Risk behaviours in transition to adulthood for people with autism spectrum disorder.

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ABSTRACT

This article explores risk behaviour in adults with a diagnosis of Asperger's syndrome (AS) or high-functioning autism (HFA) during the transition to adulthood, drawing on interviews with twelve individuals and on two focus groups comprising members of other families affected by autism spectrum disorder (ASD). The authors examine the subtle interplay between engagement in a variety of risk behaviours and the health and wellbeing of particular individuals with ASD. Feelings of anger, hopelessness and self-harming were common responses to bullying and pervasive difficulties with social interaction. There appears to be no clear causal relationship between risk behaviours and transition, which is characterised by protracted and complex period of identity formation. The current orthodoxy of service provision emphasises the importance of integration with the local community, irrespective of the challenges this may present to people with ASD. There is scope for further elaboration of the concept of 'emerging adulthood' in relation to people with disabilities in general and people with ASD in particular.

INTRODUCTION

> Nobody realises that some people expend tremendous energy merely to be normal
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> (Camus, 1998, p. 23)

The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (APA, 2013) defines the term autism spectrum disorder (ASD) as being characterised by communication deficits, such as responding inappropriately in conversations, misreading nonverbal interactions, or having difficulty in forming friendships. In addition, people with ASD may be overly dependent on routines, or highly sensitive to changes in their environment. As the use of the word spectrum implies, some individuals experience mild difficulties while others have more severe problems. Moreover, these difficulties can be more or less pronounced at

different life stages. The transition to adulthood can herald a period of great uncertainty for anyone, but especially for people with ASD. These difficulties are compounded for people with ASD who are deemed to be 'high-functioning', as expectations for this group may be unrealistically high (Howlin, 2004).

This article focuses on risk behaviour in adults with a diagnosis of Asperger's syndrome (AS) or high-functioning autism (HFA) during the period of transition to adulthood (Rydzewska, 2013)[2.] It draws on interviews with twelve individuals who had experienced or were experiencing a prolonged period of 'emerging adulthood' (Arnett, 2005); and on two focus groups with eight members of other families affected by ASD. Difficulties with social communication and interaction can lead to social isolation and feelings of self-rejection. Moreover, a lack of awareness and understanding of social norms can result in lower self-esteem or in seeking social approval from deviant groups, both of which have been linked with predisposition to risk behaviours (Wild *et al*., 2004). The focus of this article is on participants' understandings of their experiences in order to explore how these have shaped their reactions and future life choices. The role of an emerging theory is understood as a vehicle for depicting individual meanings and interpretations rather than for creating a theory in its positivist and functionalist sense (Thomas and James, 2006). It is important to bear in mind the individual person behind the statements. To this end lengthy quotations from some of the interviews have been included in order to provide an insight into the experience of a small number of people with ASD in Scotland.

RISK AND TRANSITION IN PEOPLE WITH ASD

According to Arnett (2005), between the ages of 18 and 25 individuals are engaged in a prolonged period of (self) exploration. During this period the aspiration for security and stability is mediated by the desire not to limit spontaneity. Emerging adulthood thus provides fertile ground for developing risk behaviours such as substance misuse or sexual behaviour leading to unwanted pregnancy or sexually transmitted diseases (Arnett et al., 2011). In the case of some individuals with ASD, the period of emerging adulthood can last well into mid-life.[3] This can have major implications for service providers and educators. There is a substantial body of research on risk behaviour in adolescence (Parkes *et al*., 2007; Bellis *et al*., 2008; Black *et al.,* 2009; Sweeting and West, 2009; Eaton *et al*., 2010; Bridges *et al*., 2011). However, there is comparatively little work in relation to risk behaviour in people with disabilities in general, and to those with a diagnosis of ASD in particular. This article is intended to address that gap, and to explore the subtle interplay between engagement in a variety of risk behaviours and the health and wellbeing of particular individuals. It is important to recognise that there is no clear causal relationship between risk behaviours and transition. Experiencing difficulty with an extended transition to adulthood can lead to risk behaviours, and *vice versa* (Arnett, 2001). All transitions bring with them some uncertainty, but it

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[2] All research participants had met diagnostic criteria for ASD defined in DSM-IV-TR (APA, 2000).
[3] The participants in this study were aged between 16 and 43.

appears that there are particular challenges for individuals with ASD (Rydzewska, 2012).

ASD, MENTAL HEALTH AND RISK BEHAVIOURS

All but one interviewee involved in the study had been diagnosed with ASD in adolescence or adulthood, some in their late twenties or thirties. Eight of the twelve had been diagnosed or misdiagnosed with mental health problems ranging from schizophrenia to depression and social anxiety before they obtained a diagnosis of ASD. These problems were often associated with various forms of risk behaviours such as self-harming or attempted suicide, often explicitly described during interviews. Many accounts included detailed depiction of very distressing circumstances. These powerful messages were often emotionally challenging to deal with and resonated with the researchers long after the study was finished.

Thomas[4] described how watching films helped him to control his suicidal thoughts. He explained how feeling suicidal at night was paradoxically of benefit as it thwarted his desire to end his own life. His idiosyncratic mode of expression is characteristic of some people with ASD, particularly when they are talking about complex emotional issues.

> Oh, a couple of weeks ago I was about 3.5 weeks through abstaining from watching DVDs for 4 weeks. As it turns out, I often watch a DVD when I'm feeling suicidal, so the fact that I cut that off meant that the suicidal thoughts were able to develop. I'm suicidal on irregular [alternate] evenings - that's normal for me this year, and is a big improvement from last year. It's also fairly sustainable because if I want to hang myself properly, I need to buy a rope during the day time (since that's when the shops are open), and I'm very rarely suicidal during the day time, so it doesn't really matter if I'm suicidal on irregular evenings.
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> [Thomas, 22]

One 19-year old, one of only two women with ASD involved in the study, had been diagnosed in adolescence. Her father, who took part in the interview, recalled that his daughter had been rather domineering as a child and had had difficulty in making friends. The excerpt below gives some insight into their perceptions of the difficulties Mary had faced as a child.

> Mary: … I went into myself and stopped being very sociable. I kind of thought to myself there's no point. (…) I would have preferred to play with people but I've never had the confidence much again.
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> Neil: Also she was also carrying a bit of weight at the time and once she started secondary school…
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> Mary: I developed an eating disorder and grew very depressed. And it's kind of the side effects of Asperger's that I realised that I had something.
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> Neil: She started self-harming as well. (…) It was either strangling or stealing our painkillers. My wife's on various painkillers.

For some interviewees, being sociable and engaged in work or education helped them deal with some of the difficulties they experienced on a daily basis.

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[4] Pseudonyms have been used throughout.

Several were very committed to the cause of raising awareness of autism and were actively engaged in various forms of advocacy. Others were less sanguine, as obtaining a diagnosis merely provided an explanation for their problems, not a solution. As Adam explained:

> Superficially it is a normal existence, but I must always remember that life is about juggling different balls – social life, keeping fit and healthy, work, walking the dog etc. For most people that's fine, but I have an extra ball to juggle, my diagnosis. If I forget this ball, everything else comes tumbling down with it. It is a ball that it is hard to keep airborne; I will always have to be careful of becoming clinically depressed, overly anxious, or for the next potential distracting obsession that comes round the corner. The truth is my diagnosis of autism makes my life more difficult, and to succeed I often have to work harder than others. Equally, it could be said that despite my difficulties I have succeeded more than most. I think that is probably true, but the moment I stop to be complacent will be the moment I regress.

> [Adam, 24]

In some cases risk behaviours seemed to be triggered by feelings of not fitting in or being different in some way. These feelings appeared to be linked to difficulties in identity formation, which were often exacerbated by the protracted process of diagnosis. The result was often enduring anxiety, depression and self-loathing. Interviewees described various ways of coping with these emotions. For some, there was a very thin line between what they considered to be 'coping' and 'failing' mechanisms, namely risk behaviours.

> Of course, once I realised that DVDs help stop me from getting too suicidal, I let myself watch them again. Unfortunately, I did a bit more research on suicide shortly before I realised what the problem was... and it was then that I found out a way of hanging myself fairly painlessly in my bedroom without needing to buy a rope from a shop. This is very bad because all of my coping mechanisms and everything I've done to keep myself alive has been just about enough for the previous state of affairs when I couldn't kill myself on impulse. So I'm not mentally any worse than I usually am, but I'm potentially in a lot more danger of death now.

> [Thomas, 22]

Nicole was in her forties at the time of the interviews and had suffered from mental health problems throughout her adult life. She spoke at length about the implications of obtaining a diagnosis of clinical depression followed by a diagnosis of ASD in her late thirties. She firmly believed that the fact that she did not know she was on the spectrum had had a significant impact on her life prior to the diagnosis. Nicole had developed a range of what she considered to be coping mechanisms, which helped quieten feelings of anxiety. However, eventually these behaviours took their toll, resulting in severe self-harming, alcoholism and promiscuity. She described her lengthy struggle to achieve some degree of equilibrium, and the role the diagnosis of ASD played in that process.

> Basically I ended up with what I thought of as coping mechanisms but they weren't. They were coping failures, really. So I was very dependent on alcohol. I learned early on that it made life less frightening. I was very promiscuous. Basically because autistic people do what they are told, there were a lot of people that took advantage of that. I had fallen into a pattern of behaviour where I only knew one way of being nice to men.

I didn't understand the concept of saying no. I was self-harming a lot… all sorts of ways that I had destructive behaviours, which had developed initially as ways of coping but none of them were sustainable ways of coping. What the antidepressants did was that they basically gave me a bit of solid ground to stand on so that over a period of many years I could systematically tackle [some issues].

[Nicole, 40]

Owen (aged 33) had also struggled with substance abuse in his adolescence and early adulthood. He attributed his problems to the delay in obtaining a diagnosis of ASD. His drug addiction led to involvement in criminal activity, but as he observed 'once you spend time in a Chinese prison, you never want to take drugs again.' Another interviewee explained how he started drinking as a way of coping with stress and changes in routine. Over the years he had also learned to use alcohol to feel more at ease in new social situations. Robert explained how soon after he had been diagnosed with ASD, he started drinking excessively as he struggled to come to terms with the fact that he had a life-long condition. Robert attempted suicide when faced with the diagnosis of ASD, as this coincided with a period in which he was simultaneously struggling with alcoholism, diminishing mental health and unemployment.

(…) I had a bit of a crisis and I crashed. I was drinking a lot and spending a lot of my money. By about the middle of November I'd spent all of my [university] grant money for that [academic] year. And I was still on the antidepressants but I hadn't taken them for several days and I was feeling really strange. I wanted some kind of help, emergency help. I went up to the A&E near me and I said, 'I've had enough. I just want to go somewhere and get away from it.' (…) And I thought at the time, if I do something criminal then they'll have to deal with it (…) So I smashed a window up at the hospital. I checked. No one was inside. And they waited and the police came. And a few days after that, I called the person who sent me for diagnosis and he saw me straight away. But there was nothing, as far as I know it, at the time in terms of services back then.

[Robert, 34]

The excerpt above provides an insight into service provision available to people with AS or HFA over a decade ago. Robert was well into his thirties when he participated in the project and it had taken him several years to accept his diagnosis and to start dealing with the problems associated with having ASD. However, his transition to adulthood started well before then, as it did for many of the interviewees. At the time they were interviewed many were well beyond the age associated with emerging adulthood or the period of life associated with risk behaviours (Bee and Bjorklund, 2008; Boyd and Bee, 2009; Wild *et al*., 2004). This would suggest that their lives could have been much less turbulent had they been able to obtain professional help timeously. However, as Robert's case suggests, receiving the diagnosis was not a panacea. His story illustrates what happens when one needs support, but does not know where to turn in order to obtain help. For some respondents, 'coping failures', namely resorting to excessive alcohol or drug use, seemed to be only viable option. Below we consider the role of external factors in pre-disposing some of the respondents to engage in risk behaviours.

RISK-TAKING IN THE FAMILY ENVIRONMENT

Accounts such as Robert's illustrate that lack of service provision, social support and guidance can be a contributory factor in risk behaviour. Carers of adults with ASD discussed in great detail the difficulties, frustrations and anxieties associated with the process of obtaining and coming to terms with a diagnosis of ASD, and the impact that this had on the family as a whole.

Several parents of adults with ASD spoke about their own problems in their personal relationships, which were often caused by the stress and added responsibility of raising a child with ASD and trying to obtain appropriate professional help and support for them and for the rest of the family. Some parents believed that these difficulties were to blame for the breakdown of their relationships. Such problems were also multiplied if one of the partners was suspected to be on the spectrum as well.

Such tensions, combined with lack of appropriate support, were often catalysts for engagement in risk behaviour (for example excessive alcohol consumption) by parents of people on the spectrum. The normalisation of such behaviour in families affected by ASD might have had an impact on the behaviour of young adults on the spectrum growing up in this environment (Viner *et al*., 2006; Bridges *et al*., 2011). It is not a question of attributing blame, but rather of noting the complex interpersonal dynamics in families under pressure. Daniel, whose adult son still lived with him at the time of the interview, described how his son's autism had affected his relationship with his partner. He also attributed his problems with alcohol to living in such strained circumstances.

> (…) It's obviously a big strain on any marriage (…) because sometimes you just feel like 'I've had enough'. And it gets to… In my particular case I started drinking to escape. And I was drinking 3/4 a bottle of whisky every night. And things just got out of hand so I had to volunteer to go in, you know, to some clinic. And I've been clean for two and a half years now. And I'm glad I did it. I always said, you know, I was going to try and do it at home, but I couldn't, because that was the reason I was... the stress. It was horrendous. It was a nervous place to be.... and you are just trying to escape from reality.

> [Daniel, parent]

Parents also described how their children vented their frustration in response to stress or anxiety, and the negative impact of these outbursts on family life and on the physical fabric of the home. It emerged in the course of the two focus groups with parents that a great deal of patience and effort were required in order to avoid situations or topics that triggered aggressive or anxious reactions in family members with ASD. The practical and financial consequences of incidents of aggression, anxiety or violence were also discussed. Several parents were concerned about how the state of their households, with the marks of wear and tear born out of frustration and aggression, would impact upon other people's perceptions of how they were coping, or failing to cope, with the challenges of raising a child or young person with autism. The cumulative effect of these diverse pressures had a potentially very significant impact on the family environment of a person with ASD. It is perhaps not surprising that in some cases they, and indeed their parents, were prone to seek refuge in risk behaviours.

EXTERNAL CATALYSTS FOR RISK BEHAVIOURS

The experience of having been bullied seemed to be associated with engagement in various forms of risk behaviour. Although it is difficult to determine whether there is a causal relationship between risk behaviours and the experience of being bullied by peers, colleagues or even service providers, it is a reasonable hypothesis that being bullied can be a contributory factor in substance abuse and depression. On the other hand, it is also possible that recurring mental health problems or making dangerous or unconventional choices can result in a person being perceived as odd, different or extravagant in some way. These experiences could in turn negatively shape one's self-perception and so serve to intensify the severity of risk behaviours.

Having very few close friends and experiencing exclusion, social isolation or rejection by potential friends or colleagues were identified in the accounts of adults with ASD. Interviewees discussed many instances of being bullied when in education or employment. Feelings of anger, hopelessness and acts of self-harm were identified as common responses to such incidents. Some interviewees, for example Nicole, mentioned that they found support outside their conventional peer groups.

> I mostly didn't have friends in secondary school. I had friends outside school, which helped with the bullying actually because by the time I was 15, I had met a bunch of big, scary, rufty-tufty bikers... All my life, there have been groups of people that you wouldn't normally think of as particularly caring, who have kind of taken me under their wing and protected me (…) I think some people pick up on 'this is someone who actually needs somebody looking out for them', and so when they found out I was being bullied at school, they all rode up on their bikes at lunchtime and just took to sort of sitting on their bikes, looking mean and moody (…) I'd just go and sit on the fuel tank and eat my packed lunch and chat to them (…) it kind of just stopped everyone being quite so nasty to me because there were these great big scary Hells Angels types outside looking after me."

> [Nicole, 40]

Others found it difficult to establish new friendships outside school and they adopted a variety of coping mechanisms in order to gain social acceptance, including risk behaviours. In some cases, mockery misinterpreted as friendliness was a form of bullying interviewees were subjected to when trying to make friends amongst their peer group. Robert was not aware of this fact until he had obtained his diagnosis, which prompted him to re-evaluate some of his life experiences.

> You know I liked to jump around and amuse people. I thought that if people are laughing then that's good. But more often than not, no, occasionally people would just be laughing and I wouldn't understand that they were not laughing with me, they were laughing at me. And I would think that they were friends and I'd speak to them but they really just considered me a clown.

> [Robert, 34]

Robert's words bring to mind Nicole's description of resorting to promiscuous behaviours as 'the only way of being nice to men'. Robert's strategy was "to play to the gallery", but he also turned to alcohol when he found socialising difficult.

Alistair recounted the defence mechanisms and coping strategies he used when faced with bullying at school. None of them brought the desired results.

> I was just drifting along, not quite understanding but just kind of being there. I didn't have any friends really, I suppose. Having delayed the time of school I started in, I was getting a bit picked on, a bit of bullying. Not too bad but then it was like, here's an idea. Here's an identity and a role. So I played the victim and I would come across as really [inaudible]. I played games with them, like psychological games. I'd come across as really naive and innocent and they were all having a laugh at me. And I was fuelling it, which when you think about it, doesn't make sense. But at least it was an identity for me, a role. I was getting some attention.

> [Alistair, 35]

John provided a lengthy description of the bullying he experienced at school and in a psychiatric unit.[5] John was in his forties at the time of the interview. When he was growing up, autism was attributed to lack of maternal warmth (Kanner, 1949). John had experienced catatonic episodes and recounted how the psychiatrist had recommended 'emotional separation from the mother'. John also mentioned other forms of emotional and physical bullying used as 'forms of therapy'.

> The teacher (…) used to use a persona of sarcastic wordplay humour with the boys, happy to take what he gave, that made him approachable (…) But when I told him 'I'm not a swot' and he retorted, 'we think you are', that was emotionally devastating.

> [Two psychiatrists] used to give the boys swamping intrusive hugs at any time as a way of showing dominance. Paul often kept hold of me for long periods, treating my struggles as a game, when community meeting was beginning. [One of them] had a reputation of deliberately angering the child as a therapy technique.

> [A male nurse] resumed harassing me over my packed lunches (…) and shouting a lot (…) constantly saying that eating packed lunches was like eating from a pig trough… He also became open in accusing my catatonic states of being put-on. He called them 'your sleepy sickness pretending'.

> My mother, because of the sensible safety fears given to her by my catatonias, had in place at the time an alarm system attached to our bedroom door for fear of any catatonic state events starting when she was asleep. It involved us sharing a bedroom. At a time when the unit had learned of the arrangement from sessions with my mother, but I still did not know they had, [one of the psychiatrists] in the boys' group invented out of nowhere a discussion topic allowing him to tell me to recite the pattern of furniture in my home. I tailored my description to the uncertainty of their reaction or their knowledge, which meant I said 'there is a bedroom and a spare bed in the kitchen if needed'. This description was correct no matter what they knew. As soon as I mentioned the spare bed, he interrupted and said to the boys 'because he sleeps with his mother'.

> [John, 43]

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[5] John sent a 15,000 words long email complementing the interview conversation and providing detailed information on his childhood, health history, diagnostic journey and ASD-related difficulties experienced throughout his life.

Although these experiences relate to service provision several decades ago, interviewees who were treated for mental health problems more recently gave similar examples of bullying perpetrated by professionals in the field.

There was considerable variation in the extent to which the interviewees engaged in risk behaviours. Some people on the spectrum were more prone to undertake them than others. One explanation for this in the general population is a pre-disposition for sensation seeking, as risk behaviours can provide the novelty or intensity of sensory stimulation that appeals to people who are high sensation seekers (Arnett, 1998). However, given that one of the core features of ASD includes various sensory problems (APA, 2013), a more probable explanation for undertaking risk behaviours is a lack of understanding of social norms and the desire to fit in rather than thrill-seeking *per se*.

Another possible explanation for risk behaviours in adults with ASD lies in the link between high self-awareness and a sense of autonomy. Personal autonomy and empowerment are defined as the opportunity to make choices and decisions regarding one's quality of life free from interferences. These choices and decisions are central to the principles of self-determination and the ability to be autonomous in terms of making meaningful life choices (Wehmeyer and Schwartz, 1997; Wehmeyer and Garner, 2003; Nota *et al*., 2007). However, in reality people do not make life choices entirely free from external influences or interferences. They are influenced by a variety of enabling and constraining factors enmeshed in a web of human relationships. For people with ASD, the latter can be often more problematic than lack of autonomy, as difficulties with deciphering complex meanings and interrelations of social aspects of life are part of the disorder (Boucher, 2009, Wing *et al*., 2011).

In addition, perceived loss of control has negative implications for self-esteem and self-concept, which are fluid, overlapping and integrated with consciousness, memory and self-awareness. From the social-cognitive perspective of symbolic interactionism, how we come to see ourselves is partly a reflection of how others perceive us (Cooley, 1902 and Mead 1934 cited in Jackson, *et al.,* 2011). The self can be conceptualised as the fundamental organiser of a person's social world, providing the conceptual means to establish a unique and distinctive personal identity (Damon and Hart, 1988 cited in Jackson *et al*., 2011). Yet the unchallenged orthodoxy of existing service provision emphasises the importance of integration with the local community, irrespective of the challenges this may present to people with ASD. As we have seen from the examples above, the perceptions of other people are not necessarily positive, and this can negatively impact on the perception of self and compound any pre-disposition on the part of the person with ASD to engage in behaviour that is ultimately self-harming or destructive.

The autonomy of adults with ASD can also be limited for other reasons. Lack of control over simple aspects of daily life, such as sensory environments, and limited ability to plan for the future can be associated with increased risk of mental health problems (Wehmeyer, *et al.,* 1996; Wehmeyer and Garner, 2003). Perception of loss or lack of control over important aspects of one's life has been identified as a central issue in depression (Wehmeyer, *et al.,* 1996; Wehmeyer and Garner, 2003).

James's (1909) reflections on the self as object and subject also provide a useful framework for understanding the difficulties experienced by some individuals with ASD. James (1909) divides the self into two main components, the self as object *me* and the self as subject *I*. The *me* incorporates the qualities that objectively define the self. These are material characteristics (physical features, body and possessions), social characteristics (relationships, roles and personality) and spiritual characteristics (consciousness, thoughts and psychological mechanisms) that identify the self as a unique configuration of attributes and qualities. James (1909) proposed that individuals organise the *me* into a hierarchical structure, assigning worth to each material, social or spiritual constituent. The *I* incorporates the experiential features of the self and is essentially subjective, involving awareness of self-agency over life events, awareness of the uniqueness of life experiences, personal continuity and reflexivity.

Mead (1934) proposed that by reflecting on the *me*, people implicitly assume the perspective of other people in a social group, thereby situating the *I* within a social context along with the objective self. If *me* were the only component of self, behaviour would become automatic and completely consistent with social expectations (Damon and Hart, 1988 cited in Jackson *et al*., 2011). The *I* is a person's freely chosen response to any given situation and indeterminacy of action gives rise to the experience of choice or freedom.

Conflict between the *me* and the *I* in people with ASD seems to stem from the mere existence of the *I*, as it dictates behaviour that is often in stark contrast with social expectations. If *me* were the only component of self, the difficulty in understanding social norms that is characteristic of people with ASD would potentially be alleviated by the non-existence of the *I*, instinctively directing people to provide freely chosen responses. Another difficulty in steering the *I* might be the necessity to make individual choices, which is its core element. Since freedom of choice and flexibility can increase anxiety in people with ASD, the innate preference expressed by the *I* can increase the sense of imbalance between the self and the world.

It seems that the more adults with ASD are aware of their differences, the more likely they are to negate or compensate for them by modifying their appearance and behaviour in attempts to match their subjective perception, which is not always accurate, of how others expect them to behave (Cooley, 1902 cited in Jackson *et al*., 2011; Mead 1934 cited in Jackson *et al*., 2011). It is evident that such social compromises had a negative impact on some interviewees' mental wellbeing and self-esteem. Other interviewees saw themselves as sacrificing their own integrity for the sake of social acceptance. It was quite common for them to establish risk behaviours as strategies for coping with these difficulties.

Some interviewees appeared to have been overwhelmed by the level of awareness of their differences, or by the need to make individual choices. Others learned to accept their differences and to embrace them by following behaviour patterns, routines and establishing mechanisms that helped them to function in everyday life while allowing them to maintain their sense of identity.

Although it appears that a greater degree of self-awareness or capacity for introspection can cause people to suffer disproportionately, it also has the potential

to provide them with a greater capacity for developing effective coping strategies and compensating for difficulties in conforming to social rules, situations and expectations. However, the effort required for this coupled with chronic anxiety, mental health or sensory problems as well as self-loathing suggests that this awareness can be a problem in itself. Moreover, it can result in even greater social isolation since it can bring a very strong sense of difference or 'abnormality'. In such cases developing effective mechanisms for coping with difficulties proves especially challenging.

CONCLUSION

This small-scale study raises a number of questions that are worthy of further investigation, and which are of direct relevance to teachers in mainstream and specialist settings at the secondary stage, and to educators and other service providers in tertiary educational settings who have specific duties of care or interest in the needs and aspirations of people with ASD. First, the age range of the participants in the study (16 to 43) suggests that there is scope for further elaboration of the concept of 'emerging adulthood' in respect of people with disabilities in general, and people with ASD in particular. Second, the evidence also suggests that is time to challenge certain orthodoxies in respect of service providers' assumptions about importance of integration with the local community, irrespective of the challenges this may present to people with ASD. Third, it is important to recognise that ascribing the label 'high functioning' to certain people with ASD can detract attention from their complex needs during what is often a painful and protracted period of transition. Lastly, the openness and honesty that was evident in the respondents' accounts of challenging and distressing periods in their lives should serve as a timely reminder that 'some people expend tremendous energy merely to be normal.'

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