open-ended question.</i>   |
| <ol style="list-style-type: none"><li>a. How do you know?</li><li>b. What do you mean by that?</li><li>c. Why do you think that is?</li><li>d. What day-to-day coping strategies are useful?</li><li>e. What promotes your child feeling well?</li><li>f. How did he/she react?</li><li>g. What was going on when this happened?</li><li>h. When did that happen?</li></ol>  |

**Table 3.** Quality of life domains and elements from the autism spectrum disorder dataset and their presence in the PedsQL<sup>1</sup> measure.

| ASD domains                      | ASD elements   | PedsQL <sup>1</sup> domain where an item represents the ASD element |
|----------------------------------|--|---|
| Physical health                  | Physical fitness   | Physical functioning  |
|                                  | Eating, gastrointestinal health                          | -   |
|                                  | Pain, discomfort   | Physical functioning  |
|                                  | Sleep, energy levels                                     | Physical functioning<br>Emotional functioning                       |
|                                  | Comorbidities (e.g. epilepsy)                            | -   |
| Behavior and emotional wellbeing | Aggression, self-injury                                  | -   |
|                                  | Anger, frustration                                       | Emotional functioning   |
|                                  | Stress, anxiety, fear                                    | Emotional functioning   |
|                                  | Repetitive behaviors                                     | -   |
|                                  | Sensory sensitivity                                      | -   |
|                                  | Sadness, crying  | Emotional functioning   |
| Relaxation and reassurance       | Calming, relaxing  | -   |
|                                  | Cuddling, physical contact                               | -   |
| Communication and expression     | General communication                                    | -   |
|                                  | Communication aids                                       | -   |
| Flexibility and routines         | Routines, predictability                                 | -   |
|                                  | Fixation, intense interest                               | -   |
| Leisure and recreation           | Physical activity (e.g. swimming, bowling, horse riding) | Physical functioning  |
|                                  | Constructing, innovating (e.g. blocks, drawing)          | -   |
|                                  | Use of technology (e.g. computer, TV)                    | -   |
|                                  | Music, singing   | -   |
|                                  | Reading  | -   |
| The natural environment          | Plant life, animals                                      | -   |
|                                  | Natural elements (e.g. fresh air, sun, sand)             | -   |
| Independence and autonomy        | Independence, autonomy                                   | Physical functioning  |
|                                  | Achievement  | -   |
|                                  | Learning, engagement                                     | School functioning  |
| Social desire                    | Social connectedness, acceptance                         | Social functioning  |
|                                  | Social isolation   | Social functioning  |
|                                  | Support or empathy for others                            | -   |
|                                  | Joint attention, shared enjoyment                        | -   |
|                                  | Social comparison, modeling                              | Social functioning  |
|                                  | Social disinterest, shyness, solitary play               | -   |
| Services and associated outcomes | Services, resources                                      | -   |
|                                  | Achieving desired outcomes                               | -   |

<sup>1</sup> Pediatric Quality of Life Inventory (PedsQL) contains four domains: Physical functioning, Emotional functioning, Social functioning, and School functioning (Varni et al., 2003).

