

“I definitely feel more in control of my life”: The perspectives of young autistic people and their parents on emerging adulthood

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Abstract

Long-term outcomes studies often paint a discouraging picture of the lives lived by autistic adults. Yet their outcomes are often measured against normative markers of traditional adult roles, which may not apply to autistic people making the transition to adulthood. Here, we investigated the transition experiences of a group of young autistic people followed from childhood. Twenty-six young people and their parents ($n = 28$) participated in semi-structured interviews on the process of transition and their aspirations for the future. Parents often voiced serious concerns about the ongoing support their children would require and the severe lack of services designed to support them as adults. Yet, overall, young people reported feeling more in control of their own lives, including developing a sense of identity and personal autonomy, both of which may be rooted in young autistic people's executive skills and their ability to develop and maintain trusting relationships with others – two potential candidate areas for targeted support. These results call into question whether the traditional standards to which we often hold young autistic people are developmentally appropriate and suggest that the pressures of striving towards more normative ways of engaging in the world may be detrimental to their wellbeing.

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Lay Abstract

Autistic children to grow up to become autistic adults. Researchers, practitioners, parents and autistic people themselves rightly want to know what the likely life-course outcomes might be for young autistic people as they move into adulthood. Unfortunately, the few long-term studies that have looked at autistic people's life-course outcomes often paint a discouraging picture. Yet the way that these outcomes are typically measured – in terms of having a job, living independently, and enjoying friendships and more intimate relationships – has been set against what is traditionally expected for neurotypical adults, which may not apply to autistic people. Here, we interviewed 26 young autistic people and their parents (n=28) about the process of transition from high school to more adult roles and what they wanted for their future lives. Parents often voiced serious concerns about the ongoing support their children would require and the severe lack of services designed to support them as adults. Yet, overall, young people were more positive, reporting feeling more in control of their own lives, including developing a sense of identity and being able to make decisions for themselves. These developments may be driven by two sets of underlying skills: (1) young autistic people's executive skills (their ability to plan ahead and shift flexibly from one thing to the next) and (2) their ability to develop and maintain strong, trusting relationships with others. Focusing on these underlying skills – while keeping in mind the different needs and preferences of individuals – should be the focus for targeted support in childhood and adolescence.

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The transition from school to adult life can be a particularly challenging time for young people on the autism spectrum (Friedman, Warfield, & Parish, 2013; Wehman et al., 2014). Compared to young adults with other developmental disabilities, young autistic¹ adults are significantly less likely to have regular contact with friends (Shattuck, Orsmond, Wagner, & Cooper, 2011), be enrolled in postsecondary education or engaged in some form of paid employment (Shattuck et al., 2012). Problems making and keeping friends (American Psychiatric Association, 2013), difficulties dealing with uncertainty (Boulter, Freeston, South, & Rodgers, 2014; Neil et al., 2016), and an increased risk of developing mental health problems, especially anxiety (Simonoff et al., 2013), place them at particular risk of negative transition experiences. The loss of structured support during secondary school and the concomitant dearth of available postsecondary services for young autistic adults increase this risk further (Taylor & Henninger, 2015; Shattuck et al., 2011).

These challenges may be exacerbated by broader social trends affecting young people in developed economies. The post-school period, while traditionally thought of as one when adult role transitions (finishing school, gaining employment, getting married, having children) were cemented, is now characterised by much instability and change (Arnett, 2000, 2007; see also Wyn, 2014). Young people (Millennials, Generation Y) may spend their late teens and 20s ‘trying out’ different career options (education, training, work), exploring their identity, and entering into (and exiting) close friendships and intimate relationships. Given autistic people’s difficulties dealing with uncertainty, it is not surprising that parents (Cadman et al., 2012; Müller & Cannon, 2016; Sowsony et al., 2018) and teachers (Elias, Muskett, & White, 2017) of autistic children transitioning to adult roles can be deeply anxious for their futures. Little attention has been paid, however, to the young people themselves undergoing this transition. The

¹ We use ‘identify-first’ language (‘autistic person’) rather than person-first language (‘person with autism’), because it is the preferred term of autistic activists (e.g., Sinclair, 1999) and many autistic people and their families (Kenny, Hattersley, Molins, Buckley, Povey, & Pellicano, 2016) and is less associated with stigma (Gernsbacher, 2017).

current study sought to redress this imbalance, by eliciting the perspectives of young autistic people, and those of their parents, on their experiences of transition and how they see their future lives.

Rather than relying on standard assessment of outcome metrics, this study examined young autistic people's own subjective experiences on the transition to adulthood. This is vital for three reasons. First, applying so-called 'objective' criteria in the domains of employment, relationships and independent living to determine the 'success' of autistic adults' outcomes (Billstedt et al., 2005; Eaves & Ho, 2008; Farley et al., 2009; Howlin et al., 2004; see Henninger & Taylor, 2012, for review) paints a rather discouraging picture of autistic adults' lives. But in the context of potentially deep societal change, traditional adult roles – having close friends, being employed and living independently – are no longer reliable markers of successful outcomes in typical young adults (e.g., Furstenberg, Raumbaut, & Settersten, 2005), let alone those of young autistic people's transitions to adulthood.

Second, putatively objective markers have been predominantly derived from *non-autistic* researchers and clinicians' notions of what a successful outcome is for an autistic person. Although Arnett's (2001) research on emerging adulthood sought to understand the subjective experiences of young (non-autistic) adults and what they wanted for their adult lives, in research on autistic outcomes, there is a glaring absence of their subjective experiences and what a 'good' life means to *them* (see Ruble & Dalrymple, 1996). The few studies that have taken up this challenge have revealed the disparity that can exist between narrowly-defined normative measures and broader measures of an individual's quality of life, finding that adult outcomes may be more positive when subjective factors are taken into account (Billstedt, Gillberg, & Gillberg, 2011; Müller & Cannon, 2016) or, worryingly, that objectively-defined successful outcomes do not necessarily go hand-in-hand with better quality of life (Bishop-Fitzpatrick et al., 2016).

Finally, the predominance of research focusing on traditional, normative markers of a successful adulthood has reified the outcome itself (e.g., independent living), rather than understanding the broader processes by which these outcomes are, or more commonly are not, achieved – including from the

perspectives of the adults themselves or of those who support them. One exception to this pattern is a study by Sosnowy, Silverman and Shattuck (2018), who examined the views of parents of young adults ($n = 21$) and young people (aged between 18 and 29 years; $n = 20$; 4 parent-child dyads) of what desirable outcomes might look like and, critically, how they might achieve them. While parents wanted their children to live independently at some point, they also acknowledged that realising this goal would be a gradual process, tailored to their individual child's needs and preferences, and balanced against providing the necessary support while also promoting their child's autonomy. For the most part, young adults also perceived living away from their parents as an opportunity to establish autonomy, but nevertheless identified the challenges in doing so, especially with achieving financial independence. Although Sosnowy et al.'s participants aspired to traditional outcomes – of living independently, and being in education, training or work – more important to these participants was the means by which they achieved such outcomes, particularly in developing competence to make decisions for themselves, one key marker of emerging adulthood (Arnett, 2000, 2007).

In the current study, we sought to address the limitations of existing work on outcomes, especially for those individuals transitioning to adult roles, by eliciting the views of a group of young autistic people, who had been followed from childhood (Pellicano, Maybery, Durkin, & Maley, 2006), and those of their parents, as they approached the period of emerging adulthood. In so doing, we asked the following questions: what are young people's subjective experiences of growing up autistic and their aspirations for the future? What are the processes that might underpin and shape young people's transition to adulthood?

Method

Participants

Forty-five children seen initially during childhood (see Pellicano et al., 2006, for details) were invited to take part in a 12-year follow-up. During the initial study, this group of children was identified through community contacts, including early intervention agencies, parental support groups, speech therapists, and pediatricians, and is thus considered a convenience sample. At intake, children were

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excluded from participation if they had received a medical diagnosis (e.g., epilepsy) or a neurodevelopmental diagnosis other than autism (e.g., attention deficit/hyperactivity disorder [ADHD]), a full-scale intelligence score below 80, or were in receipt of medication.

The 28 young people (26 boys, 2 girls) who agreed to take part were now aged between 16 and 20 years ($M = 17.84$ years, $SD = 1.18$ years) (see Table 1). The mean duration between intake and follow-up was 12 years, 2 months ($SD = 6$ months). All 28 participants were considered to be cognitively able during childhood, that is, they obtained verbal and nonverbal IQ scores of 80 or above on standardized measures at intake. They also met criteria for autism on the Autism Diagnostic Interview – Revised (ADI-R) (Lord et al., 1994) ($M = 41.50$, $SD = 9.82$, range = 21 – 63). Seventeen of the original children either were untraceable ($n = 11$) or declined to participate ($n = 6$). There were no significant differences between young people who participated at follow-up and those who did not in terms of initial age ($p = .99$), verbal ability ($p = .41$), non-verbal ability ($p = .55$) or algorithm score on the ADI-R ($p = .32$).

Of the 28 families, 26 young autistic people (2 female; 24 male) and 28 of their parents or caregivers (26 mothers, 1 grandmother, 1 father; hereafter, ‘parents’) agreed to be interviewed (one mother spoke about her two children). Participants reported having received co-occurring medical and psychiatric diagnoses, including developmental coordination disorder or dyspraxia ($n = 2$), dyslexia ($n = 2$), obsessive compulsive disorder ($n = 1$), anxiety and depression ($n = 2$), epilepsy ($n = 2$), Attention Deficit/Hyperactivity Disorder (ADHD; $n = 8$) and mild intellectual disability ($n = 2$). Seven reported to be currently on psychoactive medication, including for epilepsy ($n = 1$), ADHD ($n = 3$), sleep problems ($n = 1$), and depression ($n = 2$).

The majority of the group ($n = 24$; 86%) described themselves as being of White ethnic background, 11% as Asian ($n = 3$) and 4% Mixed ($n = 1$). Parents also reported the age at which they left full-time education, a widely used proxy for socio-economic status (Liberatos, Link, & Kelsey, 1987),

which was used to derive the number of years of education they received after they turned 16 years of age ($M = 2.38$ years, $SD = 2.71$, range = $-1 - 8$)².

Fifteen young people were still attending high school (53%). Of the 13 who had finished school (47%), 6 were attending college, 3 had part-time paid employment, and 4 were not in education, employment or training (NEET). Less than half (46%; $n = 13$) had taken part in either paid ($n = 6$) or unpaid ($n = 7$) work experience during or after having left school, organized by themselves ($n = 1$), their parents ($n = 9$), or their school ($n = 3$). All were living with their parents, except for one participant who attended boarding school during school terms.

 insert Table 1 about here

Procedure

Ethical approval for this study was granted by the Human Research Ethics Office at the University of Western Australia. All participants gave written informed consent prior to taking part.

All participants completed face-to-face semi-structured interviews on a single occasion either at their home or at the University, depending on family preference, with the exception of one family (young person and parent) who was interviewed over Skype because they had moved inter-state. Parents and young people were interviewed separately. They were asked similar open questions but reworded to suit their different roles (see Supplementary Table 1 for interview schedules). Where possible, interview questions were provided ahead of time to accommodate young people’s processing differences. Young people were asked about their experiences of school, goals for the future and self-perceptions. Parents were asked about their perspective on their child’s experience of school, their ambitions for their child’s future and the extent to which they felt being autistic impacted on their child’s current and future lives.

² Three parents reported leaving school at the age of 15 and so received a score of -1 when number of years of post-16 education was calculated.

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Interviews varied in length from 16 to 57 minutes and 29 to 70 minutes for young people and parents, respectively.

All 54 interviews were recorded for later transcription with participants' prior permission, and transcribed verbatim. We approached the analysis and discussions from the perspective of autism researchers, who are not formally diagnosed as autistic and are not parents of autistic children. The analytic process was conducted by two authors (SC & EP). Following Braun and Clarke's (2006) method for thematic analysis, we used an inductive ('bottom-up') approach (i.e., without integrating the themes within any pre-existing coding schemes or preconceptions of the researchers) to identify patterned meanings within each group (young people, parents; Braun & Clarke, 2006). Our epistemological stance fits within a critical realist framework, which acknowledges that we all have subjective experiences (the empirical), that an objective reality exists outside of our experience (the actual) and that causal mechanisms lie between and within these domains (the real; Willig, 2013).

Following Braun and Clarke (2006), two authors independently familiarised themselves with the data, reading and re-reading the transcripts, from which codes were generated in a systematic fashion across the entire dataset and themes were developed by collating codes into potential themes. The authors then liaised several times to review these themes and subthemes, focusing on semantic features of the data (i.e., 'staying close' to participants' language), checking to ensure that the themes were coherent for coded extracts and the entire data set, resolving discrepancies and deciding on the final definitions of themes and subthemes. Analysis was thus iterative and reflexive in nature and moved backwards and forwards between data and analysis.

Results

We identified three themes in the young people's interviews and four themes in the parents' interviews. Below, themes are highlighted in bold and subthemes are italicised and illustrative quotes are provided in Tables 2 and 3.

Young people's interviews

“I definitely feel more in control in my life”. Although some young people were positive about the support they received at school, which “managed to keep me on track”, the majority reported negative school experiences. They felt that teachers “didn’t offer guidance”, “didn’t really know about the autism aspects”, and in some cases, simply “gave up”. Young people also found it difficult to ask for help. These negative experiences were perceived to be underpinned by persistently low expectations. Consequently, they felt that *school was “really stressful”*.

Despite these negative school experiences, young people nevertheless spoke about *having come a long way since their childhood*. Some described how it was “a lot more difficult when I was a lot younger” and “more heavily autistic”, and that there was a clear progression as they became “more mature” with time. Encouragingly, they generally cast themselves in a positive light and had a positive outlook on their current circumstances.

They identified two ways that had helped them “feel more in control of my life”. The first related to *opportunities to develop confidence*. They proudly spoke of their gains in confidence through experiences in the workplace and college, and through pursuing their interests. Others spoke of how attending mainstream school was key to their “progression”. One young man summed this up:

If you want them to be more socially competent and to develop more skills and that kind of thing, you have to leave that sheltered environment and be in a [mainstream] environment where you’re not treated as though you’re different, or you’re special... Moving to a normal high school really helped develop my social skills and meant that I could have more friends and cope in that kind of environment.

The second way related to their *developing sense of (autistic) identity*. Although some young people reported being unsure of themselves, others spoke of being aware of “my autism” and having “learnt to live with it”. This manifested itself in different ways. Some young people felt that being autistic was a core part of their identity: “It gives me a view of the world that’s different to other people I know”. Rather

than thinking that “my autism was a bad thing”, they embraced it, and accepting their differences was felt to be critical to their quality of life.

In contrast, some young people’s self-assurance was driven by their desire – and perceived success – at fitting into a neurotypical world. They spoke about actively hiding their differences by being “as normal as possible in public”. They also distanced themselves from “the severely autistic kids” by suggesting that their autism was “very mild”. They spoke about being “more heavily autistic when I was younger”, and how this had changed considerably with age – to the extent that some young people stated that they “actually don’t have that diagnosis anymore”.

 insert Table 2 about here

Just need to “take it one step at a time”. In recognition that their reported gains had been hard-won, young people felt that, for them to continue to progress, they *needed more time to move on up into adulthood*. Although almost all were currently living with their families, many aspired to live independently and felt that they could reach this goal – but that it would take time. They spoke repeatedly about problems with planning, organization and future-oriented thinking, and felt that they needed extra time to process decisions, think about the future and identify their interests and passions, as well as time and space to develop everyday skills, which they felt were not the focus of school. Indeed, in one 18-year-old’s words, “24 is when you become a complete adult; you get that... snap decision-making thing in your brain”.

They felt that extra time would be *important to “sort out my mental health”*. Elevated anxiety was a commonly-reported concern. Young people talked about getting “really stressed over that really tiny thing”, which “affects [autistic] people really badly”, including leading to panic. Others reported depressive symptoms and difficulties controlling their emotions. Many therefore agreed that “my mental health would be the biggest obstacle [in my future]”. Although some had developed strategies to

overcome their mental health issues, others were aware that they had difficulties seeking help and needed more time to develop “a healthy mindset”.

Valuing deep connections with others. In addition to concerns about needing more time to adjust and the sense of making progress since childhood, young people often highlighted how deeply they valued social connections with others. This included the *often-unfailing family support* that they experienced from their parents, who were felt to be “unbelievably supportive”, and siblings and grandparents, and even extended to buddies and mentors, especially those who had been a stable part of their lives.

Young people varied in their degree of motivation for friendships. Some reported having few, if any, friends and not much desire to pursue such friendships, while others “prefer[red] being around my friends and other people as well” and wished “to have more friends”. Indeed, they were all too familiar with the consequences of being the “odd-one-out” and subsequently “left out” of their peer groups. They described being worried about people thinking “you’re a bit weird, odd, that sort of thing”. Consequently, they desperately wanted “a close group of friends” who “understand me, which is all that matters”, reflecting an emphasis on *“friendship quality not quantity”*. For those that had disclosed their diagnosis to the “closer friends that I feel I can trust”, they felt reassured by the fact that it “doesn’t really bother them at all, they still treat me the same”.

School was perceived to help maintain these friendships, and young people were anxious about what would happen to these friendships when they left high school. Indeed, this was the reality for many young people who had transitioned from school, whose *social networks had diminished considerably post high-school*. Sometimes this reduction in social connections was out of choice but others suggested that keeping up with their friends was difficult because “they’re usually busy or something”, or that “they didn’t tell me where they’d moved to, so I lost all my friends”. More often than not, however, problems maintaining friendships appeared to be driven by difficulties initiating the necessary contact. Some felt that another barrier was a lack of alignment between their interests and those of their neurotypical peers, including the “upbeat music and all that” or “partying, sex and drugs, [which] is just not what I’m into”. Some felt

overly pressured to enjoy social contact, especially from their parents, while others appreciated the need to extend their social network: “You need your friends to support you in the later years because you won’t have your family anymore”.

These social expectations also weighed heavy on many young people’s feelings about future social roles, including having intimate relationships and having children. While some young people wanted to experience, or currently enjoyed, such relationships, the majority expressed *ambivalence about getting a partner and having children*. Other young people appeared not to pursue intimate relationships to avoid the challenges that can go alongside them, while others still liked “the idea of having people that you care for and you brought up”.

Parent interviews

“We’ve come a long, long way”. All parents reported their children having made gains over the 12-year period. For some, their progress had been “at a very slow rate”, while others described how their child had “come a long way since his diagnosis”, often far exceeding their initial expectations. Some of these gains were to the extent that they felt their children were “only mildly different” or did not “look” autistic anymore. Parents attributed their children’s “leaps and bounds” to the *support that they had received*. Some felt that early intervention – that “one-to-one support right from the start” – had “had a huge impact”. For one parent, who home-schooled her two autistic children, it was about getting the environment right.

Parents also often felt that their children’s progress “just depend[ed] on the teachers”. They also reported being more confident about their children’s support at school when the principal “was very into inclusion” and “proactive” about their children’s involvement in decisions. They felt most reassured when they felt that *teachers understood their child’s autism* and “what [being autistic] means for their learning and socialisation”.

Although some parents reported not having “to fight too hard”, the majority felt it was a *hard road to getting the right – or, in fact, any – support*. They agreed that their children required individualized support

but that some schools had “no flexibility”. Indeed, some parents questioned whether their child actually received their allocated aide³ time at school. In some cases, the children had eschewed the very assistance that their parents had fought hard to obtain. For children receiving some specialist support, parents described how “he just hated it... he just did not want to associate himself with other kids with disability”. For those in regular classes, “he’d never ask for help... he wants to act normal, to be normal”. In those cases where parents felt that the “school had been helpful”, it was when they had listened to the children themselves about what type of support they wanted.

On the whole, however, parents felt that *many school staff had low aspirations for their children*, who, consequently, were not sufficiently challenged and had very much “struggled”. Others still felt that their children were actively excluded, especially from those aspects of school in which they were interested, “because it lowers the average”, or purportedly prevented the teachers from engaging the other children.

 insert Table 3 about here

“I don’t know what the future holds”. For the most part, parents believed that their children would be living with them for some time to come and reported being extremely anxious about their and their children’s future lives (“it’s constantly on my mind”), largely because “he’s going to outlive us”. As such, they felt that their *primary goal was to help their children develop autonomy* (“to reach a level where he’s able to make his own decisions”) *and, eventually, their independence*. Some parents were confident that these goals were attainable and highlighted specific qualities that would place their children in good stead for their transition to adulthood, including a general capacity for learning and being “quite empathetic”. Nevertheless, they felt that their children would need “ongoing support” for the foreseeable future – and sometimes in contrast to what their child wanted for themselves.

³ A teacher’s aide, also known as a teacher’s assistant or education aide, supports children with additional needs in the classroom.

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They identified *several factors that they felt hindered their child's transition* to an independent life. Some parents were concerned about their children's apparent lack of initiative, which was sometimes underpinned by a lack of interest. For others, it was perceived to be linked to difficulties "trying something new" or difficulty putting knowledge into practice. Notably, however, some parents described how their children had "shown improvement in that area". Yet, underlying problems in self-regulation, including difficulties regulating emotions, "forward thinking, planning, organization" and "keeping track of time", were perceived to have an especially negative impact on their transition to adulthood. Parents were also worried about their children's difficulties "articulating any plans" for their future.

Co-occurring *mental health issues were felt to be "the biggest problem"*, with reports of severe cases of anxiety, depression and suicidal behaviour. Parents reported various triggers for their children's anxiety, including new people and new places and felt that these mental health issues placed limits on the extent that their children could live independently. Promoting good mental health was therefore a priority for their children's successful transition to adult life.

Parents' anxieties about the uncertainty of their children's futures were fueled by the perceived *paucity of adult services*. Some felt that such services were simply non-existent. Others reported feeling "very let down" by the few existing services designed to help their children get into the workforce and felt that this "lack of support" had had a negative impact on their child's confidence. They also felt that the onus was on the family to provide the necessary support, which parents felt was "tough... but you've just got to keep going, there's no-one else to pick up the pieces".

The need to "keep pushing those boundaries". Parents described how school is or had been a safe, "secure, predictable environment". Nevertheless, they also felt that *school itself could be too rigid in the support they provided*, which did not necessarily set their children up for life after school. They described how school could be over-protective ("babying her, pampering her") and that their children had sometimes received "too much support" (including during early intervention), which they felt was

disabling. In rare cases, however, parents described how the school had recognised the need to be flexible with their support.

They described wanting their children to “feel like he’s got some purpose” and, particularly, to develop “ownership of where he’s going”. Parents sought to ensure that their children were safe and secure but also “pushed their boundaries”, being “adamant that he’s always exposed to change” so that their children did not “become too reliant on the structure because life is not like that”. Indeed, they were well aware that their child “probably doesn’t stretch himself enough” and “doing everything for him [was] not going to help him at all”. Some had seen the benefits of this independence but they also highlighted the *challenges in getting the balance right*: “It’s a very fine line. We can’t make him do stuff; he’s an adult. But it’s also not OK to just sit at home all day playing on the PlayStation. That’s not part of being in the adult world”.

They felt that their *children needed opportunities to help “broaden their horizons”*, such as getting work experience and learning to drive. Parents were aware that their children needed to develop confidence and a sense of purpose before “tak[ing] the next step”. Some wished that their children had received more support with “building his independence and getting out in the community” during school. While some parents were frustrated by this, others felt that teaching practical life skills – “to cook himself a simple meal or making sure he’s organized enough to pay his rent or whatever” – was not within the school’s remit, which in one case appeared to be explicitly reinforced by the school: “The principal said, ‘if you want social skills maybe you should take him out and home school him because we don’t have time to do that here’”.

Overall, however, parents, like their children, emphasized that they *needed to take things slowly*. They were worried that their children were “vulnerable” and “could easily be taken advantage [of]”. Another parent also felt that there was too much pressure for young autistic people to transition to adulthood:

We have some autistic friends who are over twenty and they’re still not ready to leave home, do further studies, or have a job. But they’ve been trying because that’s what’s

expected of them. And I think it's sad that we say, on the one hand, you're autistic, but we're not going to allow you to take the time to get to where you need to take the next step. But that's how our society is".

Having connections with people is – and will be – key for their children's futures. The final theme for parents centered on children's social connections and how they *strived to foster a supportive and accepting family environment*. Parents spoke about "always including" and supporting their autistic child "no matter what path he takes". They described how their close relationships had meant that "they talk about stuff... there's no such thing as a taboo topic". Parents also described their children's often-strong relationships with their siblings and even their carers with whom they had developed close relationships. Many described being "firmly in the 'thinking differently' camp" – that being autistic "is not bad, it's just different". Consequently, they felt that this accepting attitude helped to foster confidence.

Nevertheless, most parents were concerned about the absence of a broader social network – and, in some cases, that their children had no friends at all. They described how their children were often not included at school, instead being often "very isolated" and "quite lonely". Yet they noted considerable *differences in their children's motivation to seek out social contact*, just as their children had explained. Some described their children as "not overly motivated" to have friends – and went so far as saying that "he doesn't enjoy human interaction". Other parents described their children as "popular", "well liked" and wanting friends but also that these friendships were often not reciprocated. Parents also appreciated, however, that their children valued close connections with others: "she doesn't find it easy to make friends but when she does, her friends want to be with her".

Yet, most parents felt that their *children had significant on-going difficulties making friends with same-age peers*. They felt that these difficulties were underpinned by a lack of an "ability to give and take" or because "the conversations happen too quickly for him to process". Others felt that their children had little "understanding of what a friendship is". Above all, however, they felt that their children's limited

friendships were rooted in problems initiating social contact: “He’s very sociable at home. But if you say, how about contacting someone to do something, he doesn’t have that initiative”.

Parents therefore voiced serious *concerns about them “socially, in the future”*. They were worried about their children not having “meaningful friendships” or “companionship”, particularly for when their parents were no longer around. They were also aware of the disparity between their own concerns and expectations compared with their children’s: “I would have liked him to [have more close friends], but that’s more my problem than his”. In light of this knowledge, some parents were wary of placing “too much pressure” and too many expectations on their children. One parent identified that these social expectations were a huge concern for parents but emphasised they needed to accept that “this is just who he is”:

For a lot of parents, it’s about friends. A lot of them have said, ‘what do I do about friends?’ I said, ‘why? Why do you need to do anything?’ ‘Because he doesn’t have any’. I said, ‘is he upset about that?’ ‘No’. ‘Then why make it an issue right now? It’s not his issue, it’s your issue. You have to let go of that’.

Discussion

In today’s society, the transition to adulthood is a period characterized by instability and change (Arnett, 2000, 2007; Wyn, 2014) – and may be especially challenging for young autistic people. Indeed, orthodox normative approaches to autistic adult outcomes, those focused on rates of employment or post-secondary education, living independently and having friends, have repeatedly shown that autistic people struggle in this transition (Henninger & Taylor, 2012; Wyn & Woodman, 2006). Had we too focused on traditionally-defined outcomes, our findings would have perhaps appeared equally as bleak. Yet, interviewing young people about their subjective experiences revealed that they were more optimistic about their current – and future – lives than such traditional outcome studies would suggest. Securing a (part-time) job and living independently from their parents, were key aspirations for most, though not all, young people interviewed here. Many also wanted to be able to make decisions for themselves, secure a

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few close, quality connections with other people (friends and family) and achieve good mental health.

These aspirations appear broadly similar to those described for non-autistic young people approaching emerging adulthood (Arnett, 2000, 2007). Nevertheless, while our young autistic people also perceived this period of transition to adulthood to be a time of exploration – one in which they could try things out, broaden their horizons by participating in work and study opportunities and develop a positive sense of identity and self-control – they also felt that they needed more time to take on adult roles and responsibilities.

For the most part, their parents agreed. Similar to Sosnowy et al. (2018), they saw the transition as a gradual, long-term process in which to build their children's confidence and sense of autonomy. But they also voiced often-serious concerns about the degree and nature of support their children would require in the foreseeable future, especially with ongoing self-regulation and mental health difficulties, and the dearth of services designed to support autistic adults, which often caused them to doubt whether their children could live independently as they or their children so desired.

Overall, these results give cause for optimism. The young people interviewed reflected positively on the gains they felt they had made since childhood, which often far exceeded their own expectations, and, possibly as a result, reported feeling more in control of their lives. Such results support recent work demonstrating a disconnect between traditionally-defined successful outcomes and autistic adults' quality of life (Billstedt et al., 2011; Bishop-Fitzpatrick et al., 2016; Müller & Cannon, 2016). As such, they highlight the importance of going beyond traditional markers of adult social roles to understand what a good life means to young autistic people themselves, especially considering the intersection between the person and their environment (Ruble & Dalrymple, 1996). Indeed, for the current sample, the young people's encouraging perceptions of their current and future lives were juxtaposed with the safety and security of continued support, and often accepting attitudes, from their families, and the few close friends that they desired.

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The results also go further and help us to uncover two related processes by which young people, and their parents, felt they could achieve their goals, including their emerging positive sense of identity and achieving greater autonomy – both of which are central to the developmental challenges of transitioning from adolescence to emerging adulthood (Arnett, 2007; Zarrett & Eccles, 2006).

First, young people described the importance of their emerging social identity – that portion of the self-concept that derives from membership of social groups (Tajfel, 1981) – yet there was significant variation in how their identity was understood (see also Shattuck et al., 2014; Williams, Gleeson, & Jones, 2017). For some, it was closely connected to “being autistic” and, for others, it was firmly rooted in wanting to be considered “normal”. The importance of a strong and confident understanding of one’s identity was a common theme across this variation – but this remained a challenge to many participants. Sense-making about the self is deeply embedded in our interactions with, and perceptions of, others (Bruner, 1990; Morf & Mischel, 2012). It is especially important during school, when children’s self-appraisal is increasingly linked to how their peers perceive them (Harter, 1982; Ladd & Trooper-Gordon, 2003), and where the development of close friendships is linked to a sense of belonging, which has a positive impact on self-worth (Bagwell et al., 1998). Yet autistic students’ social interactions are often more limited – and negative – than their non-autistic peers. They have fewer reciprocal friendships (Rotherham-Fuller et al., 2010), are often on the periphery of classroom social networks (Calder, Hill, & Pellicano, 2013; Kasari et al., 2011), and are more likely to experience social exclusion and bullying (Humphrey & Hebron, 2015). It is not surprising, then, that they often construe themselves as ‘different’ to typical peers in a negative way (Williams et al., 2017). These negative social appraisals can have a detrimental impact on young autistic people’s mental health (Hedley & Young, 2006), but there can also be personal costs to ‘camouflaging’ – or “putting on my best normal” – such as stress, anxiety and negative self-perceptions (Hull et al., 2017). Promoting fewer, high-quality friendships with peers who accept young autistic people for who they are – in line with our participants’ preferences – may well serve

to buffer the negative impact of a poor sense of self-worth, especially within the context of accepting family environments.

Second, parents spoke about striving to help their children to develop autonomy, which they understood as the ability to consider the options in front of them, respond to emerging problems, make active decisions and expect to shape some of the resulting outcomes. The young people also wanted this form of decision-making power for themselves. They were nevertheless aware of their problems with planning, organization and future-oriented thinking (Hill, 2004; Pellicano, 2012), their difficulties with getting on with everyday tasks (adaptive functioning; Hus Bal, Kim, Cheong, & Lord, 2015), and their often-debilitating co-occurring mental health issues, especially anxiety (Crane et al., 2018; Simonoff et al., 2008), all of which they felt were obstacles to achieving greater autonomy in this sense.

These observations lead directly to a deeper consideration of the preconditions for achieving effective identity and autonomy in young autistic people. Two possibilities suggest themselves from the analysis. The first concerns the role of social relationships and effective patterns of *interdependence*. The emphasis on the capacity of individual young autistic people should not, that is, be understood as being at odds with the vital role played by social relationships. Instead, close, trusting friendships with peers during high school, and navigating the inevitable conflict that occurs within these friendships, have been shown to present young people with opportunities to develop autonomy understood in the way described above – and can have cascading effects into other areas of life (Karney et al., 2007; Masten & Cicchetti, 2010; Oudekerk et al., 2015). Young autistic people’s often-limited social contact may then place them at further disadvantage (Chou et al., 2017), and social relationship-building skills thus once again appear fundamentally crucial to effective transition.

It may be for these reasons that parents were often anxious about their children’s apparent lack of motivation and/or difficulties initiating and sustaining friendships. Many young people have difficulty maintaining these relationships once the structures of school have gone, but the rates of social contact are particularly low for young autistic people, the majority of whom do not have regular contact with friends

(Taylor et al., 2016; Orsmond et al., 2013; Shattuck et al., 2011). All of these studies, however, focused on the number of friends a young person has and the frequency of those interactions, not the *quality* of those connections – and all relied on parent, rather than self, report. Here, we showed an apparent tension between what parents often wanted for their children – to *broaden* their social networks – and what the young people themselves wanted – to *deepen* a few friendships rather than expand the range of low-quality social contacts (see also Calder et al., 2013).

Their discussions painted a more nuanced picture, however. Parents' wishes were in part driven by underlying concerns about their children's social support once they are no longer living (see also McCollum, LaVesser, & Berg, 2016), and the young people also recognized that the deep and trusting relationships they often sought were difficult for them to initiate and maintain – and would likely require ongoing support, especially from their families. Their seemingly conflicting desires for relationships are bound up in their acknowledgment of their reliance on support – and may not necessarily be incompatible when we understand them in the context of mutuality and interdependence (e.g., Kittay, 2011; Lawson, 2016; Oliver, 1986). We are, after all, all dependent on others throughout our lives. The focus on autistic people achieving independence or self-sufficiency with minimal (or no) support may well be perpetuating an impossible standard, and one which may deny the reality of autistic people's needs and abilities (Brown, 2012). While participants celebrated the moments when they felt they needed less support, they also felt frequently overwhelmed by the expectation that they should be able to achieve challenging tasks all by themselves.

The second underlying factor for the development of a strong sense of identity and autonomy concerns the importance of underlying cognitive skills. The young people and their parents spoke repeatedly about their, or their children's, planning and organisational difficulties, and their problems with future-oriented thinking, which they felt were real obstacles to achieving their desired outcomes. There are good theoretical and empirical reasons to suggest that such executive processes are important in shaping the long-term behavioural outcomes of autistic people. Russell (1996, 1997) proposed that the

abilities to monitor one's actions and to act with volition are thought to be critical for developing self-awareness and a conception of other minds. Consistent with this theoretical account, there is accumulating evidence of the important contribution of such executive difficulties on young autistic people's broader social outcomes (Griffith, Pennington, Wehner, & Rogers, 1999; Pellicano, 2010, 2013), as well as their everyday adaptive behaviour (Berger, Aerts, Spaendonck, Cools, & Teunisse, 2003; Pellicano, 2013; Szatmari et al., 1989) and success in school (Pellicano et al., 2017; Pellicano, 2012). Furthermore, longitudinal analyses with the same young autistic people sampled here demonstrated that executive function measured in childhood predicted significant variation in their later adaptive behaviour, over and above individual differences in general cognitive and language ability; that is, better early executive function was related to greater functional behaviour 12 years later (Kenny, Cribb, & Pellicano, 2018; see also Szatmari et al., 1989).

Intriguingly, a recent study assessed the acceptability and efficacy of an intervention program for autistic adults specifically focused, amongst other key skills, on the development of a social support network of friends *and* on executive skills (goal-setting, decision-making) – the Acquiring Career, Coping, Executive control, Social Skills (ACCESS) Program (Oswald et al., 2017). Compared to a waitlist control group, the 'intervention' group of adults improved significantly in adaptive and self-determination skills, as reported by caregivers, and (self-)reported greater confidence in their ability to access social support in response to stress. The focus on these skills specifically, and the initial findings, are indeed encouraging. Yet the data presented herein suggest that developing relationship-building skills and, especially, exercising executive function must begin earlier in development, especially given the cascading effects such targeted support might have on young people's sense of identity and personal autonomy.

Limitations

This research is not without its limitations. First, this study focused on a group of young people considered to be cognitively able in childhood (Pellicano et al., 2006). This focus was important given that the majority of longitudinal studies include autistic people with and without an additional intellectual

disability (see Howlin & Magiati, 2017, for review), which means that we know little about the specific experiences of cognitively-able autistic adults – and what a ‘good outcome’ means to them. Nevertheless, it is unclear whether our findings are generalisable to individuals with an additional intellectual disability. Future research should seek to develop accessible methods to elicit the views and aspirations of individuals from this latter group. Second, this study was situated within the context of emerging adulthood but the absence of a group of young non-autistic people at a similar developmental stage makes it difficult to determine whether these groups shared commonalities both in their aspirations and in the putative processes shaping young people’s transition to adulthood (Arnett, 2000, 2007). That said, this study sought to move beyond such normative comparisons to ensure that young people were “at the centre of the autism conversation” (Ne’eman, 2011) – thus allowing us to examine what young autistic people want for their own current and future lives, which should inform research to identify the most effective ways of supporting them to achieve their goals.

Conclusion

This study sought to understand the subjective views and experiences of young autistic people and those of their parents as they approached emerging adulthood. Overall, the findings question whether the traditional standards to which we often hold young autistic people are developmentally appropriate and further suggest that the pressures of striving towards more normative ways of engaging in the world, especially in the absence of support from adult services, may be detrimental to their wellbeing. Instead, we identified key processes through which had begun to allow them to feel more in control of their own lives, including their developing sense of identity and personal autonomy, which appeared to be rooted in young autistic people’s executive skills and their ability to develop and maintain strong relationships with others. Fostering these underlying skills – while, critically, being attentive to individual varying needs and preferences (see also Sosnowy et al., 2018) – should serve these young people better in the longer term.

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Table 1. *Participant descriptive statistics at 12-year follow-up.*

	<i>M (SD)</i> <i>Range</i>
Chronological age (in years; months)	17; 10 (1; 2) 16; 0 – 20; 2
Intellectual functioning	
Verbal IQ ^a	91.29 (20.16) 51 – 120
Performance IQ ^a	99.17 (19.36) 59 – 133
Full-Scale IQ ^a	95.00 (18.64) 62 – 130
Current autistic features	
SCQ – Current ^b	14.88 (6.00) 5 – 26
ADOS-2 ^c	6.92 (2.18) 2 – 10
Adaptive functioning	
Vineland-2 ^d	71.68 (9.88) 53 – 100

Notes: ^aIntellectual functioning was measured using the Wechsler Abbreviated Scales of Intelligence – 2nd edition (Wechsler, 2011), $n = 24$, standard scores reported here; ^bSCQ: Social Communication Questionnaire – Current version (Rutter et al., 2003), $n = 26$, scores out of 39; ^cADOS-2: Autism Diagnostic Observation Schedule – 2nd edition (Lord et al., 2012), $n = 24$, calibrated severity scores reported here (ranging from 1 – 10; Hus & Lord, 2014); ^dVineland-2: Vineland Adaptive Behaviour Scales – 2nd edition (Sparrow, Cicchetti & Balla, 2005), $n = 28$, standard scores on the Adaptive Behaviour Composite reported here.

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Table 2. Themes and sub-themes identified from young people's interviews (n = 26).

Theme	Subtheme	Illustrative quotes
"I definitely feel more in control in my life".	<i>School was "really stressful"</i>	<p>"I silently fell further and further back"</p> <p>"The whole pressure that we're constantly under"</p> <p>"Being ostracized, not being understood"</p> <p>"I just liked being the chilled guy at the back. But that couldn't happen without the verbal abuse"</p> <p>"All the pressure and stress ... it gets a bit hard sometimes"</p> <p>"Often, things can get too much and I sort of crumble under the weight"</p> <p>"They don't say it, but you're probably not going to amount to a whole lot, so don't have too high expectations"</p>
	<i>Having come a long way since their childhood</i>	<p>"From being quite noticeably autistic to, over time, it's become less and less noticeable throughout"</p> <p>"I used to wish everybody else was autistic... I guess it's because I love my life"</p> <p>"I'm generally very happy with my progress"</p>
	<i>Opportunities to develop confidence</i>	<p>"Working once a week in a law firm was really, really important to me"</p> <p>"I've already passed two courses. I've already got two certificates"</p> <p>"I'm a bit shy when meeting people but I'm always meeting people because of my art... it's broadened my mind"</p>
	<i>Developing sense of (autistic) identity</i>	<p>"I'm kind of different to a lot of people but I can't quite put my finger on why I think that way"</p> <p>"It gives me a view of the world that's different to other people I know. If that's what you call autistic, well would I want it to be any different? Not really"</p> <p>"It's definitely important to accept that you're different. Because the sooner you accept that the more happy you'll be with yourself"</p> <p>"I do see myself as different but I do try to be as normal as possible in public"</p> <p>"I try to use the same language, I'm sure I listen to similar music"</p> <p>"My autism is so light it's kind of pretty much the exact same as a normal kid"</p> <p>"I'm not like the classic autistic kids, I'm not even anywhere near their area"</p> <p>"It's less obvious now when I meet someone that I'm on the autistic spectrum"</p> <p>"I'm quite good [at] actually appearing or sounding pretty normal"</p> <p>"If any psychologist were to look at me, I don't think they'd diagnose me with [autism] again"</p>
Just need to "take it one step at a time"	<i>Needed more time to move on up into adulthood</i>	<p>"I've agreed that I'll move out once I have a job or once I have my license"</p> <p>"I may not be living independently but that's just another step that I'll eventually get"</p> <p>"I always think of the present and maybe one or two days later. But apart from that I've never actually thought of the future"</p> <p>"[School] doesn't really do anything in terms of the real world. It's like it gives you the basic knowledge, but beyond that you sort of have to go and find your own way"</p>

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		<p>“If there was one thing I’d do, I’d stretch out Year 11 and 12 to make it three years, just because you get a lot of work in a short amount of time. And all the pressure and stress, it gets a bit hard sometimes”</p>
	<i>Important to “sort out my mental health”</i>	<p>“I can feel pretty down on myself or just in general”</p> <p>“I tend not to involve other people when I’m worried, which I know is a bad thing for me. Because I worry about it too much and that makes me over think it too much. So I want help but I just don’t tell them because I get too worried. It’s just too much anxiety”</p> <p>“The darker side of me... I can get a bit aggro”</p> <p>“One thing that keeps me calm is being with my chickens”</p>
Valuing deep connections with others	<i>Often-unfailing family support</i>	<p>“My mum and dad help me to learn and my brother does, too”</p> <p>“I always ask my sister for advice”</p> <p>“[My grandmother] was probably my most important teacher”</p> <p>“It really bonds the relationship between him and me”</p>
	<i>“Friendship quality not quantity”</i>	<p>“If it were a one-on-one with a teacher then good, but with peers, people my age, not really”</p> <p>“I am very sort of in my own head sort of person. I didn’t socialise a whole lot outside of school”</p> <p>“I probably would like to have someone to talk to because no-one knows me”</p> <p>“It’s always quality not quantity. And I’ve got a lot of friends, I definitely feel good right now”</p> <p>“I prefer being around my friends and other people as well”</p> <p>“My friends all know. But to be serious, it’s not something we really ever consider, you know. They don’t see me as a person with autism”</p> <p>“People should want to know <i>you</i>, not because you have autism, but because they’re your friend”</p>
	<i>Social networks had diminished considerably post high-school</i>	<p>“I’m sad about leaving school because I may never see my friends I’ve made over the years”</p> <p>“I’m worried that they just forget about me”</p> <p>“The good bits [about school] were when I had a close group of friends but that kind of fell apart afterwards”</p> <p>“I never had a lot of friends, like close friends. I can’t say that I’m going to keep up with them all after school”</p> <p>“It’s hard to talk to people and that really confidently”</p> <p>“I didn’t socialise a whole lot outside of school. I don’t do a lot more now, the extent that I should, I suppose, according to what’s expected”</p>
	<i>Ambivalence about getting a partner and having children</i>	<p>“Most girls that I know are really into marriage and dating and they want children and all that. I need to find someone that wasn’t really. But honestly, I’d be fine on my own”</p> <p>“I probably wouldn’t bother with children to be honest. Too much work and too much money”</p> <p>“I enjoy my own company, plus, they sound like they’re a lot of work, girlfriends”</p> <p>“I’m very good with children. I’d love to be a father one day”</p> <p>“If [same-sex marriages are] legal, I might get married”</p>

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Table 3. Themes and sub-themes identified from parents' interviews (n = 28).

Theme	Subtheme	Illustrative quotes
“We’ve come a long, long way”		<p>“Before it was, not a poor prospect, but it was that he probably wouldn’t be in mainstream school, he will need a lot of support. But now I think he will live independently”</p> <p>“He’s certainly not like the boy when he was four – it’s at the point where none of his classmates would probably even guess that he’s on the spectrum”</p>
	<i>Gains were due to the support that they had received</i>	<p>“From a child that could barely speak, to one that was able to do mathematics, he was able to write, he could speak... he was just like transformed”</p> <p>“At home [school], we’ve been able to control the environment more to meet their needs, so they’ve been able to learn... they’ve been able to not feel like they’re useless or don’t fit in”</p>
	<i>Teachers understood their child’s autism</i>	<p>“[His teacher was] just amazing”</p> <p>“[His teacher] put in a lot of effort to help him, which has been good for his self-esteem”</p> <p>“It depends on the teachers. Some are just more aware of autism and what it means for their learning and socialisation. It just depends on the individual”</p> <p>“They certainly listened to [child] when he said what he wanted”</p>
	<i>Hard road to getting the right – or, in fact, any – support</i>	<p>“I always feel it’s on us [parents], always up to us to do it all”</p> <p>“All the kids are really different and they need to try and really hone in on what’s unique about that person and try to teach them”</p> <p>“The school was very much, ‘well this is our box and you have to fit into it”</p> <p>“He does have [aide] time, but [the aide] has nothing to do with him really”</p> <p>“She’s had throughout all her education two and a half days of an assistant. But what [teacher] does with those hours, God knows”</p> <p>“He’d never ask for help. He would rather get into trouble. He wants to act normal, to be normal. He doesn’t want to be treated differently to anybody else”</p> <p>“The teacher’s aide actually went round and helped everyone in the class so it didn’t look like he was the only one that was getting [help]”</p>
	<i>Many school staff had low aspirations for their children</i>	<p>“He doesn’t get any special treatment at school and it’s because he’s doing ok, because he’s relatively high functioning and also relatively well behaved. He’s not drowning but I think he could do better”</p> <p>“No-one really believed that he had autism. They couldn’t see it, unless it was a disability like Down’s Syndrome or something you could see. He was just existing there. And he struggled”</p> <p>“He was bright and loved maths, but the teachers wouldn’t have him in the class”</p>

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<p>“I don’t know what the future holds”</p>	<p><i>Primary goal was to help their children develop autonomy and, eventually, their independence</i></p>	<p>“I don’t know what his future holds. It’s constantly on my mind. I’m hoping I’ve got my health in years to come, and what’s going to happen when I’m not around” “He’s going to outlive us. That’s our biggest worry, is what’s going to happen to him when we’re gone” “The big question mark over my head is that we’ve got to start sorting his future out – or making it easy for him to sort it out and decide. Because I just can’t keep doing everything for him. It’s not going to help him at all” “My ambition for him as always been the same, that he reaches a level where he’s able to make his own decisions” “He doesn’t want to live with me, he wants to be independent, but I just can’t see it now” “I think he is going to need ongoing support definitely throughout his life”</p>
	<p><i>Several factors that they felt hindered their child’s transition</i></p>	<p>“He doesn’t want to work. He sees no point, he has no interest... we need to get him doing something. But it’s hard when he doesn’t want to” “He wants his own money and he wants to be able to do things... it’s like the ideas are there but to actually put it into practice – it’s difficult” “He looked up the course, he made the phone calls, he did the application. He did all of that without any help from me” “He gets cross [because] he can’t express himself or can’t think about things” “He struggles with everyday tasks like cooking, things like bill management and that sort of thing. I think he just really needs the planning, whether it’s motor planning or cognitive planning, it’s a real problem for him. And organization – he’s going to need a lot of support” “He has a fairly short time horizon. Anything that’s more than a few weeks ahead is just too hard for him to get his mind around... he’s very much more in the present”</p>
	<p><i>Mental health issues were felt to be “the biggest problem”</i></p>	<p>“His mental health problem got too much and during year 11, he didn’t really make it into school. And that was when we took him off all the medication and we focused more on mental health for that year, and not so much on the academic. There’s no point in having your qualifications if you’re suicidal and depressed really in the big scheme of things” “He’s not happy, he’s never been happy” “He feels he’s being useless and I think he suppresses a lot of it but, yeah, generally depressed” “He’s better in structured situations compared to unstructured social situations that are not predictable” “You’ve got all of the smells, all the sounds, all the visual clutter, all of that he’s trying [to] assimilate. And when he’s not coping, he explodes” “He really wants to get a job but then in the next breath, it will be, ‘but I know that my anxiety is ruling my life at the moment””</p>
	<p><i>Paucity of adult services</i></p>	<p>“He needs the [early intervention] now. And there’s no services for that. They’ve got different issues now and there’s nothing we can do to help him with that”</p>

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		<p>“We’ve been with three different disability support agencies and he still hasn’t had any paid employment since he left high school”</p>
<p>The need to “keep pushing those boundaries”</p>	<p><i>School itself could be too rigid in the support they provided</i></p>	<p>“That’s what the paediatrician had actually said, ‘get rid of the aides. Let him learn to fall over’. But [the school] was very reluctant to cut it back”</p> <p>“At school he was quite protected. And then he came out into the big wide world. And of course, because he looks normal and he’s with everyone else, he can’t cope”</p> <p>“He’s gone from having an aide that never left his side when he first started [school] to them really standing back purposely to give more independence. And they’re just so happy with his progress”</p>
	<p><i>Challenges in getting the balance right</i></p>	<p>“It’s getting him to something that he feels is about him, not just some structure we’ve imposed. And that he’s got the power to change that. That’s the new terrain because, all of a sudden, he’s here and is realistically talking about the future and planning for what he wants. The challenge is to let him believe that and respecting it when we’re so used to arranging everything around him”</p> <p>“I never thought he’d get on the bus or go to school by himself but he did. And now he hops on a plane. So he is capable of doing lots of things”</p>
	<p><i>Their children needed opportunities to help “broaden their horizons”</i></p>	<p>“Because he’s in mainstream, he’s not really getting opportunities to do transport training at school or shopping skills or anything like that... I wish right from the start he received more appropriate instruction for practical life skills and that sort of thing”</p> <p>“Work experience gave him a sense of responsibility”</p> <p>“It wasn’t until the year of work experience that he realised ‘I don’t like this; I want to do something else’, that he became more opinionated about his future”</p> <p>“He doesn’t get singled out and taken out in the community ... so that’s my job really” “I would like to be more of a mum than a teacher”</p> <p>“We never expected school to do our job – we think that’s our responsibility”</p>
	<p><i>Need to take things slowly</i></p>	<p>“The line I always take is for people with autism, things happen when they’re slightly older. It just takes a bit longer to get there. And it’s making sure we’re respecting those needs of his”</p> <p>“He’s probably on the verge of getting some paid work at long last”</p> <p>“There is no way at this moment that he could ever hold down a job. Obviously, his confidence will need to increase. Just keep pushing those boundaries a bit and having those successes and making him feel good about himself”</p> <p>“He’s vulnerable because he doesn’t yet have those sort of critical interpretation skills”</p> <p>“I think he could easily be taken advantage of because of his naivety. So we’re a bit wary about things like that”</p>
<p>Having connections with people is –</p>	<p><i>Strived to foster a supportive and accepting family environment</i></p>	<p>“My approach is always to stress to him that no matter what path he takes, you know, we will support him”</p>

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<p>and will be – key for their children’s futures</p>		<p>“We’ve actually got quite a close relationship ourselves and we do talk about stuff. And there’s no such thing as a taboo topic sort of thing. And I think that’s helped” “He’s even more confident than probably typical teenagers because he’s very comfortable with his autism because we’ve never made autism anything bad in our home. He is very comfortable with who he is and that shows” “He very much looks up to his siblings... he really learns a lot from them”</p>
	<p><i>Differences in their children’s motivation to seek out social contact</i></p>	<p>“He’s got one friend in the classroom that is really good with him. But at recess or lunchtime, I think he’s on his own” “He’s not a social butterfly. He doesn’t particularly want to be going places all the time” “I think she’s happy with the number she’s got” “He craves people around him” “Nobody ever asks him to go to the movies, or come home for a meal or anything like that”</p>
	<p><i>Their children had significant on-going difficulties making friends with same-age peers</i></p>	<p>“He’s really well liked by young children and by adults, but really struggles with peer relationships” “He can’t join in with the other mainstream mates because I think the conversations happen too quickly for him to process and be able to join in, so he’d rather be on his own” “Every year, he’s had a different best friend. If they’re not in his sights, they’re not his friend” “He would be happy to go if the opportunity came up... but he will never make that initial contact”</p>
	<p><i>Have concerns about their children “socially, in the future”</i></p>	<p>“Meaningful friendships - that is a big thing. And even though he may feel that that’s what he wants, I think it would be to his overall detriment if he did go down that path” “I think she would like some friends. I told her to get some, because you can’t be going out with me all the time. But she doesn’t seem to mind. But I want her to mind. Because I’m not going to live forever” “I would have liked him to [have more close friends], but that’s more my problem than his” “I feel like one of those old manipulative matchmaking mothers sometimes because I don’t want him to be lonely. But I also don’t want to put any pressure on him”.</p>