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Title: Unexpected changes of itinerary – adaptive functioning difficulties in daily transitions for adults with autism spectrum disorder

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Abstract

Adaptive functioning skills, also known as adaptive behaviours, refer to a multifaceted concept defined as behaviours necessary for age-appropriate, independent functioning in social, communication, daily living, or motor areas. In light of the growing population of children with ASD who will eventually become adults, increased understanding of adaptive functioning during the transition to adulthood is of importance, but current research in this area lacks first-hand evidence presenting adaptive skills difficulties among older adolescents and adults with ASD. This article focuses on adaptive functioning skills in daily transitions for adults with Asperger's syndrome (AS) or high-functioning autism (HFA). It draws on evidence from twelve interviews with individuals on the autism spectrum age 16-43, and two focus groups with eight family members of people affected by ASD. Particular emphasis is placed on impact of adaptive functioning difficulties on wellbeing and quality of life for adults with ASD. Grounded theory approach has been used to analyse gathered data. Interviewees reflected on daily challenges associated with unexpected changes in routine, sensory difficulties and social interactions. These in turn had an impact on their adaptive functioning skills by introducing complications in the process of making transitions between different contexts and decreasing interviewees' ability to tackle challenges of daily life. Importance placed on societal expectations towards meeting bespoke standards and conforming to norms ruling the structure and interactions of daily life were also widely discussed. Frequently such expectations did not allow for factoring in the developmental nature of ASD and related difficulties, which as a result triggered additional complexity in managing daily transitions for adults on the spectrum. Further research addressing adaptive functioning skills in daily transitions for adults with ASD is needed.

Keywords: autism spectrum disorder, Asperger's syndrome, high-functioning autism, adults, adaptive functioning difficulties, daily transitions

Introduction

Autism spectrum disorder (ASD) is a lifelong developmental disorder, characterised by impairment in social interaction and communication, stereotyped and restricted patterns of behaviour, activities and interests (Boucher 2009; Howlin and Moss 2012). Symptoms may include idiosyncrasies in speech and language, inappropriate affect or social behaviour, problems with non-verbal communication, and uncoordinated motor movements (APA 2000, 2013; Boucher 2009). In addition, people with ASD may be overly dependent on routines, highly sensitive to changes in their environment, or intensely focused on inappropriate items. Various features associated with the disorder fall on a continuum, with some individuals showing mild symptoms and others experiencing much more severe difficulties (Rydzewska 2013; Volkmar et al. 2014; Rydzewska and Pirrie 2015).

The body of evidence concerning characterising ASD during childhood and adolescence is significant, but studies examining adults are scarce (Edwards et al. 2012). In addition, research on transitions for adults with ASD is commonly concerned with transitions from children's to adult services (e.g. Friedman et al. 2013; Cheak-Zamora and Teti 2014) or transitions traditionally seen from a perspective of age and life stage appropriate developmental tasks such as gaining employment or

entering higher education (e.g. Davis 2009; Hendricks 2009; Schall et al. 2012, Friedman et al. 2013; Alverson et al. 2015). Such studies frequently focus on difficulties with being in a group care setting for the first time, e.g. lack of knowledge on expectations for such settings, social skills for engaging in more appropriate behaviours or communication skills for expressing emotions in appropriate ways (e.g. Hendricks 2009; Smith et al. 2012a; Friedman et al. 2013). Studies discussing challenges associated with daily transitions, and adaptive functioning difficulties in adults with ASD in particular, are still relatively rare (Smith et al. 2012b; Duncan and Bishop 2013; Hus Bal et al. 2015; Matthews et al. 2015).

Adaptive functioning skills in daily transitions in ASD

Adaptive functioning skills, also known as adaptive behaviours, refer to a multifaceted concept defined as behaviours necessary for age-appropriate, independent functioning in social, communication, daily living, or motor areas (Matson et al. 2009). Adaptive behaviour is defined by typical performance, rather than ability (Sparrow et al. 2005 cited in Matthews et al. 2015). The latter means that adaptive functioning can be lowered even when cognitive functioning is average, making it necessary to separately address adaptive skills in interventions for individuals with ASD (Klin et al. 2007).

Recent reports suggest that strong adaptive functioning skills are associated with optimal outcomes for adults with ASD (Farley et al. 2009 cited in Matthews et al. 2015). Patterns of negative correlation between age and adaptive functioning and cognitive functioning advantage widening with age have been found in ASD (Klin et al. 2007; Perry et al. 2009; Kanne et al. 2011). Existing research also shows that development of adaptive skills appears to stagnate in children with ASD and mild or no cognitive impairment in comparison to typically developing peers (Kanne et al. 2011). Studies examining adaptive functioning in adults with ASD and no cognitive impairment show that daily living skills (DLS) (e.g. meal preparation, money and time management) age-based standard scores are an area of relative strength when compared to the communication and socialisation standard scores (Farley et al. 2009; Matthews et al. 2015; see Klin et al. 2007 for exception). In adolescents, however, DLS standard scores do not differ significantly from communication and socialisation standard scores. This age group also shows higher communication and socialisation

standard scores than young adults and adults (Matthews et al. 2015). Previous studies of children and adolescents with ASD also report a relative weakness in socialisation compared to communication and DLS (Klin et al. 2007). This may be often driven by the fact that individuals with ASD without cognitive impairment have or develop age-appropriate verbal skills such as articulation, grammar, and semantics, despite atypical non-verbal communication (e.g. prosody), pragmatic language abilities, and social skills. As Matthews et al. (2015) suggest, if difference between the communication and socialisation domain is smallest in the learning disability group, this may suggest that the relative disadvantage in socialisation is more pronounced in cognitively able individuals with ASD.

Whilst DLS continue to develop post-adolescence in individuals with ASD, the development of age-appropriate communication and socialisation skills (Smith et al. 2012; Matthews et al. 2015) and improvement in symptoms and behaviours related to ASD (Taylor and Seltzer 2011) appear to slow with age. This pattern of adaptive functioning across age groups could be correlated with the reduction in clinical and educational support experienced by people on the spectrum, especially those without cognitive impairment, as they make their transition to adulthood (Taylor and Seltzer 2011; Rydzewska 2012; 2013).

Promoting development of adaptive functioning skills and employment may reduce the lifetime costs associated with having ASD, as well as contribute to the individual's wellbeing (Knapp et al. 2007). In light of the growing population of children with ASD who will eventually become adults (e.g. Rydzewska et al. 2016), increased understanding of trajectories of adaptive functioning skills and predictors of outcomes in this area can provide insights into intervention targets that will help promote functional independence in adults with ASD, particularly during the transition to adulthood, and especially if adaptive functioning truly stagnates with age.

Whilst the theory of emerging adulthood (Arnett 2007; 2011) was conceptualised in reference to typically developing populations to differentiate between this time period and adolescence and adulthood, this life stage may also be qualitatively distinct for individuals with ASD. Emerging adulthood occurs roughly between the ages of 18 and 25 years and is characterised by heterogeneous developmental trajectories. For individuals on the spectrum, the transition from secondary or further education into

adulthood marks a loss of services, which can further protract and complicate this process (Rydzewska 2012). Whilst young adult years are often synonymous with adjustment to new settings and roles, difficulty adapting to change is an inherent feature of ASD at any age. Therefore, additional complexities and difficulties with adaptive functioning in a prolonged process of transition to adulthood are to be expected.

New challenges may arise with taking on greater or sole responsibility for various daily activities such as preparing meals, getting ready for the day, travelling to a place of employment, running errands or tending to tasks at work. Such daily routines mark the rhythm of the day by punctuating the transient points between everyday activities, physical environments and social contexts such as work, school and social life. For people with ASD, these frequent transition points can be marked with difficulties in coping with unexpected changes in routine, physical, social or sensory environment (Matson et al. 2009). However, there is lack of evidence presenting first-hand accounts of adaptive skills difficulties among older adolescents and adults with ASD. This article focuses on adaptive functioning skills in daily transitions for adults with Asperger's syndrome (AS) or high-functioning autism (HFA)¹. It draws on evidence from twelve interviews with individuals on the autism spectrum, and two focus groups with eight family members of people affected by ASD.

Methodology

Twelve adults living in seven different local authorities in Scotland were interviewed for this study on the grounds that they had a formal diagnosis of AS or HFA. All interviewees met the diagnostic criteria for ASD defined in DSM-IV-TR (APA 2000). Time and resource restrictions determined the age of participants with ASD, who consisted of two subgroups of adults of 16 years of age or older and 25 years of age and above. This design, to some extent, provided a comparison of different experiences of transitions and changes in life expectations over time. Each age group numbered six individuals with ASD. The age range of all participants was 16-43; hence higher than originally expected since emerging adulthood and the process of transition to adulthood are normally defined as phenomena related to individuals in

¹ All research participants had met diagnostic criteria for ASD defined in DSM-IV-TR (APA, 2000).

their teens and twenties (Bee and Bjorklund 2008; Furlong 2009; Arnett 2011). Such wide age range of participants could be reflective of the complexity of transition to adulthood for people with ASD, for whom the stage of emerging adulthood could extend even up to their middle adulthood (Rydzewska 2012).

Eight relatives of adults with ASD were also interviewed for the purpose of this study. These interviews were organised in two focus groups and included family members who were not related to interviewees with ASD. Some interviews with adults with AS or HFA were carried out in the presence of close family members, or in one case a service provider, others separately. Eleven professionals working with adults with ASD across Scotland also took part in this study, but findings from this stage of fieldwork are not reported in this article.

Purposive sampling was chosen to ensure participation of autism professionals from three broad sectors of service provision: education, employment and community living and integration (Cohen et al. 2007; Flick 2009). These sectors emerged when reviewing relevant literature on transitions to adulthood for people with ASD (Wehman et al. 2009). Contacts made with service providers were used to gather data for the second stage of the study, which included semi-structured interviews with participants with AS or HFA and focus group interviews with relatives of people on the spectrum. Snowball and volunteer sampling was chosen for this stage of the project (Cohen et al. 2007; Flick 2009).

Qualitative, naturalistic methodology provided the means to examine the effect of contextual variation on different transition experiences. A grounded theory approach was then adopted to analyse gathered data (Oktay 2012; Rydzewska 2013). The underlying assumption was to locate the phenomena of human experiences within the world of social interactions (Grbich 2009). Both research methodology and theory emerging from the gathered data developed gradually as data and interpretations accumulated. Findings from twelve semi-structured interviews with adults with ASD and two focus group interviews with eight relatives of people on the spectrum are presented below.

Pursuit of routine and structure

Transition to adulthood can prove difficult for any adult due to new tasks, duties and increased level of responsibility interwoven with this life stage. There are, however, daily aspects of adulthood, which are not traditionally perceived as particularly demanding, but may prove so for individuals on the spectrum. These aspects may include mundane activities such as household chores or getting ready for work. As one interviewee with ASD, Robert [age 34] described, tending to his wardrobe or trying to be punctual could be a potential source of heightened anxiety or stress. He also commented on lack of support with such difficulties despite having a formal diagnosis of ASD.

Robert: And not a lot of students can say they have the problems which I have in forming a kind of functional routine or the problems I have in doing the things that I need to do to live an ordinary life. These things are still with me and I've not had help with them. Things like making sure I've always got clean clothes and the right clean clothes. It's just the mainstay things that would...

Researcher: Paying the bills?

Robert: Paying bills, yeah. Remembering to be on time...

Sense of routine seemed particularly important for the majority of interviewees with ASD. Some of them stated that this matter was strongly linked with different sensory problems they experienced. Owen [age 33] stated he would normally own a set of several simple black t-shirts and similar trousers, which would significantly simplify, thus improve, his experience of deciding what to wear every morning. Nicole [age 40] established a very elaborate bedtime routine to ensure she would sleep well throughout the night. John [age 43] wore shorts for the greater part of the year as he had a particular difficulty dealing with textures of certain fabrics and could not endure putting on full-length trousers. Robert [age 34] described his meticulous routine of preparing meals created with an intent to decrease the level of stress and anxiety associated with the activity.

Having meals on time is something quite difficult as well, but I've developed a routine, a system for eating. When I was doing my volunteer jobs, I had a very orderly diet. I had the same thing every day basically. A breakfast of cold porridge, and bananas. A lunch of bulgur wheat and salad. And a dinner of bulgur wheat and salad. And I was having three meals a day. I could make all of these meals up within a couple of minutes. There's only one or two ingredients, so I don't start getting anxious because I'm mixing too many

things together. And I'm fed and it's nutritious (...) And also, sleeping is always a problem. It's a big problem for me. I can be doing everything right, eating at the right time, getting up, doing something during the day, and still have nights where I only get one or two hours of sleep. The routine is something I don't have at the moment, and want to get.

[Robert, 34]

Other respondents, especially parents of adults with ASD, feared that some difficulties, for example mental health problems, experienced by their adult children were partly associated with absence of an established routine. In some cases, unemployment resulted in lack of external incentives for structuring their day or scheduling regular activities. Other parents added that their children felt excluded by their peers in a vocational or educational setting because of their strong preference for routine, which was often perceived as an eccentricity. One parent, however, whose adult son worked as an academic, stated the contrary, adding that his son spent most of his time in an environment where preferences for routine and individuality were common. Structured, solitary nature of his profession allowed for creating a daily routine that would suit his autistic traits.

He works very strange hours. It's quite a solitary job. It's very solitary. He doesn't go to work until 12 o'clock and he works until eight. He doesn't go to bed until three. I suspect the place is full of people who are like him and who are smart and focused. He's very smart (...) I'd imagine it's a very structured environment. I think, basically, he's given a job, he does it and someone else checks it or he checks somebody else. It's done like that. It's not really them working together, as far as I understand. It's not interpersonal relations.

[Simon, parent]

‘Background level’ commonly known as sensory difficulties

In recent years, more has become known about autism-related difficulties with processing everyday sensory information, such as sounds, sights and smells. They can have a profound effect on a person's daily life (Leekam et al. 2007; Lane et al. 2010; Tomchek et al. 2014). Whilst in literature these problems are often referred to as sensory integration difficulties, or sensory sensitivity, during interviews with adults on the spectrum, an analogy of a ‘background level’ emerged when discussing one’s sensory environment. A female interviewee, Nicole [age 40] explained in detail the profound impact of sensory difficulties on her everyday life.

I suppose maybe it's a bit like listening to speech on headphones. The volume setting '3' works perfectly when you listen at home, but if you are in a busy street with buses and trucks and road works and people all round, you won't be able to hear much, and won't be able to understand the small bits you can hear, or think you hear. My ability to function, and specifically to be organised, is dependent on what I call my 'background level' which in turn is determined by things like whether I've had to get a bus recently (they upset me a lot) or whether the weather is doing certain things or if the school next door is having the dinners that smell horrible or if next door is vacuuming for a whole hour or if I know I must bathe but don't want to or... or... or... And none of it is realistically within my control – and if the 'background level' is too high then any requirement to be organised will basically result in a meltdown, i.e. me crying in the corner under something and rocking. It's almost always happened (...) I will periodically end up rocking behind a table or the dustbins or under a desk or between parked cars, anywhere I can tuck myself in and feel safer.

[Nicole, 40]

Such difficulties had not only thwarted Nicole's ability to follow her everyday routine, but also had a far-reaching impact on her mental and physical health. Whilst still in higher education, Nicole suffered from severe mental health and substance abuse problems. Nicole's own interpretation and reflections on causes of these problems included constant change of routine and living environment, which exacerbated her difficulties. With time and life experience, Nicole had gained more insight into her problems.

I don't have any problem with new people, but I've got... it's been slightly moved sideways and I have a big problem with new places. Unfamiliar places are really, really frightening. I was sad about that once and my Dad said, 'but you went away, you went to university and (...) that went OK', and I just gaped at him and said, 'which part of two mental breakdowns, massive clinical depression, slicing myself to bits was so calming, and alcoholism so bad that I had a stomach haemorrhage at 23, which bit of that would come under the classification of doing OK', and he kind of went, 'oh', and he had sort of forgotten all of that happened, and I'm fairly sure now that part of that was because every couple of years I was relocating to another part of the country with not just a few new people, but hundreds and hundreds of new people, an entire university full of new people.

[Nicole, 40]

Another interviewee, Owen [age 33] also stressed an enormous physical and mental strain caused by various visual, tactile and auditory stimuli. Owen's wife, Rebecca, who was present during the interview, admitted she had not realised the severity of Owen's sensory difficulties. During the interview, it was particularly interesting to observe their gradually growing mutual understanding of the fact that

certain daily aspects of their life together were dictated by and centred on Owen's sensory difficulties.

Researcher: *Did you suspect Owen might be on the spectrum before he actually got the diagnosis?*

Rebecca: *No. We never did because... that's really interesting. I was quite interested post diagnosis in the things he started telling me about [like] daily emotional anxiety, sensory experience. I had no idea. I mean he may have mentioned some things like, 'Oh, her face looks funny on the TV'. Now I didn't realise it meant her face to him was like...*

Owen: *I see it as decoupage as I see it like stacked wrongly on top of each other.*

Rebecca: *I didn't realise that it was what it was.*

Owen: *Maybe I wouldn't say anything to you because you don't wear too much makeup. When someone wears a lot of makeup, I would just see the layers of makeup. Just a mask. So yeah I would see layers. Separately and together. Like a clown.*

I'm realising my senses kind of being a little bit different. Like hearing movement. Feeling sound. I feel sound. I can feel sound. I didn't realize that was different before (...) Sometimes I have total sensory overlap. It could be lights, it could be sound. It could be touch. One of my senses would just become so heightened it'll be as if I'm sitting right in the middle of a hurricane. Myself and Rebecca could be downstairs and we could just be chatting, then all the different types of noise become a hurricane and it's just immense and fast and sights can be too much as well. I can see too much, everything just rushes in. A huge crating tilt. Sometimes I get a ton of motion where I start drawing massive [inaudible] getting bigger and bigger. I start feeling it on my skin. I can feel that bigger and bigger and it's all consuming. And it's just all my senses going wild.

[Owen, 33]

As each individual can be affected differently by problems with perception and organisation of sensory stimuli, appreciating the impact of such difficulties can be challenging, but is of utmost importance when conducting research with and about people with ASD and bringing elements of the unknown and unexpected into their daily routines. My understanding of these difficulties grew with time by listening to individual stories as well as meeting my interviewees on more than one occasion. Encounters with research participants allowed me to fully comprehend and appreciate their need for my modifying or carefully choosing the sensory environment when conducting interviews. Meetings were arranged in relatively quiet locations, as noise was one of the main factors altering negatively the 'background level' for many of my interviewees. However, in some cases, unexpected changes of circumstances or

events halted all my best efforts to avoid such disturbance and minimise the stress element of an interview situation.

Well noise, this in particular [very loud background noise coming from a nearby building site] is quite troublesome, but I can block it out a lot of the time, and a lot of the time I can just ignore it, but there are times when I can't ignore it. And sometimes, even the noise in the supermarket is too much.

[Robert, 34]

In addition, impact of sensory difficulties on interpersonal relationships was also discussed. Nicole [age 40] explained that she usually did not accept invitations to dinner parties, as she was rather specific about texture and flavour of consumed food. Since she was aware that it could be potentially bothersome for the hosts, she preferred avoiding putting anyone in a difficult position of having to comply with her dietary routine. This and other similar learned behaviours may at first seem positive, in so far as the feelings of others are spared or a risk of any awkwardness is minimised in a social situation. However, they can also be a contributing factor in social isolation of people with ASD. The focus of such learned behaviours seems to be on people with ASD learning to adapt, and not others learning to understand or accept people with ASD.

Impact of social interaction difficulties on adaptive functioning

Difficulties with understanding, initiating or maintaining interactions with others in different contexts such as employment, education and personal life are common in ASD. People with ASD may also have difficulties with recognising the difference and variation in intimacy in interpersonal relationships, which can make daily transitions between contexts of work, school or home environment increasingly difficult. Boundaries between concepts of friendship and acquaintance can become even more blurred if they are inclusive of relationships established and maintained in virtual worlds.

Understanding behaviours of others as well as explaining one's own reactions can also prove a challenge. Interviewee with Asperger's syndrome, Duncan [age 26] identified psychology as one of his least favourite subjects in college, as he was unable to distinguish between more complex or less common emotions and feelings.

He was forced to learn their names and meanings by heart; hence to reduce a usually intuitive process of comprehending abstract concepts to a technical approach of memorisation. Another interviewee with ASD, Robert [age 34] found fine literature very informative when studying mechanisms of human behaviour.

I think for the summer I went abroad with my dad and this was when I was about 14 and I read a large part of the dictionary and Russian writers like Dostoyevsky, Crime and Punishment, and then I started reading, Anna Karenina, and it was amazing. I took a lot of human behaviour from the Dostoyevsky. You know like the way he would describe a room and people's little mannerisms that they displayed for what they thought. How people don't always mean what they say and how sometimes people mean to say one thing and mean something completely different. It was all really fascinating. It was as if I had a tutor there sitting explaining and telling me everything about what people do.

[Robert, 34]

Mark [age 21] added how frustrating it was for him to interact with people who did not have a full awareness or understanding of the difficulties he experienced.

It's also about the relationships with other students. Sometimes... and I have made friends, but there are some of them who don't understand how I operate, how I function and that gets me going.

[Mark, 21]

Hidden nature of ASD makes it increasingly difficult for people on the spectrum to be met with understanding and many simply resign themselves to being misunderstood or excluded from certain social situations. Raising awareness of ASD manifestations in everyday life can play an important role in alleviating such situations and challenging common misconceptions. Some of the ASD symptoms manifested especially in early childhood, such as lack of understanding of widely accepted social norms, may often get misinterpreted and be taken for displays of impoliteness or even selfishness. What is perfectly understandable for some may be a peculiarity for others. Having autism might mean that there is a great deal of honesty and openness about identifying aspects of everyday life that most people would find incomprehensible or illogical, but would not otherwise admit.

When I was six or seven, my school friends would phone up and say, 'oh hello, it's Jane. Do you want to come to tea on Saturday?' and I would say, 'no, not really', and put the phone down and mum and dad would have to sort of run out into the garden and bring me back and make me phone them up, and I never understood why. If I didn't particularly want to go round someone's

house for tea on Saturday, I was supposed to accept and go. Why go somewhere if you don't want to? That never made sense to me and they just thought I was incredibly rude and ill-mannered and kept trying to make me be more polite.

[Nicole, 40]

Managing a social life alongside work or education also proved challenging for some interviewees on the spectrum. Neil, father of a teenage girl with AS, reflected on the fact that it was difficult for Mary to balance her personal life and college education. Making frequent transitions between these different aspects of everyday life was overbearing for Mary and would often lead to a crisis point. Another difficulty for Mary was to accept her diagnosis and her reluctance to do so would often stop her from attending some of the activities organised for a local ASD community. Mary's strong sense of awareness of difference between her and other peers without ASD also deprived her of sense belonging to any mainstream social circles.

Mary would never consider an Asperger's group. It's like beneath her sort of thing. Daniel [Mary's brother with autism] is the exact opposite. He would go and it's things he's interested in, not people. Mary is the exact opposite and so she can't accept herself.

[Neil, parent]

Sensory difficulties or problems with accepting the diagnosis were not the only factors identified as obstacles to building a satisfactory social life. Other interviewees with ASD also mentioned how tiring it was for them to succumb to social pressure of going out, especially when it involved alcohol consumption. Some of them were prone to developing addictions, so they found it particularly difficult to socialise with people whose company would be unavoidably linked with substance use. Others were simply not interested in partaking in such activities.

Peter reflected on his former lack of interest in socialising when at university, as he did not find the activity dignified enough. He added that with time his perception has changed and he started appreciating such pastimes more. He also mentioned that he still found it most enjoyable and easiest to spend time with younger people, especially children, because he felt more accepted by them. Children's natural trustworthiness, spontaneity, literality and tolerance made him feel less judged on the

merit of his awkward behaviours and mannerisms. He felt a strong connection to his friend's son who had also been diagnosed with AS.

There is kind of an age gap between my friends. Like if you make your friends just a few years younger it's a bit more comfortable. As I got older, the age gap got bigger and bigger. I get on very well with primary school kids because there is a certain connection on a certain level. Because they don't quite know what I should be like so they take me like I am. One of my friends... one of his sons has just been diagnosed with AS. (...) So I feel a connection with him and... I've been there all his life. I'm like uncle Peter to him.

[Peter, 37]

Building intimate relationships was also identified as challenging by interviewees with ASD. Two out of twelve participants with ASD were married at the time when this study was conducted; three other interviewees were in relationships. Both heterosexual and homosexual orientation was identified amongst the interviewees. Parents of adults with ASD expressed their strong desires for their children to find life partners, but some also voiced their opinion that being in a relationship with a person with ASD required a great amount of patience and understanding of the specific difficulties experienced by people on the spectrum. Some single interviewees with ASD were not sure if they would like to be in relationships, others did not feel comfortable enough to have such intimate interactions with others. Some felt they did not know how to behave in such situations. Reasons for not entering an intimate relationship were rather varied and complex and having a diagnosis of ASD was not identified as a deciding factor.

I think I never really knew the right thing to do around women or the right thing to say. And I had girlfriends when I changed schools when I was about 16, 17 years old. I had a couple of girlfriends in school and I got along well with a lot of other girls, not really sort of in any sort of significant or meaningful way. I met a few girls when I was at university at nightclubs but nothing lasted very long (...) but it's difficult to say really how much of problems in that area is due to ASD and how much is due to the family. Because I don't think the environment I grew up in was healthy in any way at all. As far as I knew, my mom and dad hated each other or my dad hated my mom and my mom rather absurdly maintained still to love him for a long time.

[Robert, 34]

Discussion

Autonomy is essential in several important areas of life, including problem solving, decision-making, goal setting, as well as obtaining a realistic and positive

self-image (Nota et al. 2007). Expressing personal preferences, making autonomous decisions based on those preferences, and assuming personal responsibility for the course of one's choices are expressions of freedoms that are assigned significant value in market-oriented societies. Acquiring adaptive functioning skills allows for developing a repertoire of behaviours necessary for age-appropriate, independent functioning in various domains of adult life (Matson et al. 2009). For people on the spectrum, difficulties with processing sensory stimuli or deciphering meanings of social aspects of life can add to complexity of learning such behaviours necessary for autonomous functioning, thus making daily transitions in ASD increasingly challenging.

As discussed in this article, unexpected changes in routine or sensory difficulties associated with making transitions between different contexts decreased interviewees' ability to tackle challenges of daily life. Societal expectations towards meeting bespoke standards and conforming to norms ruling the structure and interactions of daily life often did not allow for factoring in the developmental, hidden nature of ASD. The latter triggered additional complexity in managing daily transitions for adults on the spectrum.

A sense of routine seemed particularly important for most adults with ASD. Parents of adults with ASD feared that certain challenges, such as mental health problems, experienced by their children were partly caused by lack of routine. In some cases, strong preference for routine in a vocational or educational setting led to peer exclusion. Support with daily aspects of living with ASD and general awareness of the disorder was highlighted as a priority area for service provision planning.

Interviewees also reported on the significant impact of sensory difficulties, which often led to increased levels of anxiety and a range of challenges with social interactions. As shown in previous research, difficulties with socialisation further affected adaptive functioning in adults with ASD (Matthews et al. 2015). Most participants tended to have few close friends rather than wider social circles of acquaintances. Parents voiced their concerns about their children's difficulties with forming intimate relationships and recognising the variation in intimacy in different interactions.

Several interviews disclosed participants' lack of acceptance of their identity as an individual on the spectrum, which distanced them from the local autism community. Strong sense of awareness of differing from peers prevented some adults with ASD from socialising. Others reflected on succumbing to social pressure to do so regardless, which often led to problems with substance use or poor mental health. This in turn made transitions between different social circles increasingly difficult, which as a result added further to the sense of exclusion.

Whilst sense of belonging and social acceptance are integral to obtaining a realistic and positive self-image (Nota et al. 2007; Wehman et al. 2009), for people with ASD this concept might be determined to a large extent by personal preference for routine or individual challenges posed by sensory and social interaction difficulties. Given that such challenges dictate the rhythm of daily lives of adults with ASD, it would seem that there is a significant discrepancy in constructing the current notion of autonomy, in that it does not allow for free expression of individual perspectives or preferences in one's closest environment despite adults with ASD being expected to do so when making life choices.

The reduction or loss of stimulating settings or interventions may truncate further the developmental trajectory of age-appropriate adaptive functioning skills in adults with ASD. Age-appropriate skills and behaviours for adults are nuanced and may be especially difficult to master in the absence of direct support. The data presented in this article did not include detailed information on clinical and educational support received by interviewees with ASD; hence it was not possible to draw any firm conclusions. However, availability and suitability of service provision for adults with ASD can have a lasting impact on general health as well as family life and relationships. Uneven developmental profile of individuals with ASD can make it increasingly difficult for service providers to evaluate their support needs and tailor transition planning accordingly. Nonetheless, the developmental element to all impairments in ASD ought to be at the core of transition planning, as even the seemingly insignificant aspects of daily journeys through various contexts can pose difficulties for people on the spectrum regardless of their age and gender.

In line with current social policy, the trend is for people with a range of disabilities to stay in independent accommodation, but to remain supported to an

extent that is dependent on the individual's level of functioning and abilities (Scottish Government 2011; 2013). Existing legislative framework recommends similar approach in relation to flexible working (Scottish Government 2011; 2012). Minor adjustments and awareness of difficulties within various contexts are often the main type of support needed in making daily transitions, but manifestation of ASD in adults is still relatively poorly understood. Increased independence for adults with ASD may be achieved through interventions that target adaptive functioning skills, start early in childhood and persist throughout the lifespan.

Conclusions

In summary, amongst the likely reasons behind the continued poor outcomes for adults on the spectrum are insufficient professional attention and understanding of trajectories of adaptive functioning skills, predictors of outcomes in this area and intervention targets that will help promote functional independence in adults with ASD, particularly during transition to adulthood; insufficient awareness of the developmental nature of ASD and its associated difficulties; a general lack of understanding as to the potential for adults with ASD to be employed, active, and contributing members of their communities; a one-dimensional notion of autonomy as well as transition norms and approaches lacking in relevance. The above matters do not focus directly on challenges of living with ASD. Instead, the potential of adults on the spectrum to manage their daily transitions successfully seems to be limited to a great extent by the systems charged with supporting them rather than by the challenges directly associated with their diagnosis.

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