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THE TRANSITION TO ADULTHOOD FOR AUTISTIC YOUNG PEOPLE

Section A:

Stakeholder experiences of the transition to adult healthcare for autistic young people: A systematic review and thematic synthesis

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Section B:

Transition to adulthood: Developing a consensus on support for autistic young people without learning disability in the UK

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Summary of the Major Research Project

Section A: This review explored the experiences of autistic young people, their caregivers and healthcare providers to provide a holistic understanding of the transition to adult healthcare services. A systematic search yielded 13 studies. Following quality appraisal, a thematic synthesis identified five themes (challenges within the healthcare system, unmet needs during the transition to adulthood and beyond, greater investment in services is required, integration and education could help services address unique needs, positive relationships can significantly support wellbeing). Improved support during the transition to adulthood is needed to achieve better outcomes for autistic young people, especially those without intellectual disability.

Section B: This research investigated the perspectives of autistic young adults, caregivers of and healthcare clinicians regarding the transition to adulthood for autistic young people without a learning disability in the UK. The study aimed to understand the key factors of a successful transition and what support and resources are needed to achieve this, agreed by stakeholders. A three-round Delphi study explored areas of consensus and divergence across a total of 46 stakeholders. Results indicated high consensus across statements and important factors of a successful transition, support and resources were identified. Clinical and research implications are discussed.

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THE TRANSITION TO ADULTHOOD FOR AUTISTIC YOUNG PEOPLE

Section A

Stakeholder experiences of the transition to adult healthcare for autistic young people: A systematic review and thematic synthesis

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Abstract

Background: Poor outcomes in adulthood are common within the autistic population, including health outcomes. Research regarding healthcare utilisation has found that autistic adolescents are not adequately supported during the transition to adulthood. To better understand the healthcare experiences of autistic young people and their families, and the support provided by services to meet those needs, this systematic review aimed to explore stakeholder experiences of transition from child to adult healthcare services for autistic young people. **Method:** Thirteen qualitative studies were identified through five electronic databases and analysed using thematic synthesis. The quality of studies was appraised and a sensitivity analysis was conducted. **Findings:** Five analytical themes were identified: 1) Challenges within the healthcare system, 2) Unmet needs during the transition to adulthood and beyond, 3) Greater investment in services is required, 4) Integration and education could help services address unique needs, 5) Positive relationships can significantly support well-being. **Discussion:** The importance of specialist training for clinicians, accurate information sharing, promoting trust within professional relationships and considering ‘readiness’ for transition were highlighted. Future research exploring the available and developing supports for autistic individuals, particularly those without intellectual disability, would be beneficial.

Keywords: autism, transition, healthcare, qualitative, thematic synthesis

Introduction

Autism spectrum condition (autism) is characterised by lifelong difficulties in social communication, sensory processing and flexibility of thought. Diagnostic criteria outline that autistic people experience significant difficulties in important areas of functioning (World Health Organisation [WHO], 2022). Shifting from the medical model, which labels individuals as their diagnosis, the social model views disability as a neutral characteristic, not an issue in need of cure; it highlights societal barriers to inclusion, such as physical obstacles and prejudice, rather than individual impairments (Dunn & Andrews, 2015). This paper attempts to reflect the preferred language of the autistic community (Monk et al., 2022). The research cited in this introduction is not limited to the United Kingdom (UK) unless stated.

Healthcare and Autism

Autistic adults were found to have different healthcare needs from non-autistic peers the same age (Zerbo et al., 2019), and were five times more likely to experience poor health outcomes (Rydzewska et al., 2019). Research has evidenced heightened morbidity and early mortality for autistic individuals compared to non-autistic people (Bilder et al., 2013; Hirvikoski et al., 2016; Hwang et al., 2019). This may be associated with more unmet healthcare needs, receiving less preventative care, reduced attendance at routine cancer screenings, and increased utilization of emergency care for both physical and mental health issues (Nicolaidis et al., 2013; Vohra et al., 2016; Nicolaidis et al., 2015).

Mental health difficulties are common in autism, with 70% of individuals experiencing one psychiatric disorder throughout their life and 40% experiencing two or more (Barlattani et al., 2023). Across the lifespan, autistic young adults face greater risk of heightened anxiety, depression and suicidal behaviour compared with non-autistic peers and clinical control groups (Mattys et al., 2018; Cassidy et al., 2022; Barneveld et al., 2014).

Furthermore, autistic adults are more vulnerable to negative life experiences, such as domestic abuse, which partially explains high co-occurrence of mental health issues and lower life satisfaction compared to non-autistic adults (Griffiths et al., 2019). These findings highlighted the vulnerability of autistic adults and the need for improved support services.

Unsurprisingly in the context of these needs, research showed autistic adults had significantly higher rates of emergency department use and hospitalization for ambulatory care sensitive conditions than non-autistic people (Vohra et al., 2017; Zerbo et al., 2019). Two studies identified that autistic adolescents are not adequately supported through the transition to adulthood, as they experience increased social communication issues whilst potentially managing the onset of mental health conditions during adolescence (Liu et al., 2017; Weiss et al., 2018). These studies suggested proactive care initiatives should be implemented to support autistic young people (AYP) through their transition years (Weiss et al., 2018), although further research is needed to determine the most effective initiatives.

Transition to Adulthood

The transition to adulthood refers to the period of life between childhood and adulthood. Erikson's theory of psychosocial development outlines adolescence as the period in which people develop their identity, independence and engage in intense exploration, before entering early adulthood where focus shifts to forming close bonds and reciprocal relationships with others (Erikson, 1963). These stages present challenges for everyone, yet can be particularly difficult for AYP who may struggle with managing change, cultivating daily living skills and the impact of societal stigma (Fisher et al., 2019; Turnock et al., 2022; Duncan et al., 2021).

Families are often heavily involved in the care of AYP, with additional responsibilities beyond the average parent (Broady et al., 2017). Family life cycle theory emphasizes key stages and tasks that families navigate in response to developmental transitions and challenges, such as launching children into adulthood, renegotiating parent-child relationships, and adapting to changes in caregiving responsibilities (Carter & McGoldrick, 1980). For AYP and their families enduring challenges navigating transitions are faced throughout their lives, largely due to the scarcity of available service providers and resources, including stringent and restrictive criteria for programs and funding (Milen & Nicholas, 2017). It is important for service providers to also be sensitive to parents' experiences and ready to provide support (Yu et al., 2018).

The difficulties AYP experience during transition often lead to poor outcomes in adulthood compared to non-autistic people. One review of demographic-based disparities in the transition to adulthood for AYP found that ethnic minority and low-income individuals were more likely to be disconnected from educational, occupational, and social activities upon entering adulthood (Eilenberg et al., 2019). As few as fifteen percent of autistic adults live independently (Lambe et al., 2019). The majority of autistic adults are unemployed despite wanting to work and those who do can struggle to maintain employment (Griffiths et al., 2016). Autistic students attending higher education are at greater risk of drop-out than their non-autistic peers (Dijkhuis et al., 2020). Autistic adults participate less in their community and have lower perceived importance of participation in productive, social and recreational activities compared to the general population (Song et al., 2022). Planning for and ongoing support during the transition to adulthood is necessary to improve outcomes for AYP.

Existing Transition Support

Bronfenbrenner's ecological systems theory suggests that human development can be understood within the context of the various systems (termed microsystem, mesosystem, exosystem, macrosystem and chronosystem), and emphasises the reciprocal interactions between individuals and their environments across multiple dimensions (Bronfenbrenner, 1977). Various systems exist around autistic individuals to support them during the transition to adulthood, including family, healthcare professionals and schools (microsystem), healthcare systems and service policies (exosystem), to legislation, cultural beliefs and sociopolitical movements (macrosystem).

The UK Children and Families Act (2014) led to reform whereby any child with special educational needs (SEN) could request an assessment to obtain an education, health and care plan (EHCP). These offer support up until age 25 and include planning for the transition to adulthood. Unfortunately, for AYP there are huge discrepancies in EHCP's across local authorities (Gaona et al., 2020). Occasionally, school staff did not support requests for EHCP needs assessments for autistic pupils, assuming the threshold for support would not be met (Martin-Denham, 2022). Since these reforms, parents of AYP have reported en-masse that their experiences have not improved (Crane et al., 2023).

A review of interventions supporting healthcare access for autistic persons found the most utilised interventions related to care planning and were typically person-centered (Walsh et al., 2023). Emerging literature suggests healthcare professionals in child and adult services should support early transition planning with AYP and their families to enhance opportunities for meaningful interactions with AYP and progress at a pace suitable for developing an understanding of their autism and mental health needs (King et al., 2020). Transition planning (a document outlining a young person's needs, wants, preferences and concerns ahead of the transition to adult mental health services) is an effective intervention for supporting AYP beyond their teenage years (White et al., 2019). The extent to which transition planning happens consistently within healthcare settings remains unclear. One study estimated that 25% of AYP had worked with their doctor to understand changes to their healthcare as they age, significantly less than peers with other mental, behavioural or developmental conditions (Zablotsky et al., 2020). A review examining stakeholders' experiences of transition between child and adult healthcare services would gain a holistic insight into transition planning and the support services provide to meet the needs of AYP.

Previous Reviews

No previous systematic reviews exploring stakeholders' experiences regarding the transition to adult healthcare services for AYP were identified. However, a review looking at the transition between mental health services for all young people identified service gaps for those with neurodevelopmental conditions (Hill et al., 2019).

Two reviews more broadly focused on the transition to adulthood for autistic individuals, including education and social care (Anderson et al., 2018; Crompton & Bond, 2022). Anderson et al. (2018) reported factors contributing to poor transition outcomes including environmental fit, uncertainty around parental roles and a lack of appropriate services. Crompton and Bond (2022) reported the challenging experiences of participants and barriers to support in addition to facilitative factors such as increased inter-agency collaboration, inclusivity and individualisation.

Rationale and Aims

To summarize, autistic adults experience poor outcomes compared to non-autistic adults across various domains, including mental and physical health. This results in persistent healthcare utilisation in adulthood and, in too many cases, early mortality. Research regarding healthcare utilisation found that autistic adolescents are not adequately supported during the transition to adulthood.

The transition to adulthood is a particularly difficult period for AYP and their families to navigate. A change in UK legislation in 2104 led to reforms aiming to improve support for individuals with additional needs, including planning for the transition to adulthood in collaboration with health and social care services. However, these reforms have reportedly not led to meaningful change. Interventions related to transition planning can be effective in supporting the transition between healthcare services for AYP and their families, although the extent and consistency of transition planning varies between services. Exploring stakeholders' experiences of the transition between child and adult healthcare services for AYP may enable a deeper understanding of the healthcare needs of AYP and their families, and the support required by services to meet these needs. This knowledge may have valuable implications for clinical practice and policy.

This review sought to review and critically appraise existing qualitative literature investigating the healthcare transition experiences of autistic individuals, their caregivers and healthcare providers working with AYP. Qualitative research, which solicits the viewpoints of those with lived experience of the issues being investigated, is uniquely positioned to understand the processes underlying poor outcomes.

This review aimed:

1. To examine key stakeholders' experiences of transition planning and support provided by healthcare, mental health and neurodevelopmental services for transition-age AYP.
2. To get an in-depth understanding of what the core difficulties are during transition to adult services and how services could better support AYP.

Method

Search strategy

A search of five electronic databases (ASSIA, MEDLINE, CINAHL Complete, PsycINFO and Web of Science) was conducted in May 2023 to obtain relevant papers across health and social science literature. Two papers identified by Google Scholar were also included.

Eligibility criteria

Inclusion and exclusion criteria are outlined in Table 1. Eligible papers used qualitative designs, as this review aimed to explore the in-depth experiences of stakeholders. In studies recruiting individuals with other neurodevelopmental disorders, at least 50% of the sample required an autism diagnosis for inclusion, ensuring that autism remained central to the review. Papers were not limited to the UK, which would maximise relevance to the National Health Service (NHS), as a feasibility search indicated a lack of UK-based research. To ensure studies related to recent and relevant policy, papers were limited to those published between 2014-2023. Studies reporting on targeted transition interventions were excluded, as they did not qualitatively explore experiences.

Table 1

Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
• Research exploring the experiences of stakeholders on the transition between child and adult healthcare services for autistic young people	• Research that did not explore the experiences of stakeholders on the transition between child and adult healthcare services for autistic young people
• In neurodivergent samples, at least 50% of the sample had a diagnosis of ASC	• In neurodivergent samples, less than 50% of the sample have a diagnosis of ASC
• Qualitative design or mixed methods with a qualitative element e.g. interviews	• Only quantitative data are reported
• Published from 2014 onwards	• Research over 10 years old
• Published in English language	• Not accessible in English
• Published in a peer-reviewed journal	• Not peer-reviewed research
	• Not primary research (e.g. review articles)
	• Research exploring the experience of targeted transition interventions

Literature search

Initially, Google Scholar was searched to consider the terminology used in relevant articles and develop search terms (Table 2).

Table 2

Review search terms

Search terms	Boolean Operator	Search location
Autis* OR Asperger	AND	Abstract
Transition to adult*	AND	Abstract
Mental health service OR healthcare service OR neurod* service	AND	Abstract
Experience OR perspective OR view OR perception	AND	Full text

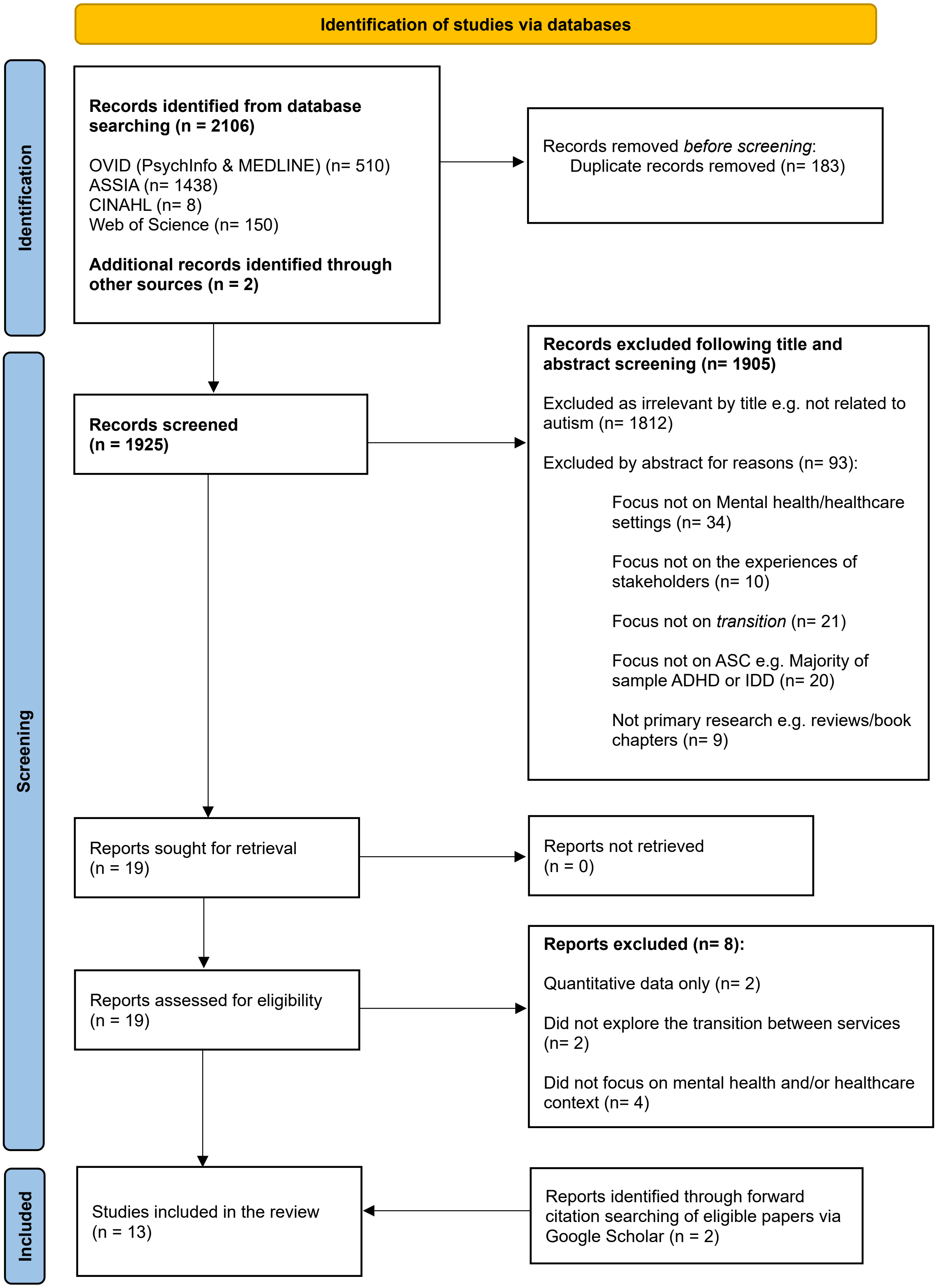
Stakeholder OR young p* OR adolescent OR young people OR young adult OR parent OR carer OR famil* OR staff OR professional OR clinician	AND	Full text

This review was performed according to the Preferred Reporting Items for Systematic Review and Meta-analyses (PRISMA; Moher et al., 2009), see Figure 1.

Three databases were searched separately, PsycInfo and MEDLINE were searched through the platform OVID, yielding 2106 results. All results were imported into ‘RefWorks’, a web-based database manager, and duplicates were removed. Papers were screened by title, then 113 papers by abstract and finally 19 papers by full text to assess their relevance; 11 were identified as eligible. The reference lists of eligible papers were hand-searched for relevant articles and forward citation searching via Google Scholar identified two new papers. To ensure this review furthered existing knowledge, PROSPERO was searched for similar reviews and in their absence a systematic review protocol was registered (registration number: CRD42023467407). Finally, grey literature was searched using ‘OpenGrey’ to mitigate the possibility of publication bias, however this did not yield any results. A total of 13 papers were included in the review.

Figure 1

PRISMA flow diagram



Approach to quality appraisal

Several tools exist to evaluate the methodological rigour of qualitative studies. The primary quality tool for qualitative evidence synthesis used within the Cochrane and WHO guidelines is the Critical Appraisal Skills Programme (CASP; Noyes et al., 2018). The CASP comprises a 10-item checklist, each appraising a distinct methodological aspect of qualitative research to assess strengths and limitations of a study. It focuses on uniquely qualitative characteristics, such as the reflexivity of researchers, making the CASP tailored to qualitative evaluation (CASP, 2018).

The CASP was used in this review as it is an easy-to-understand framework for novice researchers which is widely recognized in health and social care research (Singh, 2013; Hannes & Bennett, 2017). However, the CASP is limited by its failure to address the clarity and suitability of a study's qualitative paradigm. Qualitative researchers need to report their philosophical approach to inquiry as this impacts how their methodology is understood (Dixon-Woods et al., 2004). Long et al. (2020) recommended that a study's theoretical underpinnings should be considered during quality appraisal and proposed an amended CASP. A fourth response option was used when authors 'somewhat' met the specified criteria. The adapted CASP checklist (Long et al., 2020) was used to appraise the quality of included studies.

The quality of the appraised studies varied according to CASP criteria. As no standardised threshold for the inclusion of papers following quality appraisal exists, the subjective threshold being applied should be reported (Carroll & Booth, 2014). A variety of rationales have been reported, for example, inclusion is decided based on the review aims (Long et al., 2010), transparency in the reporting of decision-making (Noyes et al., 2018) or determined by the level of rigour, credibility and relevance of studies (Chenail, 2011). Published reviews have based thresholds on a certain number of criteria being met, ranging from all criteria (Franzel et al., 2013) to studies being excluded if they satisfy only 25% of criteria (Carroll et al., 2012). Cochrane recommended practice is to sort studies into categories of low, medium and high quality (Noyes et al., 2018). Without guidance on what constitutes low, medium and high quality existing, this review categorised quality based on the number of criteria answered with ‘yes’ (1-3: Low, 4-8: Medium and 9-11: High). Therefore, at least 4/11 CASP criteria need to be marked ‘yes’ per paper to be considered satisfactory quality and included in the review.

Approach to synthesis of findings

Sections titled ‘Findings’ or ‘Results’ were extracted from included papers and imported into NVivo Qualitative Data Analysis Software, including text in abstracts and all quotations presented. As this review aimed to understand the transition to adult services for AYP through the experiences of key stakeholders involved in transition planning and support, thematic synthesis was considered to be an appropriate approach for developing new interpretations of data as a whole. The method of thematic synthesis was developed for use in systematic reviews to understand public health issues from the experiences of those targeted by specific interventions (Thoman & Harden, 2008).

Following quality appraisal, a thematic synthesis was completed using the method outlined by Thomas and Harden (2008). Thematic synthesis began with line-by-line inductive coding producing at least one code based on the meaning and content of each sentence (Thomas & Harden, 2008). This resulted in a total of 45 initial codes, a sample is presented in Appendix B. This stage also included axial coding, checking for consistency across the interpretation given to coded text before moving on to the second stage (Fisher, 2006). Secondly, codes were grouped based on similarities and differences to produce 12 descriptive themes. Finally, descriptive themes were interpreted to develop five analytical themes in line with the review question.

To improve reliability within the coding process, a peer familiarised with thematic synthesis and independent of this review organised all descriptive themes into analytical themes, achieving an inter-rater agreement of 100%. The framework developed was reviewed by the research supervisor and discussed to reach a consensus. An external supervisor was available to resolve disagreements although was not needed. A sensitivity analysis, whereby studies of ‘lower quality’ were excluded from the synthesis to evaluate their impact, was conducted to ensure the rigour and transparency of results as recommended in existing research (Carroll & Booth, 2014; Langer et al., 2015).

Whether the exclusion of studies following critical appraisal is meaningful to the synthesis of data has been debated. A post-hoc sensitivity analysis can quantify the impact of excluding studies and was conducted in line with previously published reviews using thematic synthesis, by identifying the lowest quality studies based on critical appraisal criteria and removing them from the synthesis (Carroll et al., 2012; Franzel et al., 2013).

Reflexivity

The main reviewer has direct professional and indirect personal experience supporting transition age autistic people and their families. As a result, the review was performed with familiarity of the issues faced by autistic young people that informed the synthesis of findings. For example, working within a healthcare system facilitated relation to both the barriers faced by autistic young people and the organisational limitations outlined within the findings of papers. It was important to be aware of this positioning to prevent attributing greater meaning to such findings than was warranted from the published text.

Results

Summary of papers

Overall, 13 papers published between 2015-2023 met the inclusion criteria. Eleven papers used fully qualitative methodology, with two (Crane et al., 2019; Merrick et al., 2020) using a mixed-methods approach. Ten papers included caregivers of autistic individuals in their sample, six included AYP, and four included healthcare professionals. Four studies were conducted in the UK, six in the USA, one across the USA/Canada, one in Canada, and one in Australia with some European participants. This demonstrates a white Western individualistic bias commonly noted within psychology research which limits the transferability of findings (Nielsen et al., 2017; Taylor & Rommelfanger, 2022).

The aims of included studies varied. Eight studies aimed to explore the experiences of healthcare transition (Cheak-Zamora & Teti, 2015; Cheak-Zamora et al., 2017; Anderson & Butt, 2018; Crane et al., 2019; McMinn et al., 2019; Merrick et al., 2020; Shanahan et al., 2020; Ames et al., 2023). Five studies sought to identify strategies and support to improve healthcare services and facilitate transition (Kuhlthau et al., 2015; Crane et al., 2019; Culnane et al., 2020; Ames et al., 2023; Berg et al., 2023). Three studies aimed to understand the issues and barriers surrounding transition support for AYP (Culnane et al., 2020; Schwartz et al., 2020; Ghanouni & Seaker, 2022). Table 3 denotes study characteristics. Predominantly, participants were white, middle-class and represented the experiences of autistic males (Table 4).

Table 3

Summary of study characteristics

Authors/Year	Title	Country	Aim(s)	Sample	Design	Methods	Analysis	Key findings
Cheak-Zamora & Teti, 2015	“You think it’s hard now … It gets much harder for our children”: Young people with autism and their caregivers perspectives of healthcare transition services	USA	To generate new understanding around the healthcare transition experiences of both young people and caregivers.	19 primary caregivers of an AYP aged 15-25 years *AND* 13 young people with ASC aged 15-25 years and “at least minimal verbal ability”	Qualitative	Semi-structured focus groups	Theme analysis	• Caregivers felt there was little support during the transition from paediatric to adult-oriented care, which created tremendous ‘angst’ and unease for both caregivers and young people. • Caregivers felt their healthcare providers did not understand autism, how it manifested in each person, and the needs of young people and caregivers. • All caregivers worried about losing guardianship, believing it would result in reduced access to needed care and poor health outcomes for young people. • Young people were largely unaware of the transition process and what role providers could/should play in their lives. • Caregivers and young people felt the transition to independence was important and worrisome, but their views about it were largely discordant.
Schwartz et al., 2020	Caregivers’ perspectives on health-care transition in autism	USA	To advance understanding of issues in transitioning to adult care for adults with ASC of ethnically diverse backgrounds. To focus on provider and system-level factors, such as interactions	9 primary caregivers in the home setting to an adult with ASC (mean age 23 years)	Qualitative	Semi-structured interviews lasting 30-60 minutes	Inductive theoretical analysis	•Quantity of healthcare services: Difficulties finding providers, refused treatment due to challenging behaviour, “ageing out” of paediatrics and consequently “going without” services. • Quality of healthcare services: Some high-quality medical care whilst low-quality healthcare included poor communication and long wait times or ineffective services. • Cost of services: High financial costs to manage the health of autistic family members. Families paid to receive higher quality services/products than those covered by health insurance, or went without services/health items.

			with healthcare systems and insurance.					• Cascading effects: Barriers with quantity, quality and cost of services created negative spirals.
Crane et al., 2019	‘Something needs to change’: Mental health experiences of young autistic adults in England	England	To find what young autistic people’s views and experiences of mental health problems and services are. To explore how we can best support young autistic people who are experiencing mental health problems.	130 participants aged 16 to 25, who had received a diagnosis of ASC and lived in England	Mixed-methods	Online survey and semi-structured interviews	Inductive thematic analysis	• Not understanding my normal: participants felt uncertainty regarding the distinction between autism and mental health, as well as experiencing difficulties navigating a neurotypical world. • Stigma was commonly reported. Participants felt it was important for professionals to address issues such as stigma with friends/family members of a young person. • Barriers to support include a lack of available services, not meeting thresholds for services and lengthy waiting times. It was felt that services are not often tailored to individual needs, often discharge young people before they feel ready and different services seem “disjointed”. The poor transition from child to adult services was seen as an area of particular concern. • Family and friends were perceived as a strong source of support. Strong, trusting relationships were strived for with professionals too.
Berg et al., 2023	“Don’t Promise Something You can’t Deliver:” Caregivers’ advice for improving services to adolescents and young adults with autism	USA	To amplify caregivers’ priorities in recommending improvements to system-level services and supports provided to transition-age young people with ASC.	174 primary caregivers to an adolescent or young adult (age 16 to 30), who had been diagnosed with ASC	Qualitative	Semi-structured interviews lasting 50-180 minutes	Inductive reflexive thematic analysis	• A clear “roadmap” for navigating the service landscape is needed. • Need to improve access to existing services by removing barriers (e.g., inadequate funding, policy limitations, extensive waiting lists). • An absence of needed services and appropriate training for professionals. • More education on autism needed; for providers, for families and especially the need for societal awareness and education, alluding to experiences of intolerance and disrespect.

								• Nearly half of the caregivers (46%) who provided a logistical directive for how services could be improved also articulated a need related to relationship-building.
Culnane et al., 2020	Development of the Fearless, Tearless Transition model of care for adolescents with an intellectual disability and/or autism spectrum disorder with mental health difficulties	Australia primarily (9 European participants)	To understand the barriers to achieving effective transition and the supports required from the perspective of parents and carers, adolescents with intellectual disability and/or autism spectrum disorder and co-existing mental health disorders (often termed 'dual disability'), and those who provide services to this group. To develop an informed model of shared care to improve the transition of adolescents with dual disabilities.	18 carers of young adults with dual disabilities *AND* 1 young adult with a dual disability *AND* 62 internal and external stakeholders were also Interviewed e.g. general practitioners, paediatricians and policy makers	Qualitative	Surveys and semi-structured interviews	Inductive thematic analysis	• Stakeholders recognized variability in planning for the transition of patients as a challenge. • The disconnect between the health and disability sectors was perceived as a barrier (flawed communication systems and inherent differences between paediatric/adult health, and health/disability systems). • A lack of available/appropriate services in the community was consistently reported by clinicians and carers. • Lack of family and patient preparedness to transfer, resulting in high levels of carer anxiety. • Carers consistently reported their child's medical, social, vocational, developmental, and sexuality needs were not met to their satisfaction during the transition period. • Providing specialized training opportunities to upskill and empower mental health/general practitioners was noted as a primary area of importance, along with the need to develop an expert network.

Merrick et al., 2020	Experience of transfer from child to adult mental health services of young people with autism spectrum disorder	UK	To gain a greater understanding of the experience of transition for individual young people with both ASC and additional mental health problems. To identify predictors of transfer to adult mental health services or discharge to primary care.	93 young people aged 14–21 years, with ASC and additional mental health difficulties	Mixed methods	Case study approach using clinical notes, questionnaires, observation and “discussions”	Framework analysis	• Varying engagement regarding medication, accepting help and attending appointments found. • Support services accessed included counsellors at school/college, local authority services, autism teams and family practitioner support. Gaps in services/unmet needs reported. • Mental health impacted school/work e.g. changes in medication, anxiety and depression, re-referrals to services. • Crisis incidents varied (A&E attendance, self-harm, crisis team involvement and urgent appointments). • Family experiences included parental concern and advocacy, conflict, challenges around AYP leaving the family home and family physical/mental health difficulties. • Mixed education and post-education opportunities e.g. college/university, meaningful day-time activities, volunteering, work. •Adolescent and developmental needs included romantic relationships, independent skills, bullying/friendships, experience of transition and pervasive effect of autism.
Shanahan et al., 2020	Experiences of transition from children's to adult's healthcare services for young people with a neurodevelopmental condition	England	To gather evidence from young people (and their families) who had experienced transition from children's to adult specialist healthcare services	6 young people aged 18-24 years with a self-reported diagnosis of ADHD, ASC and/or ID *AND* 11 family members were interviewed	Qualitative	Semi-structured interviews	Interpretative phenomenological analysis	• Parents as advocates: parents were the dominant voice and navigated systems that seem “unfathomable”. • A lack of social opportunities and adult healthcare services was found. Private healthcare was sought and families worried about when EHCPs ended. • Lack of information sharing: confusion around where to get help, what support is on offer, and experiences of having to search for help rather than it being offered. • Transition as a binary, abrupt change: this was difficult for young people to understand, leading to stress and confusion for them and their families.

				on behalf of the young person if they were unable to verbally communicate with the researchers.				
Cheak-Zamora et al., 2017	Exploration and Comparison of Adolescents With Autism Spectrum Disorder and Their Caregiver's Perspectives on Transitioning to Adult Health Care and Adulthood	USA	To explore and compare the perspectives of adolescents with ASC and their caregivers by examining their healthcare transition and health-related independence experiences and needs through interviews and focus groups	27 dyads of adolescents aged 16-25 years with ASC and their primary caregivers	Qualitative	90-minute focus groups for caregivers AND 30-60 minute semi-structured interviews for adolescents	Thematic analysis	• Efforts towards independence: health-related independence was challenging (identifying a medical need, making/ accessing/attending an appointment, and following medical instructions). • Low Self-Efficacy for Adolescents' Independence: Caregivers' lacked confidence which stemmed from uncertainty about their child's capacity as well as what role they should have assumed to best support their child's autonomy. Adolescents also expressed uncertainty, but their lack of confidence came from a lack of experience of independence. • Desire for Independence: Nearly all caregivers said independence/autonomy of children was a desired goal, most adolescents agreed. What that independence should look like and how it could be achieved were more challenging questions.
Ghanouni & Seaker, 2022	Healthcare Services During the Transitions to Adulthood Among Individuals with ASC Aged 15–25 Years Old: Stakeholders' Perspectives	Canada	To investigate the stakeholders' experiences and views about barriers to receiving healthcare services for young people with ASC during their	17 parents of individuals with ASC aged 15-25 years *AND* 3 service providers who worked with individuals	Qualitative	60-minute semi-structured interviews	Interpretive description with thematic analysis	• Accessibility and Quality of Care: Autistic individuals often required specific healthcare services, which highlighted the importance of the role and interactions of healthcare providers with patients and families. • Tensions and Conflicts: The different perspectives between stakeholders made the process of transition challenging. • Navigation and Integrated Care: During the transition, the landscape of services and how to receive them often drastically

			transition to adulthood.	with ASC for at least one year				changed and adaptation to the new situation resulted in several challenges.
McMinn et al., 2019	Mothers' experiences of the transition of young people with autism spectrum disorder to adult care	England	To explore the experiences that mothers of children with autism spectrum disorders have had of the transition from child to adult support services.	6 mothers of a young adult (age range 18-24) with a diagnosis of ASC	Qualitative	45-75 minute semi-structured interviews	Interpretative phenomenological analysis	• Negative experiences: All mothers had an adverse emotional response to transitioning their children to adult services and struggled with a perceived lack of control over the process. • Resources to cope: Taking care of autistic children was physically and emotionally exhausting. Accounts included the personal resources that were available to them which enabled them to cope with the proliferating stresses of transition. • Facilitating self-preparation: This theme highlighted considerations that influenced self-preparedness in these mothers e.g. "the influence of an informed other" and a "cultivating activism-maintaining passivity" continuum.
Ames et al., 2023	Opportunities for Inclusion and Engagement in the Transition of AYP from Paediatric to Adult Healthcare: A Qualitative Study	USA	To place autistic perspectives and experiences at centre stage in order to directly and accurately capture their healthcare transition experiences. To identify opportunities and improvements to make healthcare more inclusive	8 paediatric and adult primary care and mental health providers working with transition-aged patients with an ASC diagnosis *AND* 14 AYP aged 14-25 years *AND* 17 caregivers of AYP	Qualitative	30-120 minute semi-structured telephone interviews	Thematic analysis	• Leaving the paediatric comfort zone and navigating the healthcare transition without guidance: there were unclear expectations for the transition among autistic patients, caregivers, and providers with respect to patient agency in healthcare decision making, assessments of transition readiness, and shifting roles of the caregiver. • Health consequences of a passive healthcare transition: Passivity manifested in two problematic patterns, (a) an episodic model of adult care defined by crisis management rather than regular preventive care, and (b) neglect of sexual health topics, both of which made AYP more vulnerable to certain adverse health consequences in adulthood. • Strategies for inclusion and continuous engagement: more gradual timing of transition, support for the handoff between

			and accessible to neurodivergent individuals.					paediatric and adult care, and transition-focused clinical tools and accommodations.
Kuhlthau et al., 2015	Paediatric provider's perspectives on the transition to adult health care for young people with autism spectrum disorder: Current strategies and promising new directions	USA & Canada	To identify the current strategies that ASC-expert paediatric providers are using or designing to help facilitate transition to adult health care for this specific group.	19 healthcare professionals	Qualitative	1 hour semi-structured interviews	Framework analysis	• Five interventions to facilitate transition were in place and seven were identified as needed. Strategies were being used in some locales, while desired in others. • All of the interventions in place were operating within paediatric practices serving autistic individuals. Among the needed interventions, three would operate within paediatric practices and three would be implemented outside. Two of the desired strategies would be implemented both within and external to paediatric practices.
Anderson & Butt, 2018	Young Adults on the Autism Spectrum: The Struggle for Appropriate Services	USA	To find out more about families lived experience of the availability and quality of publicly funded adult services.	35 families including a young adult with an ASC diagnosis who had left high school within the last 15 years	Qualitative	Unstructured interviews	Constant comparative method	• Bureaucracy and Fighting for Access: Families found the need to master the jumble of intersecting systems and services for autistic adults daunting, yet they felt intense pressure to do so or they'd be left without services at all. • Staffing Issues: The restricted funding available for adult services had a number of consequences related to service-providing personnel from inadequate wages to poor staff quality. • Program Suitability: The heterogeneity of the autism spectrum meant that programs that were good for one individual were not be suitable for another. • "Doing It Yourself": If a family had no access to services, or felt available services were not suitable, they ended up having to create their own activities as well as screen and hire staff.

Table 4

Summary of participant characteristics

Authors/Year	Title	Total Participants	Age	Gender	Ethnicity	Socioeconomic factors
Cheak-Zamora & Teti, 2015	"You think it's hard now … It gets much harder for our children": Young people with autism and their caregivers perspectives of healthcare transition services	AYP (n=13)	Range 15-22	Male (n=11) Female (n=2)	Unknown	Unknown
		Caregivers (n=19)	Unknown	Male (n=2) Female (n=17)	Unknown	
Schwartz et al., 2020	Caregivers' perspectives on health-care transition in autism	Caregivers (n=9)	Mean age= 57.25	Male (n=1) Female (n=8)	White (n=5) Hispanic (n=4)	Parent education: College education or more (n=9)
		AYP represented (n=9)	*Mean age= 23*	*Male (n=7)* *Female (n=2)*	*White (n=7)** *Hispanic (n=4)** **reported ethnicity of AYP >100% which may indicate mixed ethnicity, but this is unclear*	
Crane et al., 2019	'Something needs to change': Mental health experiences of young autistic adults in England	AYP (n=130)	Range 16-26	Male (n=42) Female (n=66) Non-binary (n=19) Prefer not to say (n=3)	White (n=115) Black (n=1) Asian (n=6) Mixed (n=5) Other/prefer not to say (n=3)	Highest qualification: General Certificate of Secondary Education (n=29) A/AS levels (n=50) First degree (e.g. BA, BSc) (n=23) Higher degree (e.g. MA, MSc, PhD) (n=7) National Vocational Qualification (NVQ) (n=7) Other or no qualifications (n=8)
Berg et al., 2023	"Don't Promise Something You can't Deliver:" Caregivers' advice for improving services to adolescents and young adults with autism	Caregivers (n=174)	Range 35-72	Male (n=15) Female (n=159)	White (n=139) Black (n=26) Other (n=9)	Household income: <$40,000 (n=33) $40,000 to $74,999 (n=42) $75,000 to $99,999 (n=22) $100,000 to $150,000 (n=40) $150,000+ (n=37)
		AYP represented (n=174)	*Range 16-30*	*Male (n=125)* *Female (n=49)*	*Ethnicity of AYP not explicitly reported*	
Culnane et al., 2020	Development of the Fearless, Tearless Transition model of care for adolescents with an intellectual disability and/or	AYP (n=1)	Unknown	Female (n=1)	Unknown	Unknown
		Caregivers (n=18)	Unknown	Unknown	Unknown	Unknown
			Unknown	Unknown	Unknown	Unknown

	autism spectrum disorder with mental health difficulties	Professionals (n=62)				
Merrick et al., 2020	Experience of transfer from child to adult mental health services of young people with autism spectrum disorder	AYP (n=93)	Range 14-18 at the beginning and 16-21 at the end of the study	Male (69.5%) Female (30.5%)	White British (98.3%) Other unknown	Education/Employment: Full/part-time education (n=77) Employed (n=7) Not in education or employment (n=9)
Shanahan et al., 2020	Experiences of transition from children's to adult's healthcare services for young people with a neurodevelopmental condition	AYP (n=5) Caregivers (n=11)	Range 18-24 Unknown	Male (n=5) Unknown	Unknown Unknown	Unknown
Cheak-Zamora et al., 2017	Exploration and Comparison of Adolescents With Autism Spectrum Disorder and Their Caregiver’s Perspectives on Transitioning to Adult Health Care and Adulthood	Autistic young adults (n=27) Caregivers (n=27)	Range 16-25, Mean age= 19.19 Unknown	Male (74.1%) Female (25.9%) Male (11.1%) Female (77.8%) Unknown (11.1%)	Non-Hispanic White (96.3%) Unknown (3.7%) Non-Hispanic White (96.3%) Unknown (3.7%)	Household income <$15,000 (8%) $25,000–$49,999 (32%) $50,000–$99,999 (44%) $100,000 (16%) AYP highest level of education: Some high school (15.4%) High school (61.6%) Some college or vocational program (19.2%) Bachelor’s degree (3.8%) Mother’s highest level of education: High school (15.3%) Some college or associates degree (50.2%) Bachelor’s degree (19.2%) Graduate degree (15.3%) Father’s highest level of education: High school (32.0%) Some college or associates degree (28.0%) Bachelor’s degree (20.0%) Graduate degree (20.0%)

Ghanouni & Seaker, 2022	Healthcare Services During the Transitions to Adulthood Among Individuals with ASC Aged 15–25 Years Old: Stakeholders' Perspectives	Caregivers (n=17)	Mean age= 48.93	Male (n=1) Female (n=16)	Unknown	Unknown
		Professionals (n=3)	Mean age= 35.33	Male (n=1) Female (n=2)	Unknown	
		AYP represented (n=17)	*Range 15-25, Mean age = 17.76*	*Male (n=17)*	*Unknown*	
McMinn et al., 2019	Mothers' experiences of the transition of young people with autism spectrum disorder to adult care	Caregivers (n=6)	Unknown	Female (n=6)	Unknown	Parent occupation: Charty director (n=1) Local parent support group lead (n=1) Retired nurse (n=1) Merchandiser (n=1) Former social worker/full-time carer (n=1) Learning support (n=1)
		AYP represented (n=6)	*Range 18-24*	*Unknown*	*Unknown*	
Ames et al., 2023	Opportunities for Inclusion and Engagement in the Transition of AYP from Paediatric to Adult Healthcare: A Qualitative Study	AYP (n=14)	Unknown	Unknown	Unknown	Unknown
		Caregivers (n=17)	Unknown	Unknown	Unknown	
		Professionals (n=8)	Unknown	Unknown	Unknown	
Kuhlthau et al., 2015	Paediatric provider's perspectives on the transition to adult health care for young people with autism spectrum disorder: Current strategies and promising new directions	Professionals (n=19)	Unknown	Unknown	Unknown	Occupation: Physician (n=5) Psychologist (n=5) Social workers or care coordinators (n=7) Registered nurse/paediatric nurse practitioner (n=2)
Anderson & Butt, 2018	Young Adults on the Autism Spectrum: The Struggle for Appropriate Services	Caregivers (n= 43)	Range 48-65 years	Male (n= 9) Female (n=34)	Ethnicity of parents not explicitly stated	Household income: $25K–$49,999 (n=2) $50K–$74,999 (n=2) $75K–$99,999 (n=2) $100K–$149,999 (n=12) $150K+ (n=17)
		AYP represented (n=36)	*Range 19-31 years*	*Male (n=29)* *Female (n=7)*	*White (n=30)* *Black (n=4)* *Hispanic (n=2)*	

Quality appraisal

Every study fully satisfied at least 4/11 CASP criteria. The lowest quality study at least ‘somewhat’ met 8/11 criteria. There was a weakness in describing theoretical underpinnings and addressing reflexivity across studies (Table 5). Each study reported with adequate transparency and demonstrated an acceptable level of rigour, credibility and relevance. All 13 studies were deemed satisfactory quality for inclusion in the review. The full quality appraisal can be seen in Appendix A.

Table 5

Summary of quality appraisal using the adapted CASP criteria

Paper	Clear aims?	Appropriate methodology?	Design appropriate to address aims?	Theoretical underpinning described?	Recruitment strategy appropriate?	Data collection addresses the issue?	Researcher-participant relationship considered?	Ethical issues considered?	Data analysis rigorous?	Clear findings?	Is the research valuable?
Cheak-Zamora & Teti, 2015	Yes	Yes	Yes	No	Yes	Yes	No	Somewhat	Somewhat	Yes	Yes
Schwartz et al., 2020	Yes	Yes	Yes	Yes	Somewhat	Yes	Yes	Somewhat	Somewhat	Yes	Yes
Crane et al., 2019	Yes	Yes	Somewhat	Yes	Yes	Somewhat	No	Somewhat	Yes	Somewhat	Yes
Berg et al., 2023	Yes	Yes	Somewhat	No	Yes	Yes	Yes	Somewhat	Yes	Yes	Yes
Culnane et al., 2020	Yes	Yes	Somewhat	No	Somewhat	Somewhat	No	Yes	No	Somewhat	Yes
Merrick et al., 2020	Yes	Yes	Somewhat	No	Somewhat	Somewhat	No	Yes	Somewhat	Yes	Yes
Shanahan et al., 2020	Yes	Yes	Yes	No	Yes	Yes	Somewhat	Yes	Somewhat	Yes	Yes
Cheak-Zamora et al., 2017	Yes	Yes	Yes	No	Yes	Somewhat	No	Somewhat	Somewhat	Yes	Yes
Ghanouni & Seaker, 2022	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
McMinn et al., 2019	Yes	Yes	Somewhat	No	Yes	Yes	No	Yes	Somewhat	Yes	Yes
Ames et al., 2023	Yes	Yes	Somewhat	Somewhat	Yes	Yes	Somewhat	Yes	Somewhat	Somewhat	Yes
Kuhlthau et al., 2015	Yes	Yes	Yes	No	Yes	Yes	No	Somewhat	Somewhat	Yes	Yes
Anderson & Butt, 2018	Yes	Yes	Somewhat	Yes	Somewhat	Somewhat	No	Yes	Yes	Yes	Yes

Aims and Method

Each study stated their aims and described appropriate qualitative methodologies to explore these aims. All studies explored the views and perspectives of stakeholders regarding the healthcare transitions of AYP, although exact topics differed. Generally, studies addressed a combination of three topics: understanding experiences of healthcare services and transition, exploring barriers to receiving transition support or exploring improvements to transition support.

Research Design

Most studies collected data using interviews and/or focus groups, with one study (Merrick et al., 2020) utilizing a case study approach. Six papers reported rationales for the chosen design; others provided a rationale for adopting a qualitative approach without explaining the specific design chosen (e.g. interviews over focus groups).

Theoretical underpinnings

The majority of studies did not report their theoretical underpinnings. Eight did not comment on guiding theory or epistemology. Four studies stated their theoretical framework, for example, Crane et al. (2019) described using an essentialist framework whilst Ghanouni and Seaker (2022) referred to social constructionist epistemology. Ames et al. (2023) vaguely described approaching their research “through the lens of a social model of disability”. Overall, this area was a weakness across studies and not enough information was provided to comprehend how guiding theories corresponded to chosen methodologies.

Sampling and data collection

All studies used purposive sampling; some described their approach to sampling better than others. Ghanouni and Seaker (2022) outlined a snowball sampling process with the procedure for recruitment clearly described whilst Schwartz et al. (2020) mentioned a convenience sampling method without an explicit rationale. Six papers recruited volunteers and another six approached individuals to participate, however, only two studies reported reasons for non-participation. Inadequate reporting of non-participation can conceal selection bias, which affects the credibility of findings when samples are not representative of the intended population.

Most studies reported diagnoses and co-occurring conditions of participants. Nine studies included tables of demographic characteristics, although the breadth of these varied. Age was most commonly reported (10 papers), whereas socioeconomic status was outlined financially in three studies (Berg et al., 2023; Cheak-Zamora et al., 2017; Anderson & Butt, 2018). Gender information was provided by the majority of studies. Ethnicity was recorded in six studies with some commentary on the lack of ethnic diversity within predominantly white samples (Anderson & Butt, 2018; Crane et al., 2019). Demographic information is needed to contextualise findings and assess their transferability. If demographic data is limited in a study then its contribution to knowledge is modest at best (Gibbs et al., 2007).

Studies generally provided clear descriptions of data collection. Detailed accounts gave rationales for conducting interviews, described the interview schedule and stated how data was recorded (Shanahan et al., 2020). Ames et al. (2023) shared their interview guide for full transparency, although example questions were shown in 11/13 studies. Of the remaining two studies one adopted a case study approach (Merrick et al., 2020) and another utilized semi-structured interviews (Culnane et al., 2020). Interview questions and their development should be reported to enhance replicability and allow readers to assess methodological rigour by judging if the questions appropriately addressed the research aims (Koch et al., 2014).

Reflexivity and ethical considerations

A significant area of weakness across studies was researcher reflexivity. Eight studies did not critically examine the relationship between researcher and participant. One described efforts to ensure researchers had not previously worked with participants (Shanahan et al.,

2020) and another reported there were no established relationships between researchers and participants (Schwartz et al., 2020). Ghanouni and Seaker (2022) mentioned that researchers reflected on their own assumptions, although *how* researchers worked reflexively was unclear. All accounts were too vague to understand how researcher bias influenced findings.

Every paper addressed ethical issues to some extent as 11 documented ethics committee approval. Two studies mentioned consent and nine described detailed consent processes. Confidentiality was discussed in two papers (Schwartz et al., 2020; Ghanouni & Seaker, 2022). Two studies considered adaptations for autistic participants (Cheak-Zamora et al., 2017; Ames et al., 2023) and mental capacity was addressed by Shanahan et al. (2020).

Data analysis and findings

All studies named their approach to data analysis. One paper failed to describe the analysis process (Culnane et al., 2020). The most common approach was thematic analysis, followed by framework analysis (Kuhlthau et al., 2015; Merrick et al., 2020) and interpretive phenomenological analysis (McMinn et al., 2019; Shanahan et al., 2020). Theoretical analysis and the constant comparative method were also used (Schwartz et al., 2020; Anderson & Butt, 2018). Some studies used quality measures such as double coding and reaching consensus (Cheak-Zamora et al., 2017; Merrick et al., 2020). Every study provided example data and/or direct quotations to support the results presented. However, the ability to understand conclusions is limited in the absence of clearly stated theoretical underpinnings (Long et al., 2020), as the interpretation of conclusions are subjective, which may introduce personal bias and undermine the validity of findings. Studies presented clear findings related to the research aims and most discussed issues of credibility.

Value of research

The value of research is evaluated by considering the extent to which findings contribute to existing knowledge, if the implications of findings are discussed, if areas for future research are suggested, and if limitations of the study are addressed. Every paper discussed a combination of these topics and clearly outlined the contribution to knowledge made. Areas for future research were commonly suggested. One study failed to address research limitations (Merrick et al., 2020). The transferability of findings was discussed in seven studies (Cheak-Zamora & Teti, 2015; Schwartz et al., 2020; Berg et al., 2023; Culnane et al., 2020; Cheak-Zamora et al., 2017; Ghanouni & Seaker, 2022; McMinn et al., 2019). One paper referred to limited 'representativeness' (Ames et al., 2023) and two considered limited diversity within samples (Crane et al., 2019; Anderson & Butt, 2018).

Synthesis of findings

Five analytical themes emerged from the synthesis: 1) Challenges within the healthcare system; 2) Unmet needs during the transition to adulthood and beyond; 3) Greater investment in services is required; 4) Integration and education could help services address unique needs; 5) Positive relationships can significantly support well-being. Each analytical theme describes lived experiences, identified needs or support strategies of stakeholders during the transition of AYP to adult healthcare. The themes and subthemes identified through thematic synthesis have been integrated based on Bronfenbrenner's ecological model (1977) and are depicted in Figure 2. These themes are summarised with corresponding text in Table 6. Following this, the themes are described in detail with descriptive themes denoted in bold italics.

Figure 2

Synthesis of Themes and Subthemes into a Diagrammatic Model of Transition to Adult Healthcare Services for Autistic Young People

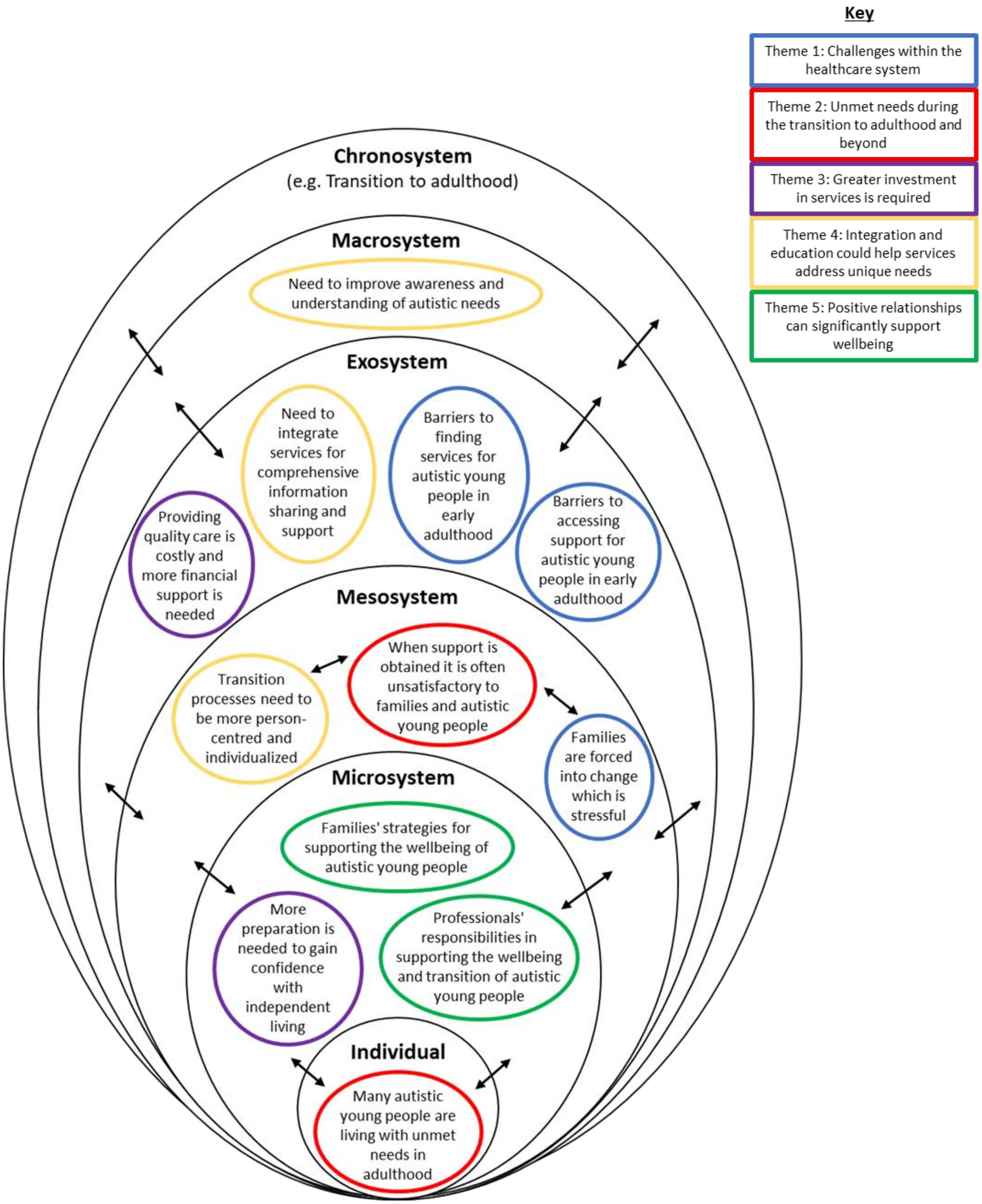


Table 6

Themes, codes and quotes used in the thematic synthesis

Analytical theme	Descriptive theme	Codes	Papers	Corresponding text (study) *Participant quotes* / researcher report
Challenges within the healthcare system	Barriers to finding services for autistic young people in early adulthood	Struggles to find services	10	"*So much falls on me as a parent*" and "*It would've been nice if services could have come to me instead of me searching for services*." (Berg et al., 2023, p. 4) "Clinicians reported experiencing frustrations when trying to find the right service and referring to adult health and disability services." (Culnane et al., 2020, p. 562)
		Low availability of services	8	"The lack of availability of adult healthcare services was mentioned in every interview." (Shanahan et al., 2020, p. 1434) "*I think what's really hard is that there are no providers within our community that are autism adult providers. There is one good psychiatrist in town who is probably ridiculously inundated at this point […] But other than that, there is really no one else that's taking on these guys*." (Kuhlthau et al., 2015, p. 267)
		Inconsistent information	8	"*I don't want a token support. I want real support that there's some kind of meaningful sharing of information…why can't this patient be at the centre of the practice group that brings two silos together and bridges a silo between paediatric and adult care?…because you really need that liaison between those two worlds*." (Ames et al., 2023, p. 1857) "Parents were unsure where to go to ask for the appropriate services: '… *he transitioned into adult's services, I don't even know where they are. I haven't got a clue, I don't know where they are based, I don't know what, you know, I don't know what disciplines there are in that team, I have no idea*'." (Shanahan et al., 2020, p. 1435)
		Impact of location	2	"Elisa, a service provider, exemplified distribution of services in rural areas and said: '*people in rural areas have a much harder time accessing services and service providers have a harder time delivering services to those in rural areas. It's way more expensive, and so the motivation isn't always there to provide accessed services to those that are farther away'*." (Ghanouni & Seaker, 2022, p. 2579) "Those who had moved away from home to attend university commented on how services in different locations did not work together effectively: '*I essentially got bounced around between systems'*." (Crane et al., 2019, p. 485)
		Ageing out of services	9	"Participants also reported that they liked their family member's childhood health-care providers, but clinic or payor policy often resulted in 18-22 year olds "aging out" of their

Families are forced into change which is stressful			paediatric provider and needing to find a new adult health-care provider.” (Schwartz et al., 2020, p. 157) “One parent described her and her child’s upset over having to leave an engaged, sensitive provider that they trusted: *‘[They had] a six year relationship. [The doctor] knew him and [asked] questions that she remembered from the last visit… That’s a doctor you want to hang on to … I think that’s hard for [our kids], not only for them but for us to trust somebody else’*.” (Cheak-Zamora & Teti, 2015, p. 995)
	Abrupt change	5	“*’It [healthcare transition] was just sort of an abrupt change… there was a conversation, but I didn’t really follow it completely and I didn’t really have that much of a care about it.’* (Post-transition patient).” (Ames et al., 2023, p. 1855) “[Parents] were frustrated with how sudden the change was for their children with there being ‘*… absolutely no continuity’*.” (Shanahan et al., 2020, p. 1435)
	Lack of control	4	“[…] all of them [mothers] indicated a sense that they were not in control of the outcome of transition or, indeed, of many circumstances within their lives.” (McMinn et al., 2019, p. 133) “[…] *as soon as you are 18, whether you’re ready or not you are being treated, [with] a different system* […]” (Ghanouni & Seaker, 2022, p. 2583)
	Learning to navigate new systems	8	“*It is just this bureaucratic system… I think that it is very difficult to navigate the system and to find the resources*.” (Anderson & Butt, 2018, p. 3916) “Caregivers described the need for a clear “roadmap” (metaphor invoked by caregivers during member checking) for navigating the service landscape.” (Berg et al., 2023, p. 4)
	Automatic legal changes	4	“Aria, a parent of a young person with ASC, explained: *‘If they [parents] had a child with an intellectual disability, up to 19 the parents are the legal guardian, but once a child turns 19, they’re considered an adult, and once you’re 19, you are assumed to have full capacity. Unless otherwise stated’*.” (Ghanouni & Seaker, 2022, p. 2580) “*Her signing a contract? The fact is she’s not going to be able to read it, and she’s not going to be able to understand it. And, someone’s going to make her legally responsible? No, no, no*.” (Cheak-Zamora & Teti, 2015, p. 996)
Barriers to accessing support for autistic young people in early adulthood	Accessing support is hard	8	“Participants identified the lack of access to specialized care, as one of the major barriers in the quality of healthcare services they receive.” (Ghanouni & Seaker, 2022, p. 2578) “Riley’s mother felt she had found a well-respected day and employment program for him, but gave up on it when she encountered barriers to access: ‘*We could not get in the first round. I remember them saying he was on a waiting list, but then I found out later that we had to reapply. It is just such a crazy system’.* ” (Anderson & Butt, 2018, p. 3917)

Long wait times	6	“*Another five, four or five year waiting list in my area and my mum basically said that she wouldn’t take me home until they assessed me because it would just end up with me having another breakdown again and again and again without an answer.*” (Crane et al., 2019, p. 492) “Caregivers reported health-care experiences that include long wait times and poor communication with the parents and adults with ASC.” (Schwartz et al., 2020, p. 158)
Time-consuming tasks	3	“An additional frustration was the fact that families were asked repeatedly to complete lengthy forms and provide years’ worth of documents to establish that their child did indeed have a disability.” (Anderson & Butt, 2018, p. 3916) “Ellie, a healthcare provider, expressed a similar sentiment from the perspective of one of her clients: ‘*Every year, you have to apply for the autism, like its autism, it’s a life-long disability, there’s no cure, … you know you have to go fill out these forms to access the money. Can they just deposit the money in there?’*.” (Ghanouni & Seaker, 2022, p. 2581)
Rigid processes	9	“One young person recalled how she sought help from a charitable/non-profit organisation as well as via CAMHS, but found out (at a time when things were progressing very well) that this additional support was not permitted.” (Crane et al., 2019, p. 485) “Another parent described feeling helpless when her son was admitted to the psychiatric hospital and did not permit anyone to help him: ‘*He’s been in [the hospital] 13 times. I know what his medications are. I know what’s going on; what the plan is. But, he would go in and say, “No! I don’t want anybody to know I’m here!” So I can’t call or talk to them. I can’t get any information. I can’t get anything’*.” (Cheak-Zamora & Teti, 2015, p. 996)
Training needed for clinicians	8	“Trainings for adult providers were perceived to be the most important and highly endorsed intervention. One paediatric provider captured the need for this training by saying: *‘I think there’s a long way to go with the adult providers around … just kind of understanding the disorder, understanding the perspective that a child with autism might come into with their visit—in terms of sensory sensitivities, anxiety, need for sameness, or need for advance preparation’*.” (Kuhlthau et al., 2015, p. 267) “Carers frequently cited that their health care providers, especially general practitioners, were not experienced in dealing with people with autism and other developmental disabilities.” (Culnane et al., 2020, p. 562)
Fighting for support	4	“We struggle and fight. . . I have to fight for every service. 'The answer is always ‘no’ in pursuit of services until I have to kick someone’s ass.” (Berg et al., 2023, p. 4) “All “activist” mothers made frequent use of the word fight and other warlike synonyms, such as battle and battlefield, to describe their experiences of acquiring support services.” (McMinn et al., 2019, p. 135)

Unmet needs during the transition to adulthood and beyond	When support is obtained it is often unsatisfactory to families and autistic young people	Dissatisfaction	3	“Interviewees were generally unhappy about the standard of the services they accessed: ‘*I wasn’t very happy with any way that my mental health was handled my whole entire life really’*.” (Crane et al., 2019, p. 486) “They were also unhappy that staff sat at a separate table during lunch playing on their phones instead of facilitating social interaction for the young adults with ID and ASC under their charge. ‘*It’s essentially babysitters’*, said Theo’s father. Dissatisfied, he and his wife were planning to switch to self-directed services.” (Anderson & Butt, 2018, p. 3918)
		Ineffective care	11	“Several parents and young people commented that 6 monthly/yearly follow-up medication clinic appointments did not meet the wider needs of young people coping with a broad range of concerns about mental health and other social and educational needs.” (Merrick et al., 2020, p. 5) “A few others described how doctors did ‘*nothing else’* (besides medication management) to help them transition to adulthood. The young people felt this was too narrow; many wanted to have broader discussions about how their medical problems and medications fit into their life as they age.” (Cheak-Zamora & Teti, 2015, p. 997)
		Negative transition experience	6	“The emotions associated with the experience of transition, for the four who had already completed the process, included accounts of fear, frustration, and anxiety” (McMinn et al., 2019, p. 132) “*There would be situations where a staff wouldn’t recognize that, “Oh, this is a special needs patient. Family needs to be in the room.” And they would ask the parent to wait outside. And then, you have this patient that’s not necessarily the most comfortable just meeting with a physician one-on-one. And the parent would become very distressed, and there would just be a very—unhappy first encounter.* (Adult provider)” (Ames et al., 2023, p. 1855)
		Poor communication	9	“Several adolescents, like E.E., were upset when their doctors did not talk directly to them: ‘_I’ve had doctors that have ignored me. That have experimented on me. . . I sat there and was like in my head, Okay, f*** you, too’_.” (Cheak-Zamora et al., 2017, p. 1034) “*They haven't really reached out to contact me or anything*.” (Shanahan et al., 2020, p. 1435)
	Many autistic young people are living with unmet needs in adulthood	Being turned away from services	6	“Family members with ASC who would demonstrate challenging behaviours, such as inability to comply with medical examinations, eloping and hitting, would be refused subsequent treatment” (Schwartz et al., 2020, p. 157) “Sue, a parent of a young people with ASC, recalled a time when she was refused a program as her son did not “fit” their criteria. She mentioned: ‘*we got a letter back [from organization] saying, ’you know I’m sorry we cannot look at your issue, your child doesn’t fit’ and they have a huge autism program’*.” (Ghanouni & Seaker, 2022, p. 2581)

		Losing support	8	“[…] another reported being dropped from their paediatric practice at age 18, with no preparation.” (Cheak-Zamora & Teti, 2015, p. 995) “You hit 18 and all your services just go poof and just disappear.” (Crane et al., 2019, p. 486)
		Going without formal support	8	“In the end, she could not place him there [within an agency] and ended up providing “*self-directed services*” at home.” (Anderson & Butt, 2018, p. 3917) “A lack of professional support resulted in many young people relying on an informal network of friends and family.” (Crane et al., 2019, p. 486)
		Diversity under considered	4	“Some caregivers identified a lack of socially inclusive services for persons of colour. One mother distilled that ‘*People who are of colour and have autism, and their families, struggle and feel excluded*’.” (Berg et al., 2023, p. 6) “Carers consistently reported their child’s medical, social, vocational, developmental, and sexuality needs were not met to their satisfaction during the transition period.” (Culnane et al., 2020, p. 563)
Greater investment in services is required	Providing quality care is costly and more financial support is needed	Expensive interventions	5	“Emma, a parent of a young people with ASC, commented on the cost of the specialized healthcare services that her son required: ‘*There was a behaviour therapist who came to my house and then um, there was no other behaviour therapist who had the same service but the problem is, her fee is $7000 a month-Where can I get the $7000 a month?’*.” (Ghanouni & Seaker, 2022, p. 2579) “Concerned about cost, one mother mentioned the need for flexible fee structures: *‘It’s a very expensive condition. Having services that have sliding scales for those in need is important’*.” (Berg et al., 2023, p. 5)
		Limitations of health insurance	4	“*Unfortunately, my daughter has had some very serious medical issues, […] We have doctors who don’t know anything about it and the doctors who do know don’t have room [for us] or won’t take Medicaid*.” (Cheak-Zamora & Teti, 2015, p. 995) “The caregivers stated that their insurance did not cover needed health expenses, such as vision, dental or therapy services” (Schwartz et al., 2020, 158)
		Families paying for quality if able	5	“ ‘*I've had concerns about [young person] over the summer and I've had to go privately … Only because I have concerns and I don't think going into the adult's services those concerns are necessarily going to be met*’.” (Shanahan et al., 2020, p. 1434) “Participants mentioned that the increase burden of care on parents can limit their ability to work full time, which further reduces the family income to afford services. Lily, a parent of a young people with ASC, explained this situation by saying: ‘*parents after having to cut back*

				[work], and go to part time to take care of their autistic child, and [then] how many can afford to pay 100 dollars an hour to mental health?'." (Ghanouni & Seaker, 2022, p. 2579)
		Funding implications in services	4	"According to families, the restricted funding available for adult services had a number of consequences related to service-providing personnel from inadequate wages to poor staff quality." (Anderson & Butt, 2018, p. 3918) "Others reported how funding for these services could be (and often was) withdrawn at short notice." (Crane et al., 2019, p. 485)
	More preparation is needed to gain confidence with independent living	Prepare early	8	"Caregivers underscored the importance of providers helping to prepare young people with ASC and their families well before key transitions. One mother simply advised, '*Get to the pipeline early'*." (Berg et al., 2023, p. 5) "One pre-transition patient appreciated how an earnest conversation with his paediatrician about entering adulthood with autism was important to his transition preparation: *'[...] It was interesting. I mean, it wasn't one of the best conversations but later on, it was probably time to talk about this, too'."* (Ames et al., 2023, p. 1854)
		Lack of confidence in independence	6	"Her son, M.L. said that '*I'd like to live alone someday'* but agreed that '*I'm worried about being alone. I'm afraid I can't take care of myself'."* (Cheak-Zamora et al., 2017, p. 1033) "There were also reported concerns about the effect of ASC characteristics on independence." (Merrick et al., 2020, p. 4)
		Practicing independence in steps	6	"One provider said young people should: '*understand what they have, and then understanding what their medicines are and then helping them learn how to refill their medicines if they can do that independently or with some help. And can they make appointments on their own, can they keep a calendar of their appointments and when they need to return to follow-up for a specific clinic*?" (Kuhlthau et al., 2015, p. 267) "Another young person stated interest in assuming more responsibility over his care, but also described how he would need to plan carefully for success: *'I'm going to have to ask [my parents] what some of the papers that they usually turn in to some of the doctors [are]. I'm going to have to ask what some of the definitions mean, because I'm going to get some random words dizzied or who knows what*." (Cheak-Zamora & Teti, 2015, p. 997)
Integration and education could help services address unique needs	Need to improve awareness and understanding of autistic needs	Educating systems about autism	3	"Four mothers indicated that they were cultivating activist attitudes: '*I want to do everything I can now to try and improve the system's awareness and understanding of people like my son'*." (McMinn et al., 2019, p. 135) "They [caregivers] urged providers to '. . .*educate the public on autism; educate adults on respect'* and identified that '*the main problem we encounter is an intolerant society*'." (Berg et al., 2023, p. 7)

	Multispecialty needs	7	“The adults with ASC required multispecialty care for multiple medical conditions seeing a variety of health-care providers such as primary care providers, specialists (neurologist, psychiatrist, gerontologist, pulmonologist, etc.), therapists (applied behavioural analysis, occupational, physical and speech and language), as well as other health professionals (such as dentists and optometrists).” (Schwartz et al., 2020, p. 156) “Several parents and young people commented that 6 monthly/yearly follow-up medication clinic appointments did not meet the wider needs of young people coping with a broad range of concerns about mental health and other social and educational needs.” (Merrick et al., 2020, p. 5)
Transition processes need to be more person-centred and individualised	Different needs per individual	10	“*We’re all different, we’re all unique and we all have our own different needs and it’s okay to meet those needs*” (Crane et al., 2019, p. 485) “[…] *when you’re talking about Autism, we’re talking about complete individuality with our children … All children with ASC are not going to look the same*.” (Cheak-Zamora & Teti, 2015, p. 995)
	Consider readiness not age	4	“Several caregivers wondered if the healthcare system could accommodate factors like developmental delays in its determination of transition readiness: ‘*Because really, even though they have a certain age… the assumption is based on that, when you become 18, you arrive at this set of knowledge that makes you adult. These kids don’t have that’*.” (Ames et al., 2023, p. 1854) “Parents expressed concern their children were 18 years biologically, but in terms of their understanding about their care, were much younger.” (Shanahan et al., 2020, p. 1435)
	Need for flexibility	5	“Adding that individuals should be looked at case by case to allow for the most flexibility and gradual shift to adult care when the young people is ready. She [parent] said: *It’s about professionals having the flexibility to think about transition as a long-term period not just a day or a week. That’s [having flexibility is] a big struggle with our system, that as soon as you are 18, whether you’re ready or not you are being treated [with] a different system’*.” (Ghanouni & Seaker, 2022, p. 2583) “She and her husband had chosen self-directed services for their son from the beginning. According to Elliott’s mother, flexibility was an advantage of such services.” (Anderson & Butt, 2018, p. 3921)
	Facilitating engagement	4	“Caregivers suggested that starting transition planning a few years earlier would facilitate their child’s engagement in the process, including choosing and getting to know their new doctor, and sustain a person-centred healthcare experience.” (Ames et al., 2023, p. 1857)

				“Those in the ‘doing well’ group had made positive references to levels of engagement with services…” (Merrick et al., 2020, p. 4)
	Need to integrate services for comprehensive information sharing and support	Disjointed services	4	“One caveat with electronic medical records (EMR) is that they are site- or organization-specific, meaning if an individual were to change from one provider to another, his or her EMR does not necessarily translate easily if the new provider uses a different electronic program.” (Kuhlthau et al., 2015, p. 265) “Participants argued that in addition to service eligibility criteria potentially being inconsistent in a city, the provincial views on ASC may also be inconsistent, making the process more challenging.” (Ghanouni & Seaker, 2022, p. 2581)
		Need for centralisation and connection	5	“Caregivers reflected on the value of a more integrated service system, stating, ‘*It would be great if they could have a one-stop shop for getting all services’* and ‘*There needs to be a place that lets you know everything available*’.” (Berg et al., 2023, p. 4) “[…] *There might be other services out there, but there is not one place where you can go and find all of the services*.” (Anderson & Butt, 2018, p. 3916)
		Varied approaches across settings	2	“Clinicians, policy makers, and educators perceived variability in planning for the transition of patients with dual disabilities in the health, disability, and community settings as a challenge.” (Culnane et al., 2020, p. 562) “The young people felt that AMHS gave more control and power to the service users to manage their own mental health.” (Crane et al., 2019, p. 486)
Positive relationships can significantly support well-being	Professionals responsibilities in supporting the well-being and transition of autistic young people	Professional attunement	6	“*She really listens. It’s not in and out, the feeling what’s going on in your body, what’s going on. She spends a lot of time with you, does blood-tests very often, which I like. Every three months or so, she’s thorough, kind, and if there is any doubt whatsoever she sends you to another specialist*.” (Schwartz et al., 2020, p. 158) “*If I go with a problem, he’s [adult provider] not just addressing my immediate concerns. He’s nice. He kind of shows a commitment to long-term help and helping me with a healthier… life in general*.” (Ames et al., 2023, p. 1858)
		Communication is important	5	“Caregivers directed, “*Be patient, use repetition, and stay calm*,” and “*Listen to the person with autism. Talk to them as a person. Have patience. Know who you are talking to, and adjust your interaction accordingly*.” (Berg et al., 2023, p. 7) “The handoff between paediatric and adult care was identified as a critical opportunity for proactive communication, not just between doctors but also between the doctors and the family.” (Ames et al., 2023, p. 1857)

	Ideas for helpful interventions	5	“For example, Paula, a parent of a young people with ASC, suggested: ‘*if there was a place or technology enabled system navigation, that would be helpful. I have been on a lot of different websites, and just to me it seems that I’m pulling together information from different sources’*.” (Ghanouni & Seaker, 2022, p. 2582) “Transition checklists were also described. Checklists vary in the types of information asked for and reported, but traditionally they provide an organized timeline of events (developmental stages/progress of the young people) and a basic “to-do list” to be completed either by the young people and their families or in collaboration with the paediatric provider, who would oversee the implementation.” (Kuhlthau et al., 2015, p. 265)
Families strategies for supporting the well-being of autistic young people	Family involvement	13	“She worked to create volunteer positions for her son, educating the local library and other organizations about his disability and the tasks he could perform: ‘*I got all these jobs for him… I just knew what my son is capable of. What he enjoys is being outdoors or in a library… I created jobs around that. Again, it was not easy […]’*.” (Anderson & Butt, 2018, p. 3920) “N.T. explained how she wrote a script to help her daughter communicate with a provider independently: ‘*I write down a [script]. . . “Here’s your name. Here’s your birthdate. Here’s your telephone number.” Because when she gets like nervous, she can’t remember those things, even though she knows all of them. I make her write it all down* […]’.” (Cheak-Zamora et al., 2017, p. 1032)
	Being proactive	2	“Two of them [mothers] focused on working through problems in a systematic manner, demonstrating a task-oriented approach: ‘*I kind of think, all the time, we’ve got to try and get the right sort of things to be written on his record so that, at some point in the future, if we’re not able to be there and they’re having to advocate for him, it’s all in writing that he’s got these support needs*’.” (McMinn et al., 2019, p. 133) “*If you as a parent aren't pro-active, in planning for the next step, the next step just ends up being a train crash because the statutory agencies don't wake up to it*.” (Shanahan et al., 2020, p. 1432)
	Peer support	4	“[…] the acts of meeting these people were identified as key events, altering their perceptions and emotional experience of the transition: ‘*I would say because I go to this [carers’] forum, these meetings, these coffee mornings, I got information from [parent carers], you know’*.” (McMinn et al., 2019, p. 135) “The young people emphasised the importance of having strong, trusting relationships with friends and family members […]” (Crane et al., 2019, p. 486)

Theme 1: Challenges within the healthcare system

In the majority of studies, participants described ***barriers to finding services for autistic young people in early adulthood***. The struggle to find services was a common experience, with families often unaware of what services existed. Some parents believed help should be offered by the healthcare system instead of needing to search for support (Shanahan et al., 2020; Berg et al., 2023). Where information had been shared to help families seek support, it was inconsistent and incomplete: “I’m having to figure all of this out, I get a little bit of information from different people” (Ghanouni & Seaker, 2022, p.2582). Clinicians also struggled to find appropriate services to refer to (Culnane et al., 2020). Difficulty finding support was likely linked to the low availability of adult healthcare services for AYP, highlighted in eight studies. There were not enough adult services or services specialised in providing for the autistic population (Kuhlthau et al., 2015; Anderson & Butt, 2018; Ghanouni & Seaker. 2022). The low availability of services was exacerbated by location, as families in rural areas experienced greater difficulty procuring support (Ghanouni & Seaker, 2022).

Several AYP and their parents spoke positively of the support they received before transitioning to adult services, mentioning good relationships with their paediatrician. Subsequently ‘ageing out’ of paediatrics and the mandatory move to adult care meant leaving familiar circumstances and was viewed negatively by many. One autistic adult commented “I would see my paediatrician if I had the chance.” (Ames et al., 2023, p.1854). The change was abrupt, with limited prior preparation and little continuity in care (Shanahan et al., 2020). This demonstrated how ***families are forced into change which is stressful***, for AYP and caregivers. There was a perceived lack of control during this transition, as processes were ultimately determined by policy and law with little input from families. Commonly, the transition to adult services occurred alongside a legal change in decision-making. For example, parental responsibility ends when a young person reaches 18 under the UK Children Act (1989), whilst privacy laws in the USA state that parents cannot make medical or financial decisions for children beyond age 18. Therefore, AYP and their families experienced multiple changes in this period and had to navigate new systems simultaneously.

Barriers to accessing support for autistic young people in early adulthood were also experienced after appropriate services were identified. Application systems made securing support hard due to ambiguous eligibility criteria and seemingly bureaucratic procedures, with one parent stating “it is just such a crazy system” (Anderson & Butt, 2018, p.3917). Nine studies described how rigid processes contributed to the difficulties experienced by families. For example, receiving statutory and non-statutory services simultaneously was prohibited and some interventions could only be completed once. Therefore, barriers to procuring support were experienced by families both before and after an appropriate service had been identified.

Participants used ‘war-like’ language in four studies (Berg et al., 2023; Shanahan et al., 2020; McMinn et al., 2019; Anderson & Butt, 2018). Parents spoke of battling or fighting against healthcare systems, implicating the strength and determination required to pursue access to support. Services had long wait times, reportedly up to five years, where families continued to provide support before young people were seen by a professional (Crane et al., 2019). Families completed time-consuming tasks to ensure continued support such as repeatedly applying for funding or providing documentation to evidence eligibility. Some families felt the effort exerted to find and access services did not merit the support received, if adult providers did not possess adequate skills to work successfully with AYP. Eight studies reported further training is needed for clinicians.

Theme 2: Unmet needs during the transition to adulthood and beyond

Negative experiences were reported overwhelmingly more than positive experiences. This could suggest that ***when support is obtained it is often unsatisfactory to families and autistic young people***. Eleven studies referred to ineffective care, with medication management often named as the primary -and sometimes only (Cheak-Zamora & Teti, 2015)- intervention received. A sense of dissatisfaction with statutory services was referenced in three studies, and six studies explicitly referenced a negative transition experience. One mother commented “It feels quite frightening, the danger of him being left with nothing” (McMinn et al., 2019, p.132). Notably, complaints of poor communication from services and professionals were mentioned in nine studies, contributing to the experience of unsatisfactory support.

Losing support during the transition to adult healthcare was frequently referenced; Crane et al. (2019, p.486) reported that AYP felt the support offered in adult services was “less structured than what they experienced in child services”. Six studies recounted how AYP were turned away from services, either due to complex presentations, strict eligibility criteria or higher thresholds for support within adult healthcare. Caregivers noted a significant lack of socially inclusive services for black, Asian and minority ethnic AYP and autistic women (Berg et al., 2023). Consequently, ***many autistic young people are living with unmet needs in adulthood***. Those denied support were left to ‘go without’ and either turned to self-directed services or relied on the support of friends and family.

Theme 3: Greater investment in services is required

Seven studies referenced the financial impact of providing care to AYP. Over half the studies conducted in the USA mentioned limitations of the public health insurance program, Medicaid. Their insurance did not cover complete or quality care and was not widely accepted by providers, meaning some families went without needed support (Schwartz et al., 2020). This was not experienced within other countries, although alternative financial concerns were raised. Some families, when dissatisfied with freely available services, sought higher quality care at their own expense. However, many families could not afford this (Shanahan et al., 2020). Specialized/private healthcare interventions were expensive globally, costing up to tens of thousands in local currency. One mother stated “it is 60 and 70 thousand dollars a year and they want you to mortgage your house” (Anderson & Butt, 2018, p.3921). Providers were also impacted by the huge financial cost of healthcare, as inadequate funding led to poor wages, high staff turnover and cuts in the extent of support offered to families. Ultimately, ***providing quality care is costly and more financial support is needed.***

A greater investment of time was called for, as ***more preparation is needed to gain confidence with independent living***. AYP and their caregivers lacked confidence in independence and activities of daily living, which some attributed to a lack of practice or not knowing what to expect (Cheak-Zamora et al., 2017). Earlier preparation for transition is needed to facilitate a steady, gradual change (Ames et al., 2023). Seemingly, AYP who felt more comfortable with independent tasks had been practising in small steps or had a plan to take greater responsibility for themselves (Cheak-Zamora & Teti, 2015).

Theme 4: Integration and education could help services address unique needs

There was a recognized need for services to provide holistic care for AYP, who frequently required support across multiple specialisms within physical health, mental health and occupational therapy. Stakeholders identified a distinct lack of social support, including sexuality needs, for AYP and requests were made for social skills training and socialization services (Culnane et al., 2020; Ames et al., 2023; Berg et al., 2023). The ***need to improve awareness and understanding of autistic needs*** was highlighted in eight studies with caregivers expressing that macro-level education on autism is required, within healthcare organizations and society as a whole.

The challenges of providing support to suit all AYP were deliberated; most papers referenced the differing needs of each individual and emphasised that “one size does not fit all” (Berg et al., 2023, p.6). The need for greater flexibility in the operation of healthcare services was raised in five studies and several suggestions were offered, for example with location (i.e. home appointments), meeting times (e.g. outside working hours for parents) and the length of the transition period. Several parents discussed a difference in the biological and developmental age of their children and believed providers should consider ‘readiness’ when deciding the appropriate time for transition to adult healthcare (Ames et al., 2023). Therefore, ***transition processes need to be more person-centred and individualised***. Offering some degree of choice to AYP regarding their transition, e.g. input on who their adult doctor will be, could foster greater engagement with the process and potentially improve outcomes in adulthood.

An additional ***need to integrate services for comprehensive information sharing and support*** was acknowledged throughout studies. Experiences of disjointed services and processes that do not translate across systems i.e. between health and social care, were commonplace. The variation in approach between child and adult services contributed to a sense of inconsistency, uncertainty and a lack of continuity (Culnane et al., 2020; Shanahan et al., 2020). Five studies emphasized the need for greater liaison and connection between services, alongside calls for more centralized information sources and support in the future via improved care coordination or ‘transition centres’ (Kuhlthau et al., 2015).

Theme 5: Positive relationships can significantly support well-being

This theme highlighted the critical role of relationships in providing transition support to AYP. Firstly, ***families' strategies for supporting the well-being of autistic young people*** often included huge contributions from parents, evidenced by the mention of family involvement in every study. Parents frequently took responsibility for monitoring and anticipating the health needs of AYP, gathering information and procuring services, organizing and planning appointments or activities, transporting and accompanying their children to access support, advocating on their child's behalf, implementing medical advice and much more. Some parents also facilitated wider well-being needs, e.g. employment, as one mother commented "I just knew what my son is capable of. What he enjoys is being outdoors or in a library… I created jobs around that." (Anderson & Butt, 2018, p.3920). In two studies, parents spoke of their internal resources to cope with the demands they faced, such as problem-solving abilities or taking a proactive approach to planning (McMinn et al., 2019; Shanahan et al., 2020). Families often sought peer support; Parents sometimes valued the advice of other parents of AYP above professional opinion, and AYP found emotional support in their friendships.

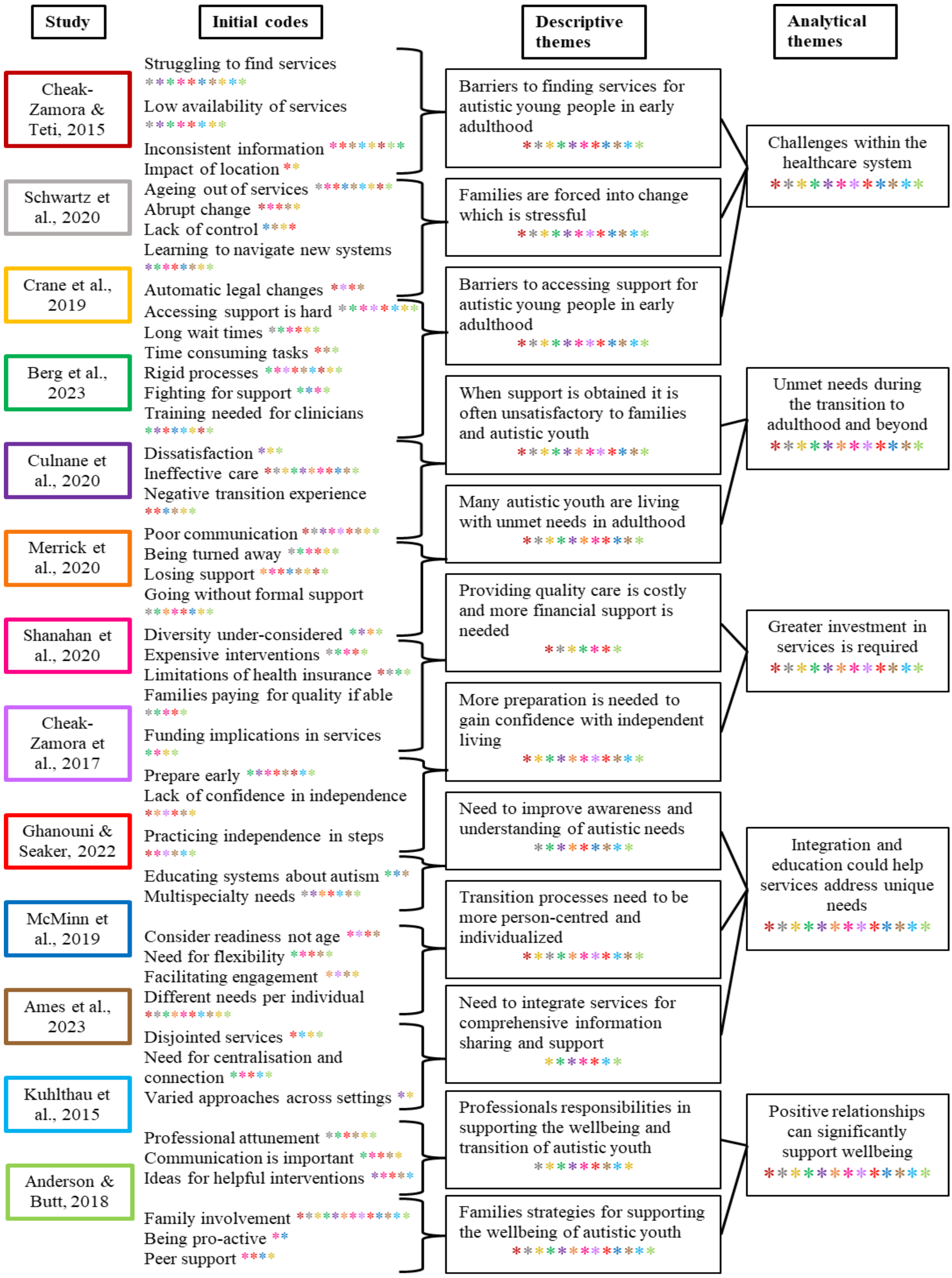
Secondly, nine studies referenced ***professionals' responsibilities in supporting the well-being of autistic young people***. It was considered the professional's responsibility to maintain good working relationships that benefitted AYP, both by listening to the views of families and liaising with multi-disciplinary colleagues across services. How a clinician communicated with AYP and characteristics such as compassion, empathy and patience were considered central to providing high-quality care (Berg et al., 2023). Caregivers highlighted the importance of professional attunement with AYP and experiences of exemplary support were remembered, such as a congratulatory goodbye letter given to an autistic individual transitioning to adult care by their paediatrician (Ames et al., 2023). Five studies advised it would be good practice for professionals to continuously consider new and improved ideas for helpful interventions and to listen to the suggestions of families.

Sensitivity Analysis

A sensitivity analysis was conducted to evaluate the impact of including all 13 studies. Firstly, the criteria of ‘low quality’ was changed (1-5: Low, 6-8: Medium and 9-11: High). Consequently, two studies were excluded (Culnane et al., 2020; Merrick et al., 2020). The evidence for each theme and sub-theme provided by these studies was removed from the synthesis. It was found that the exclusion of these studies did not impact the synthesis as they did not add any novel themes, suggesting data saturation had been achieved (Carrol et al., 2012; Franzel et al., 2013). An adapted coding tree (using coloured stars instead of lines) depicting how each study contributed to the codes and themes developed, can be seen in Figure 3.

Figure 3

Adapted coding tree of thematic synthesis



Discussion

This review examined key stakeholders' experiences of transition planning and support for AYP in healthcare services. The review aimed to gain an in-depth understanding of the experiences of transitioning AYP and their families, including core difficulties faced and how to better support AYP. These aims were addressed through a systematic literature review and thematic synthesis of 13 studies, resulting in five interacting analytical themes:

1. Challenges within the healthcare system
2. Unmet needs during the transition to adulthood and beyond
3. Greater investment in services is required
4. Integration and education could help services address unique needs
5. Positive relationships can significantly support well-being

This section discusses key findings within the context of existing literature before considering implications for practice and research.

The transition to adult healthcare often occurs when young people turn 18 without consideration of the developmental ‘readiness’ of autistic individuals. Subsequently, AYP and their families find themselves labouring to navigate processes they may not feel prepared for or agree with. Family life cycle theory suggests that difficult experiences during the stage of launching adult children may disrupt the process of separating and individuating, potentially affecting the emotional well-being of all family members (Carter & McGoldrick, 1980). This highlights the importance of appropriately timed transition planning. It has been suggested that transition should be guided by an assessment of readiness, starting as early as 12 years old (Derhammer et al., 2022). The use of transition readiness measures might imply that children’s healthcare services ought to be commissioned with no upper age limit, requiring reform in current policies. However, existing measures do not adequately measure readiness for AYP with varying degrees of ID or correlate with health outcomes (Hart & Chisolm, 2023). This suggests that further development and validation of such measures is required before an assessment of readiness can meaningfully inform transition planning within healthcare services.

There was an overwhelming sense of losing support during the transfer from child to adult healthcare, regardless of access to formal support, as adult services place more responsibility on service users to manage their own health needs (Crane et al., 2019). This suggests that AYP are more likely to be living with unmet needs in adulthood than in childhood. The drastic shift in support received between child and adult providers has been called ‘the services cliff’ (Roux et al., 2017; Ishler et al., 2022). This is particularly evident for AYP without co-occurring intellectual disability (ID), as mandated services for adults are typically directed towards ID or mental health, meaning many AYP without ID only become eligible for services once serious problems have emerged (Lorenc et al., 2018; Laxman et al., 2019). Calleja et al. (2020) investigated healthcare access for autistic adults and found that ineffective communication is the greatest barrier. This aligns with current findings, as nine studies contributed to the code ‘poor communication’. Miscommunication and subsequent disengagement from services could be a core factor in losing support, contributing to the number of autistic adults living with unmet needs.

The findings of this review note a lack of time and funding to adequately prepare AYP for adulthood. Many participants described the transition as a sudden change and requested a longer, gradual and planned procedure. The UK Children and Families Act (2014) recommends that transition planning start no later than age 14, with some charities advocating this reduces to age 12 (American Academy of Paediatrics, 2022; Autism speaks, n.d; Mencap, n.d.). It is unclear how many AYP have an EHCP and consequently receive support until the age of 25 years. Steady preparation would allow adequate time for AYP to plan for independent living and gain confidence in performing daily living skills through ‘real world practice’, which is needed for the generalization of skills (Duncan et al., 2021). The findings indicate that guidance is not consistently applied in practice and transition might not be considered until AYP are approaching 18, when transition to adult services is looming. This could be related to the lack of funding and available resources mentioned previously. Cost-benefit analysis of interventions for transitioning AYP may be valuable in guiding how current levels of funding could best be implemented.

The current findings accentuate the demand for increasingly individualised support. Despite primarily focussing on healthcare, every study referenced social, educational, vocational or community needs, emphasizing the interplay between biopsychosocial domains in the well-being of AYP. Ecological systems theory provided a helpful framework to make sense of these reciprocal interactions (Bronfenbrenner, 1977). For example, professionals working directly with AYP may hold beliefs about autism shaped by the macrosystem and societal views of autism, which influences their working interactions. This review and prior research identified that autism training for healthcare professionals would be beneficial (Bradshaw et al., 2019; Malik-Soni et al., 2022).

Findings also corroborate literature indicating that integrated services are needed to improve information sharing, continuity of care and facilitate communication (Chun et al., 2022; Anderson et al., 2018). One method enabling the integration of services is care coordination, a position that oversees communication and the provision of necessary resources (Lobar, 2016). Nursing professionals often fulfil this role as their training crosses subspecialty divisions (McAllister et al., 2018). Care coordination has effectively aided participation and advocacy within typically rigid healthcare systems (Parker et al., 2019; Harvey et al., 2022) and was found to mediate the relationship between autism complexity and parental outcomes (Parker & Killian, 2020). Therefore, assigning a care coordinator to autistic individuals could facilitate a more person-centred transition into adult healthcare services and provide a central point of communication for caregivers, who often fulfil this role themselves.

A narrative of individuals ‘going the extra mile’ to support AYP appeared across studies. The review highlighted the importance of relationships in providing quality care to AYP and how singular people can make a big difference. Autistic adults reported that a considerate approach, demonstrated by abiding by agreed timeframes, using layman's terminology and having a sincere interest in individuals, helps to build trusting relationships with clinicians (de Broize et al., 2022). A model of supportive relationships for autistic individuals identifies ‘trust’ as one of three core elements alongside ‘unity’ and ‘support’, and states that effective support is collaborative, consistent and flexible (Robledo & Donnellan, 2016). Consequently, adults caring for AYP must build consideration and trust into their interactions to form supportive relationships that promote well-being and positive experiences of healthcare transition.

Strengths and limitations

This review is seemingly the first qualitative synthesis capturing the experiences of stakeholders on the transition to adult healthcare for AYP. Systematic reviews produce a comprehensive overview of relevant literature through objective analysis; the rigorous methodology of systematic reviews and thematic synthesis guarantees transparency in the research process. Common themes were identified across included studies and new interpretations of the data were offered. Quality appraisal and sensitivity analysis enabled a credible synthesis of studies of acceptable quality. This review contributes to a growing body of literature by summarizing the experiences of stakeholders in addition to identifying the needs of AYP and the support provided by healthcare services.

There are limitations in the transferability of findings due to largely white, middle-class samples that largely represented the experiences of autistic males, in addition to study locations perpetuating white Western individualist bias. The range of countries contributing research to the review offers some insight into cross-cultural variation and global trends, however there are significant differences in the healthcare systems within these countries, which limits the applicability of findings to the UK and NHS. Additionally, the sampled stakeholders may not fully represent the diversity and complexity of all relevant groups; for example studies that primarily sampled social workers were excluded. The possibility of publication bias also needs to be considered in any systematic review, which can lead to an overrepresentation of certain findings in the analysis.

The qualitative nature of the review increases the risk of researcher bias as the original interpretations of authors are being reinterpreted, which may lead to alternative explanations being overlooked. To moderate this effect, the use of verbatim quotations was prioritized (Thomas & Harden 2008). However, it is still advised that results be considered with caution as the quality appraisal highlighted weaknesses in the reporting of theoretical underpinnings and reflexivity across studies, leading to potential misinterpretations and limited applicability of findings to real-world situations.

Clinical implications

The findings of this review offer several implications for clinical practice. Poor communication could prevent engagement with services and contribute to a negative transition experience. All healthcare professionals should be required to complete training focussed on understanding autism. This should cover the unique needs of individuals on the spectrum, techniques to enable effective communication and guidance on engaging AYP in their care. For example, healthcare staff in the UK are now required to complete The Oliver

McGowan Mandatory Training on Learning Disability and Autism (Health Education England, 2024), in line with the Health and Care Act (2022).

Participants described experiences of fragmented information, inconsistencies across services and no centralized source of support. Therefore, it could be beneficial to employ care coordinators within healthcare services to liaise with families and professionals within relevant agencies, and oversee the transition of AYP to adult services. Local information sessions, for example webinars for families facilitated by staff across child and adult services, might enable more accurate information sharing.

Supportive relationships with professionals played a key role in the well-being of many participants. Therefore, it may be helpful to promote strategies for building trusting relationships within clinical guidance, such as using jargon-free language, abiding by agreed plans and maintaining a sincere interest in the perspective of AYP and caregivers.

Opportunities to evaluate and develop the readiness of young people for transition over and above biological age were sought by many participants. Therefore, it may be helpful for services to use transition readiness measures as a means to inform and improve transition planning. Studies that enable the development and validation of transition readiness measures are implicated for future research.

Research implications

Additional research is proposed to build upon the findings of this review. As a feasibility search indicated a lack of UK-based studies, further research exploring stakeholders' experiences of transition to adult healthcare services for AYP is required to better understand the impact of local legislation and policy. Future UK studies ought to utilise policy analysis to explore the establishment and execution of current policy regarding the integration of health and social care services. Additionally, conducting cost-benefit analyses of emerging interventions aiming to support the transition to adult healthcare services could guide how current funding is invested and inform future commissioning.

The volume of negative healthcare transition experiences reported significantly outnumbered positive experiences and identifying effective support for AYP was not always clear. A direction for future qualitative research could be to explore the views of stakeholders with self-reported successful experiences of transition to adulthood, including adult healthcare, to focus on existing effective supports. Occasionally ideas for supportive interventions were discussed that did not have an established evidence base; additional research should be orientated towards randomised controlled trials evaluating new interventions.

The diverse needs of individual AYP and the necessity for person-centred care were clear across reviewed studies. However, it was noteworthy that those without ID have been found to be at greater risk of facing ‘the services cliff’. Approximately 50-60% of autistic people are not diagnosed with ID (Children's Hospital of Philadelphia Research Institute, 2020; Autistica, n.d; Mencap, n.d.). Nevertheless, autistic people without ID are often understudied in healthcare literature and underserved in the community relative to autistic individuals with ID (Vogan et al., 2017; Lorenc et al, 2018; Laxman et al., 2019). Future research should investigate available and developing supports for autistic individuals without ID.

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HANNAH L. BOWMAN

THE TRANSITION TO ADULTHOOD FOR AUTISTIC YOUNG PEOPLE

Section B

Transition to adulthood: Developing a consensus on support for autistic young people without learning disability in the UK

Word count: 7990 (350)

For submission to Autism (Sage Journals)

Abstract

Background: The transition to adulthood can be difficult for autistic young people without a learning disability, who often lose support from services at 18. Whilst barriers to transition are known, knowledge of facilitators is limited. This study aimed to explore the experiences of stakeholders to understand which factors are agreed to represent a successful transition, what support is needed and what resources are most important. **Method:** A three round Delphi method was conducted online. An initial qualitative questionnaire (n=20) was analysed using thematic analysis to develop a second quantitative questionnaire (n=42). A third questionnaire (n=34) finalised consensus across autistic young adults without a learning disability, parents of and clinicians caring for transition-age autistic young people without a learning disability. **Findings:** Overall consensus was high. It was agreed that ‘understanding themselves and their needs’ is key to a successful transition, and ‘helping young people to know when/how to seek support for themselves’ is core support. It was agreed a directory of local support services is a needed resource. **Discussion:** Increased support during transition is required for autistic young people without a learning disability and their families to improve outcomes in adulthood. Implications for clinical practice and research are discussed.

Keywords: autism, transition, adulthood, stakeholders, Delphi.

Introduction

"*Disability results not from autism itself but instead from living in a society which tends to be physically, socially and emotionally inhospitable towards autistic people*"

(den Houting, 2019, p.271)

Autism spectrum condition (autism) is a lifelong neurodevelopmental condition which affects approximately 1-in-100 children globally (World Health Organization [WHO], 2023). The National Autistic Society ([NAS], 2023b) estimates that there are more than 700,000 autistic people in the United Kingdom (UK). Recent studies report the prevalence of autism in the UK is increasing, with recorded diagnoses rising 787% between 1998-2018 (Russell et al., 2022). Nevertheless, many autistic people remain unrecognized by healthcare services in the UK (Underwood et al., 2022).

Autism is characterized by pervasive difficulties in social communication across a range of situations and specialized interests (WHO, 2019). The heterogeneity of autism is vast, exceeding the diversity seen in other conditions (Waterhouse, 2013). Autistic individuals vary in their verbal ability, presentation of characteristics, additional needs, and may have a co-occurring learning disability[1] (Chapman, 2020; Lenroot & Yeung, 2013). Diversity is also observed in the strengths of autistic people, with exceptional artistic, scientific and reading abilities demonstrated by some individuals (Uddin, 2022). An autistic 11-year-old holds the world record for mental mathematics skills (Marcus, 2021).

The variability in autism characteristics means individuals' support needs vary greatly. Those with a learning disability may need support with specific tasks such as understanding information, following instructions and performing specific tasks, or they may require full

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[1] Here 'learning disability' is used to reflect the terminology within NHS England (n.d.)

time care (NAS, 2023a). However, it is approximated that half of autistic people do not have a learning disability (Mencap, 2019), yet may still require support in areas such as interpreting social interactions, recognising emotions in themselves and others, or coping with change (NHS England & NHS Improvement, 2019). Across the lifespan, autistic people without learning disability found adolescence and young adulthood to be the most difficult period and may require more support due to the demands of social relationships, educational pressures, employment and independent living (Tantam, 2003; Barnhill, 2007; Kapp et al., 2011).

The transition to adulthood

The transition to adulthood (hereafter ‘transition’) describes the timeframe within which adolescents develop into adults. Arnett’s theory of emerging adulthood described ages 18-25 as a period characterized by ongoing development in the regions of education/employment, independent living, social identity, relationships and health (Arnett, 2000, 2014) in addition to ongoing brain development (Arain et al., 2013). This phase of life can be especially challenging for autistic young people (AYP), who are expected to simultaneously adapt to novel developmental expectations and new social environments that are typically less accommodating (Chun et al., 2023).

Self-determination theory proposes three innate psychological needs (autonomy, competence and relatedness) of humans, which are essential for motivation, well-being and optimal functioning (Deci & Ryan, 1985). In Erikson’s theory of psychosocial development, these needs are core developmental successes that humans strive for between early childhood to early adulthood (1968). Maslow’s hierarchy of needs model suggests that individuals must satisfy lower-level needs (food, rest, safety) before they can meet higher-level human needs such as feeling loved and that they belong, developing esteem through feelings of accomplishment, and eventually achieving one’s full potential (Maslow 1943, 1987). If the psychological needs (love, belonging and esteem) of autistic people are not met during transition, their well-being may be negatively impacted, which could inhibit optimal functioning and ultimately achieving self-actualisation.

Poor outcomes in adulthood have been well documented for autistic adults across biopsychosocial domains. Currently, outcomes in education (Cage & Howes, 2020), employment (Office for National Statistics, 2022), independent living and parenthood (Helles et al., 2017; Roy et al., 2015) for autistic young adults are diminished compared to non-autistic people. This is consistent for autistic individuals without learning disability. For example, autistic students in UK higher education report significant challenges with the social components of university life and experience more mental health difficulties than their non-autistic peers (Gurbuz et al., 2019). The Department of Work and Pensions (2024) recently reported that after 15 months, autistic graduates are twice as likely to be unemployed compared to their peers with only 36% securing full-time employment. Moreover, autistic graduates found themselves trapped in precarious zero-hours contracts and overqualified for their positions.

The severity of mental health outcomes for autistic adults without learning disability is stark. Autistic young adults are at greatest risk of depression and anxiety disorders, above the general population and autistic people with a co-occurring learning disability (Rai et al., 2018; Nimmo-Smith et al., 2020). Most strikingly, autistic people without learning disability have been found to be at especial risk of self-injury and suicidality (Moseley et al., 2019; Newell et al., 2023). In England, 10.7% of individuals who died by suicide exhibited evidence of autism or elevated autistic traits; 11 times higher than the prevalence of autism within the general population after accounting for previously undiagnosed cases (Cassidy et al., 2022). It is clear that this population require additional support to improve outcomes in adulthood, with particular need for mental health support.

Support systems

At present in the UK, adult autism services are not routinely provided (Colver et al., 2019). Most young people with mental health difficulties, including autistic young people without learning disability, often lose support from mental health services close to their 18th birthday and are discharged to primary care (Singh et al., 2010; Colver et al., 2019; Crane et al., 2019). AYP identified barriers to accessing support from services, both in relation to autism and mental health, such as a higher service thresholds and a sudden loss of support at 18 (Crane et al., 2019). Additionally, when AYP transferred to adult services, the quality of transition between services was extremely poor (Paul et al., 2013; King et al., 2020). Autistic young adults reported dissatisfaction with the support received in adult services, which was not tailored to individual needs, lacked understanding for potentially delayed independence and were discharged before feeling ready (Crane et al., 2019).

Conversely, the support available for AYP with a Special Educational Need (SEN) in the UK can extend to the age of 25 years with an Education, Health and Care Plan (EHCP; Children and Families Act, 2014; NHS England, 2015). Annual EHCP reviews should be held, during which ‘preparation for adulthood’ is considered as young as 13-14 years. The SEN Code of Practice outlines this as preparing for education/employment, independent living, participating in society through friendships and contributing to the local community and being as healthy as possible in adult life (Department of Education & Department of Health, 2015). In practice, educational professionals faced difficulties obtaining EHCPs for AYP, especially those without a learning disability whose additional needs may be overlooked if their academic attainment is good (Boesley & Crane, 2018). In mainstream education, AYP reported that accessing appropriate support was challenging whereas those in SEN schools felt well supported (Crane et al., 2022), highlighting additional challenges for AYP without a learning disability.

Difficulties obtaining support impacts the family system; mothers of AYP in the UK described feelings of isolation, anxiety and hopelessness (Keville et al., 2024). Parents of AYP without a learning disability reported lower functioning of both themselves and the family unit, higher levels of parenting stress and poorer mental health and quality of life than parents of non-autistic children (Pisula & Porębowicz-Dörsmann, 2017; Schiltz et al., 2017). Parents of AYP can carry a huge caregiving burden, predictors of which include autism symptom severity (Bozkurt et al., 2019; Picardi et al., 2018). Caregivers of AYP encounter significant hurdles in comparison to caregivers of children with other developmental disabilities, mental health conditions, or a combination of both, including difficulties accessing services, a lack of consistent care sources, inadequate insurance coverage, limited involvement in decision-making and care coordination, and adverse effects on family well-being (Vohra et al., 2014).

Society and culture

In addition to the lack of appropriate services, research has underscored the significant concerns surrounding isolation and stigma experienced by AYP and their families, indicating a pressing need for public initiatives aimed at increasing awareness and fostering better understanding of autism in society (Trew, 2024). Dehumanisation is a key component of stigma (Goffman, 1990) and a UK study found evidence of the dehumanisation of autistic people by non-autistic people, with emphasised denial of ‘human uniqueness’ traits (Cage et al., 2019).

There is growing support of the neurodiversity paradigm, which suggests neurodiversity is another form of societal diversity alongside protected characteristics such as ethnicity, religion etc. and that difficulties experienced by neurodiverse individuals is largely due to societal structures which exacerbate these differences (Strand, 2017; Kapp, 2020). In the UK, attitudes towards autism are in flux and social debate is ongoing, however there is evidence to suggest that acceptance of the neurodiversity movement could have positive implications within healthcare and education (Green, 2023; Tang et al., 2024). With increasing support of neurodiversity as a concept, there are concerns that dividing autistic people by those with/without a learning disability may lead to underrepresentation of specific individuals and the breakdown of 'autism identity' (Pukki et al., 2022). However, the evidence presented above demonstrates differences in the lived experiences and outcomes of autistic people with and without learning disability in the UK, due to the limited systems of support available for autistic people without a learning disability.

Rationale and study aims

There is ample evidence of poor outcomes in adulthood, particularly mental health, and dissatisfaction with existing systems of support for AYP without a learning disability and their families during the transition to adulthood. Existing literature has highlighted the barriers faced in obtaining support, however there is significantly less research dedicated to outlining factors for a 'successful' transition to adulthood. Furthermore, whether any such factors are viewed as helpful across key stakeholder groups is unknown.

Subsequently, this study aimed to better understand what autistic young adults, the parents/carers of and healthcare clinicians working with AYP without a learning disability (stakeholders) agree is necessary for a successful transition to adulthood. It is hoped that this information will help to inform future service provision and lead to clinical implications in considering the support needed for AYP without a learning disability during the transition to adulthood. Specifically, this research aims to answer these questions:

A. What are the key factors for ‘successful’ transition to adulthood that are agreed across stakeholders?
B. What support do stakeholders agree is helpful from systems (i.e. services, schools or charities) to achieve a successful transition to adulthood?
C. What resources (e.g. planning, measures/tools and protocols) do stakeholders agree are most important to achieve successful transition to adulthood?

In this study, ‘support’ refers to the guidance and assistance provided by services to aid AYP without a learning disability during their transition, whilst ‘resources’ refers to tangible assets, tools and services available to facilitate transition.

Method

Design

The Delphi method was used to gather the perspectives of three stakeholder groups with direct experience of AYP without a learning disability transitioning to adulthood. The Delphi method aims to explore a range of opinions from groups of 'experts' and establish a consensus on disputed areas (Hsu & Sandford, 2007; Iqbal & Pipon-Young, 2009). Delphi studies use sequential 'rounds' of data collection and analysis to determine a consensus. This method was established assuming group judgements hold higher validity than individuals, thus through developing a group consensus Delphi methodology goes beyond the scope of interviews or focus groups alone (Dalkey & Helmer, 1963; Keeney et al., 2011). It is often a mixed methods approach, combining qualitative and quantitative methods to enable a comprehensive picture of the subject being studied (Hasson et al., 2000; Norcross et al., 2002). There is no definitive protocol for Delphi methodology although it has been successfully utilized across a range of disciplines including healthcare research (Skulmoski et al., 2007; Jorm, 2015).

The current study follows the approach outlined by Powell (2003), which has been used in published research (South et al., 2015). The study was conducted online for participants' convenience (Cole et al., 2013; Taylor, 2020). The round one questionnaire (R1Q) asked participants to complete open-ended questions regarding the research topic. The qualitative data collected was analysed to develop statements, forming the round two questionnaire (R2Q). This was sent to existing participants and a wider sample of participants with relevant expertise, who were asked to rate their agreement with each statement. Finally, the round three questionnaire (R3Q), which contained some of the same statements along with the sample's average ratings per item and the participants' previous response, was sent to all those who had completed R2Q. R3Q prompted participants to consider their rating in the context of group judgment and review their responses if wanted.

To account for the possibility of high levels of agreement on all statements, participants were asked which three statements they considered to be most important at the end of R2Q and R3Q. This adaptation seemed appropriate as the Delphi method can be modified to achieve the purpose of the research whilst retaining the main principles (Shariff, 2015) and is an adaptation that has been used in previous studies (Forsyth, 2021).

Ontology and epistemology

A critical realist approach underpinned this study, retaining the idea that human knowledge of the world is based on perspectives and experiences, which is a fragment of a deeper and vaster reality (Sayer, 2004; Fletcher, 2017). This research maintained that participants would have perceived ‘good’ and ‘bad’ experiences of preparing for transition without representing a universal truth, as this is influenced by context and varies between participants. The iterative nature of the Delphi methodology allows participants to engage with other perspectives which may influence their experiences.

Co-production and Consultation

This study was developed with two research supervisors, both have extensive experience working with AYP. Additionally, one supervisor is the parent of an autistic young adult, bringing first-hand experience and knowledge to the research design. The initial research materials (participant information documents, consent information and R1Q questionnaire) were created via consultation with an autistic young adult independent to the project, who provided valuable feedback as an expert by experience (EbE). Consequently, the wording and design of materials were changed to improve their accessibility to autistic individuals.

Ethics

This research was approved by Hampshire A Research Ethics Committee, Health Research Authority, and the Research and Development Office (Appendices C-E). The British Psychological Society (BPS) code of ethics was adhered to throughout the study.

Participant information documents outlined the purpose, procedure, confidentiality agreement and benefits/risks of the research (Appendix F). Participation was voluntary and the right to withdraw was outlined. The opportunity to request reasonable adaptations was provided in R1Q consent forms (Appendix G). Consequently, two autistic participants completed R1Q with the lead researcher via video calls. A consent process was embedded into the beginning of questionnaires to obtain informed consent before participation. All participants consented to their anonymous responses being shared in this report. Participants received a unique ID number to ensure anonymity and identifiable information was kept separate from data collected on a password-protected database. At the end of each questionnaire (Appendices I-K) participants were signposted to free sources of support. A summary of the results (Appendix H) was shared with all participants.

Recruitment

This study used the following inclusion criteria to recruit ‘experts’:

1. Autistic young adults (aged 18-30) without a learning disability who have lived in the UK for at least 10 years.
2. Parents or carers of AYP aged 16-25 without a learning disability.
3. Healthcare clinicians with at least two years’ experience working with transition-age (13-25) AYP without a learning disability.

The age range for the autistic young adult group was selected to recruit individuals who had sufficient experience of the transition adulthood to reflect on, whilst the age range selected for the parent group was determined to limit potential distress and anxiety caused by thinking about the transition to adulthood. Hereafter, these groups are referred to as ‘autistic adults’, ‘parents’ and ‘clinicians’ respectively.

Purposive sampling was utilized to ensure a breadth of opinion. Recruitment occurred through a national NHS autism service and advertisement within appropriate autism charities, support groups and online forums.

Participants

A total of 46 participants were included in the study (19 autistic adults, 11 parents and 16 clinicians). As samples larger than 30 rarely improve results within Delphi studies (de Villiers et al., 2005), the aim was to recruit approximately 45 participants to allow for attrition, which is a common issue within Delphi research (Trevelyan & Robinson, 2015). Recruitment of parents was unexpectedly difficult for R1Q, however a minimum of 10 participants were eventually recruited to each expert panel in an attempt to ensure a balanced input between groups.

In total 20 participants completed R1Q and 42 completed R2Q. Sixteen participants from R1Q completed R2Q (80%). Finally, 34 participants from round 2 completed R3Q (81%). Therefore, response rates over 70% were maintained between rounds, which is considered necessary to preserve rigour within Delphi methodology (Hasson et al, 2000; Sumsion, 1998). Participant demographics per round are shown in Tables 1-3.

Table 1

Round 1 participant demographics

		Autistic young adults (n= 10)	**Parents/ Carers** (n= 3)	**Healthcare clinicians** (n= 7)
Age	18-25	7	0	0
	26-34	3	0	2
	35-44	0	0	2
	45-54	0	2	2
	55-64	0	1	1
Gender	Female	4	3	5
	Male	3	0	2
	Non-binary/ third gender	3	0	0
Ethnicity	White British	9	3	5
	White European	0	0	2
	Vietnamese	1	0	0
Occupation	Student	8	0	0
	Sales Associate	1	0	0
	Market Researcher	0	1	0
	Disability Advisor	0	1	0
	Psychologist	0	0	6
	Consultant Paediatrician	0	0	1
	Missing data	1	1	0

Table 2

Round 2 participant demographics

		Autistic young adults (n= 17)	**Parents/ Carers** (n= 11)	**Healthcare clinicians** (n= 14)
Age	18-25	10	0	0
	26-34	7	0	2
	35-44	0	1	6
	45-54	0	8	4
	55-64	0	1	2
	65-74	0	1	0
Gender	Female	9	10	11
	Male	5	1	3
	Non-binary/ third gender	3	0	0
Ethnicity	White British	13	10	9
	White European	1	1	2
	White Other	0	0	2
	White & Black Caribbean	1	0	0
	Vietnamese	1	0	0
	Indian	1	0	0
	Other: “Mixed”	0	0	1

Occupation	Student	7	0	0
	Sales Associate	1	0	0
	Market Researcher	0	1	0
	Disability Advisor	0	1	0
	Psychologist	0	0	8
	Consultant Paediatrician	0	0	1
	Medical doctor	0	0	1
	Occupational Therapist	0	0	2
	Speech and language therapist	0	0	1
	Dietician	0	0	1
	Missing data	9	9	0

Table 3

Round 3 participant demographics

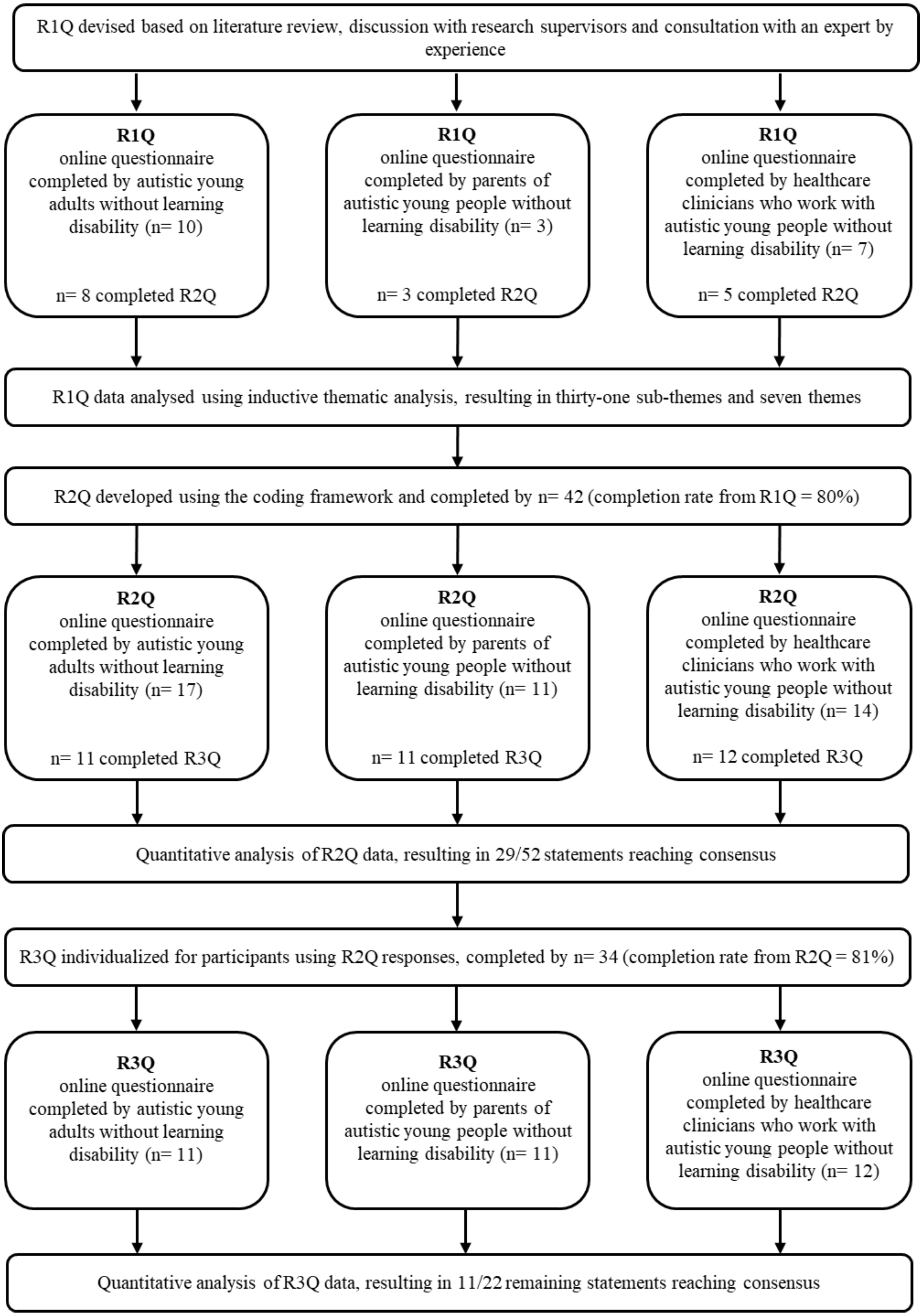
		Autistic young adults (n= 11)	**Parents/ Carers** (n= 11)	**Healthcare clinicians** (n= 12)
Age	18-25	6	0	0
	26-34	5	0	2
	35-44	0	1	5
	45-54	0	8	3
	55-64	0	1	2
	65-74	0	1	0
Gender	Female	4	10	9
	Male	4	1	3
	Non-binary/ third gender	3	0	0
Ethnicity	White British	8	10	7
	White European	1	1	2
	White Other	0	0	2
	White & Black Caribbean	1	0	0
	Vietnamese	1	0	0
	Indian	0	0	0
	Other: “Mixed”	0	0	1
Occupation	Student	6	0	0
	Sales Associate	1	0	0
	Market Researcher	0	1	0
	Disability Advisor	0	1	0
	Psychologist	0	0	8
	Consultant Paediatrician	0	0	1
	Medical doctor	0	0	1
	Occupational Therapist	0	0	1
	Speech and language therapist	0	0	1
	Dietician	0	0	0
	Missing data	4	9	0

Data Collection and Analysis

Data collection took place between June 2023 and March 2024. The process was the same for all participants. Analysis of the data and subsequent development of questionnaires was completed by the lead researcher and reviewed by the primary research supervisor. Figure 1 depicts the Delphi procedure including the flow of participants throughout the study.

Figure 1

Delphi procedure flowchart with participant response rates



R1Q

The first questionnaire (Appendix I) was developed in collaboration with research supervisors and pilot-tested with an EbE. Open-ended questions were created to cover a range of areas related to transition originating from relevant literature and real-world experience, both clinical and personal. The wording used was carefully chosen to ensure applicability to all three expert groups. Demographic information was collected at the end of this questionnaire. Data collection for R1Q used the Gorilla research platform and took six months.

R1Q was analysed using reflexive inductive thematic analysis outlined by Braun and Clarke (2006, 2021a), a method in which researchers actively recognise and reflect on their role in the analysis process. To aid reflexivity and facilitate an analysis that was representative of the data collected, the lead researcher kept a diary (Appendix L) to help notice bias and attend to assumptions made, which was a vital tool during the coding process. The main researcher has direct professional and indirect personal experience supporting transition age autistic people and their families. This experience of supporting families alongside possessing strong family values may lead to the assumption that families are the dominant form of interpersonal support. Consequently, care was taken during the coding process to ensure that increased importance was not attributed to family relationships than the data warranted. For example, some responses clearly indicated that friendships felt more supportive.

Data was coded by question, to hold in mind the context of responses. Initial codes (n= 242) were derived from the data (sample in Appendix M) using NVivo software before being transferred to Microsoft Excel for greater flexibility in reorganizing codes. This resulted in 31 sub-themes (example in Appendix N) which were further refined into seven themes. The thematic framework was reviewed and agreed with the primary research supervisor. To support reliability within the coding process, a peer experienced in thematic analysis independently organized the initial codes into sub-themes, resulting in an inter-rater agreement of 99%.

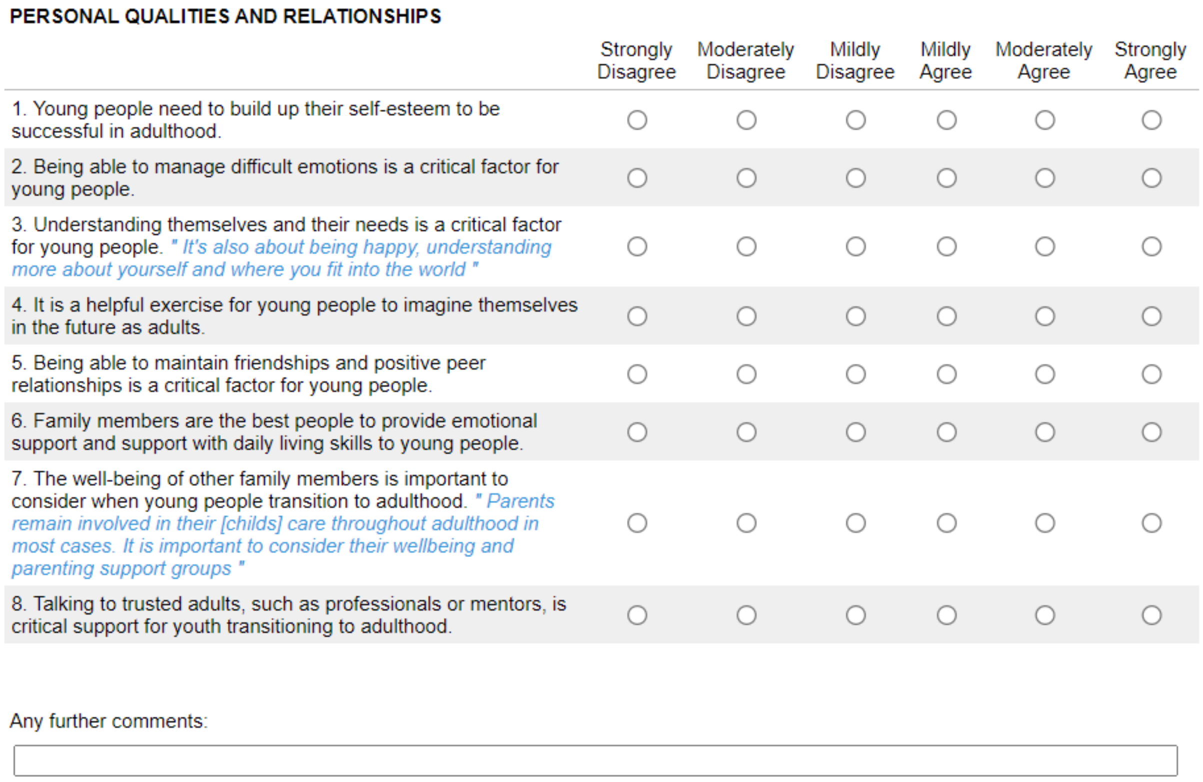
R2Q

The seven themes developed became question blocks in R2Q (Appendix J), comprising statements based on the sub-themes and worded closely to data. Direct quotations were used in each block to add meaning to statements. The participants were asked to rate the statements on a six-point Likert scale ranging from ‘strongly disagree’ to ‘strongly agree’ (Figure 2), as no mid-point prevents neutrality and the optimal number of options has been found to lie between four and seven (Trevelyan & Robinson, 2015).

Participants were invited to leave comments throughout and choose three statements they felt to be most important at the end. This final item was added to help identify stakeholders’ priorities in the possible scenario that all statements reached strong consensus. This method was chosen as it has been used in previous research (Forsyth, 2021) and asking participants to rank all statements would have significantly increased the time taken to complete the questionnaire and risked attrition. Completion of R2Q took approximately 20 minutes and was live for 3 weeks via Qualtrics (due to a change in university licensing).

Figure 2

Example of round 2 statements



PERSONAL QUALITIES AND RELATIONSHIPS

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	Moderately Agree	Strongly Agree
1. Young people need to build up their self-esteem to be successful in adulthood.	○	○	○	○	○	○
2. Being able to manage difficult emotions is a critical factor for young people.	○	○	○	○	○	○
3. Understanding themselves and their needs is a critical factor for young people. *" It's also about being happy, understanding more about yourself and where you fit into the world "*	○	○	○	○	○	○
4. It is a helpful exercise for young people to imagine themselves in the future as adults.	○	○	○	○	○	○
5. Being able to maintain friendships and positive peer relationships is a critical factor for young people.	○	○	○	○	○	○
6. Family members are the best people to provide emotional support and support with daily living skills to young people.	○	○	○	○	○	○
7. The well-being of other family members is important to consider when young people transition to adulthood. *" Parents remain involved in their [childs] care throughout adulthood in most cases. It is important to consider their wellbeing and parenting support groups "*	○	○	○	○	○	○
8. Talking to trusted adults, such as professionals or mentors, is critical support for youth transitioning to adulthood.	○	○	○	○	○	○

Any further comments:

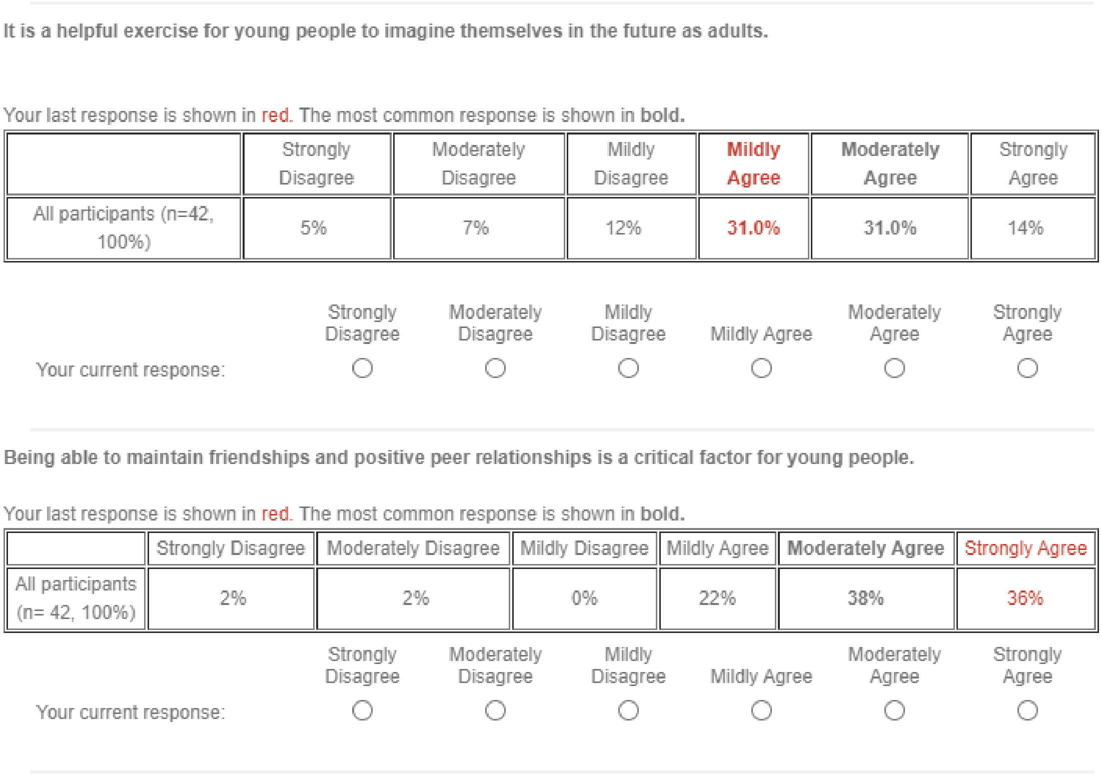
R3Q

The R3Q questionnaire (appendix K) consisted of statements that had not reached ‘strong’ consensus in R2Q based on overall percentage agreement. It was thought that a shorter R3Q would aid completion rates and reduce attrition, a substantial issue within Delphi studies (Shang, 2023). In this round participants reconsidered their responses in the context of overall sample responses, and decided whether to change their responses. Completion of R3Q took approximately 15 minutes and was live for 3 weeks via Qualtrics.

R3Q was individualised to participants, displaying the most common response of the total sample from R2Q and the participants' previous response (Figure 3). Percentages of selected responses from R2Q were listed alongside Likert points in R3Q. Qualitative comments from R2Q were displayed at the start of each block to support consensus development, as this iterative process helps participants understand the thinking behind others' responses (Lilja et al., 2011). Participants were also shown how frequently each statement was voted as most important and their previous choices; the option to review their answer was given.

Figure 3

Example of individualised round 3 items



It is a helpful exercise for young people to imagine themselves in the future as adults.

Your last response is shown in red. The most common response is shown in **bold**.

	Strongly Disagree	Moderately Disagree	Mildly Disagree	**Mildly Agree**	**Moderately Agree**	Strongly Agree
All participants (n=42, 100%)	5%	7%	12%	**31.0%**	**31.0%**	14%

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	Moderately Agree	Strongly Agree
Your current response:	○	○	○	○	○	○

Being able to maintain friendships and positive peer relationships is a critical factor for young people.

Your last response is shown in red. The most common response is shown in **bold**.

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	**Moderately Agree**	Strongly Agree
All participants (n= 42, 100%)	2%	2%	0%	22%	**38%**	36%

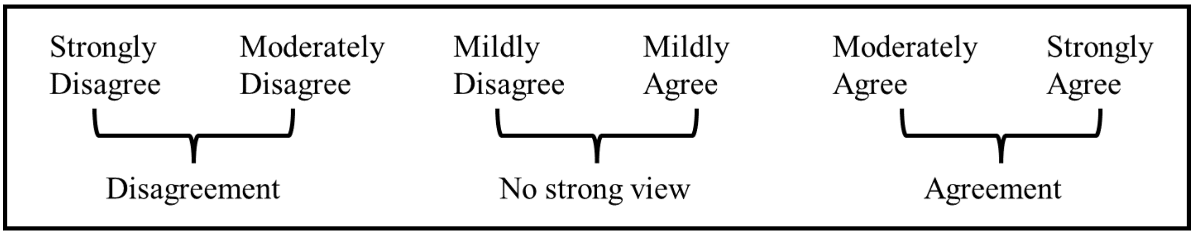
	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	Moderately Agree	Strongly Agree
Your current response:	○	○	○	○	○	○

Consensus and divergence

Following R2Q and R3Q data collection, the six-point Likert scale was split into three categories of agreement (Figure 4) in line with previous research (Fenton et al., 2021). Agreement and disagreement were calculated per statement by expert group and the overall sample. Participants ratings of importance were analysed by frequency per group and overall.

Figure 4

Collapsed categories of Likert scale points



The definition of consensus was decided a priori, similar to most Delphi studies in a review of health science research (Niederberger & Spranger, 2020). Whilst a general standard for measuring Delphi consensus does not yet exist, a 'certain level of agreement' approach can be meaningful when Likert scales have been utilized (von der Gratch, 2012). In a systematic review of defining consensus in Delphi studies, the most common definitions of consensus used 'percentage agreement', with the median determination of consensus being 75% (range 50-97%) (Diamond et al., 2014). This was considered alongside published research (Fenton et al., 2021) to operationalize consensus levels for the current study (Table 4). Divergence between groups was considered to be two or more levels of difference i.e. strong-weak or moderate-no consensus.

Table 4

Consensus categories used

Consensus Category	Level of agreement ('moderately' and 'strongly' agree) or disagreement ('moderately' and 'strongly' disagree)
Strong consensus	≥75%
Moderate consensus	62.5-74.9%
Weak consensus	50-62.4%
No consensus	<50%

Quality assurance

Though dedication and research rigour are needed to yield effective results, the Delphi method is highly appropriate for developing evidence-based design suggestions and considerations tailored to healthcare environments (Taylor, 2020). To ensure rigour in this study, triangulation was upheld through the heterogeneous sample and mixed methods design. Delphi quality indicators outlined by Landeta and Lertxuni (2023) were incorporated where possible, such as seeking group experts with sufficient experience, presenting clear and unbiased questions, and providing opportunity to change opinions.

Decisions regarding research design were documented in a diary (Appendix O). Achieving quality within the thematic analysis was guided by Braun and Clarke's (2021b) recommendations, for example, reporting of the analysis described what the author did instead of generic methodological steps. Finally, frequent consultation with supervisors facilitated reflection on potential study design flaws and the interpretation of results, improving overall research quality through peer review.

Results

Round 1

This research aimed to determine what stakeholders agree the key factors for a successful transition are, including what support is needed and what resources are most important to achieve this. Thematic analysis of R1Q data identified seven themes. The first was **personal qualities and relationships**, which considered factors of internal and interpersonal development. The second theme, **goals for daily living**, looked at the practical tasks and skills required for everyday life. The third theme, **inclusivity**, highlighted issues of social inequality and stigma. The fourth theme considered **areas of development for mental health services** and consisted of suggestions to improve services based on lived experiences. Fifth was **other sources of support** which considered support outside the healthcare system such as education and non-statutory organisations. The sixth theme, **views on transition planning**, focused on the preferred timing and style of transition planning. Finally, theme seven investigated **helpful tools and processes** that have been or could be used to support transition for AYP without a learning disability. Table 4 presents the themes and subthemes alongside supporting quotations and the 52 statements developed for R2Q.

Table 5

Development of round 2 statements from thematic analysis themes and sub-themes

Theme 1: Personal qualities and relationships		
Sub-themes	**Example quotes**	**Statements**
Self-esteem	"I'm listening to my voice now and instinct but that took time. I started to trust myself and that I can be right and know things recently..." – Autistic young adult	1. Young people need to build up their self-esteem to be successful in adulthood.
Managing emotions	"[Successful transition is] Having supporters around you to be able to help you feel emotionally contained when making choices and coping with the change that the transition to adulthood brings." - Clinician	2. Being able to manage difficult emotions is a critical factor for young people.
Internal development	"It's [successful transition is] also about being happy, understanding more about yourself and where you fit into the world… for people to have understanding and awareness of the struggles they may have and how they may feel." – Parent	3. Understanding themselves and their needs is a critical factor for young people.
Future thinking	"I cannot remember a specific age where I thought about this [transition], however when I was a child I used to imagine myself as an adult." – Autistic young adult	4. It is a helpful exercise for young people to imagine themselves in the future as adults.
Maintaining peer support	"I think friends are most important especially if living far from home. I often find it hard to keep in touch with my parents due to their busy schedules, so I have found that having a small group of close friends is extremely important!" – Autistic young adult	5. Being able to maintain friendships and positive peer relationships is a critical factor for young people.
Intensive family support	"In general, family [are most important], that's a definite... Having an understanding, patience and encouraging family is important. You look to family for help and approval, so if you don't have that or they're not doing that it makes things harder." – Autistic young adult	6. Family members are the best people to provide emotional support and support with daily living skills to young people.
	"Parents remain involved in their [autistic child's] care throughout adulthood in most cases. It is important to consider their well-being and parenting support groups." - Clinician	7. The well-being of other family members is important to consider when young people transition to adulthood.
Support from trusted individuals	"I talked to my parents and teachers about what I wanted to do, I trusted them." – Autistic young adult	8. Talking to trusted adults, such as professionals or mentors, is critical support for youth transitioning to adulthood.

Theme 2: Goals for daily living

Sub-themes	**Example quotes**	**Statements**
Daily living skills	"[For successful transition you need] guidance on how to handle certain situations such as the importance of communication, e.g., how to construct concise formal emails and how to manage time and improve organization skills." – Autistic young adult	9. Learning organisational skills and how to balance multiple demands is a critical factor for young people.
	"If you summarised the ideals, it's about becoming independent. Being able to live alone, cook, clean, shop, make calls, drive, organise bills." – Parent	10. Practicing daily living skills (e.g. hygiene, shopping, cooking, managing finances) is a critical factor for young people.
	"Preparing for adulthood should be taught in school, I don't know the process for job hunting or renting a house and we're just expected to be okay with it." – Autistic young adult	11. Daily living skills should be taught as part of the curriculum in secondary school.
Health and safety	"A successful transition would allow young people to form relationships and be safe and healthy" - Clinician	12. Keeping physically healthy and safe is a critical factor for young people.
Meaningful activities	"A successful transition would allow the young person to be able to engage in an enjoyable and meaningful activity (eg studying or work)." - Clinician	13. Engaging in meaningful activities and hobbies is a critical factor for young people.
	"When I think about young people, it is often about going to university and learn how to become more independent, having their first rented flat." – Clinician	14. Attending and succeeding in higher education is a critical factor for young people.
	"Having a job as an adult and the independence that follows is the most important part about being an adult to me." – Autistic young adult	15. Obtaining and maintaining employment is a critical factor for young people.
Living independently	"I live by myself with a family in their attic, my landlord and I are good friends through family… The room in the attic is nice for privacy and helps me feel independent. My own space away from my family helps me settle down and be myself, no one around to tell me what to do" – Autistic young adult	16. Moving out of the family home and living independently is a critical factor for young people.

Theme 3: Inclusivity

Sub-themes	**Example quotes**	**Statements**
Advocacy	"To me as an ASD person I think success in transition to adulthood is learning to be more responsible for your actions and making smart decisions" – Autistic young adult	17. Enabling and encouraging young people to make decisions and advocate for themselves is a critical factor for a successful transition.
	"Every company needs to be aware of autism, what it's like and how hard work can be. I am constantly trying to push the boundaries with autism awareness. I asked to give an awareness presentation at work. More people need to do this. I'm passionate about diversity and inclusivity." – Autistic young adult	20. Training and education regarding autism should be delivered routinely within organizations.
	"[I want] people to have understanding and awareness of the struggles they [autistic young people] may have and how they may feel." - Parent	21. There should be more initiatives to improve awareness and understanding of autism in society.
Equal opportunities	"It appears to be something of a post-code lottery and sadly there continues to be a degree of socio-economic/racial exclusion. The statistics would suggest young men with social difficulties, with diverse cultural backgrounds, from less wealthy backgrounds will often go to prison rather than other services. It could be argued that the prison estate is the greatest provider of care for young men with neurodiversity and/or mental health vulnerabilities." - Clinician	18. Social inequalities and stigma are the biggest barriers preventing young people from successfully transitioning to adulthood.
	"I think this [successful transition] should be as 'normal' as possible with the same opportunities and options as a person from a neuro-typical background." – Clinician	19. More needs to be done to ensure autistic people receive equal opportunities to non-autistic people.

Theme 4: Areas of development for mental health services

Sub-themes	**Example quotes**	**Statements**
Limited awareness and access to support	"A clearer indication of what support is actually available would be good, I'm in my mid-twenties and I know of barely anything -like one charity and the GP." – Autistic young adult	22. Services need to ensure families are aware of existing adult mental health services.

Experiences of change	"For some young people, I think the idea of taking more of a lead in their own care can be very empowering. However, I think it is more often a very worrying time, especially for the parents, as there is such a difference between paediatric and adult services, and the change from parents having control to letting the young person take responsibility can be very difficult to accept." - Clinician	23. Helping parents to step back and young people to take more responsibility is a critical area of support needed.
Service Limitations	"I am not aware of one service that could holistically support autistic young people in managing the transition to adulthood in all the areas [needed]." - Clinician	24. More specialist adult autism services need to be created.
	"The adult services are severely understaffed and underfunded, barely managing with massive wait times, and that is for those already diagnosed." – Autistic young adult	28. There needs to be more investment into NHS services to improve access to services and availability of resources.
More support for minoritized autistic groups	"Those without a learning disability still suffer with many aspects of life, and that is often overlooked by general health services." – Autistic young adult	26. Providing individualized support for all demographics of autistic people (e.g. autistic females, black and minority ethnic autistic people, autistic people without learning disability) is a critical area of support needed.
Services should be opt-out not opt-in	"There should be some form of introduction to adult mental health services before deciding if you need them or not, rather than being dropped and self-referring afterwards." -Autistic young adult	25. Transfer from child to adult services should happen routinely for young people instead of needing to seek a referral for support from mental health services.
	"The best form of support would have been understanding myself better and the tools to even seek support. If you don't understand your own needs how do you get help for them. A clearer indication of what support is actually available would be good, I'm in my mid-twenties and I know of barely anything" – Autistic young adult	27. Helping young people to know when and how to actively seek support for themselves is a critical area of support needed.
Theme 5: Other sources of support		
Sub-themes	**Example quotes**	**Statements**
Universally accessible support	"I also look up things online to help me plan and prepare. Information mainly. I feel comfortable transitioning if I know as much of what to expect as possible. Forums, to talk to people who have done it before." – Autistic young adult	29. Having universally accessible resources (e.g. online information and advice) is a critical support for young people.

Non-statutory organizations	"There are youth groups for teenagers and young adults with autism and other learning disabilities. The one I go to is really good because I don't get judged for being different and there are nice and welcoming people there." – Autistic young adult	30. Having easy access to non-statutory organisations (e.g. community groups, charities, youth groups) is a critical support for young people.
Educational support	"It was super helpful when he used to see a SEN staff member once a week. She kept it regular and casual and I felt she was interested in how he was doing as well as practical things like helping him get organised and plan his revision." – Parent	31. Having easy access to educational support (e.g. special educational needs coordinator, tutors, autism champion positions) is a critical support for young people.
	"When I moved to [university], I applied for extra support and time for exams again and I managed to get a first overall in 2nd year! I think knowing that you are not alone is crucial. The university was able to give me that comfort and I am really grateful!" – Autistic young adult	32. Having easy access to support at university (e.g. career support, mental well-being, mentors, educational accommodations) is a critical support for young people.
Employment needs	"The [government agency] was awful and put massive pressure on him [son]. He was totally overwhelmed. We sought advice from [charity] and he is now working with [company], who are great. They are working on skills to get him into employment, but they are also working on what employment he would like and what he can cope with." - Parent	33. Having easy access to employment support (e.g. job interview preparation, liaison with managers, general employment skills) is a critical support for young people.
Theme 6: Views on transition planning		
Sub-themes	**Example quotes**	**Statements**
When to begin planning	"For my child I began to think about this [transition to adulthood] from approx 11/12 years of age when the transition to Secondary school clearly was a challenge and I realised that preparation for adulthood would need to be managed carefully to ensure success." – Parent	34. Planning for the transition to adulthood should start when young people begin secondary school.
	"[Transition planning should start] When young people are around 14." – Clinician	35. Planning for the transition to adulthood should start when young people turn 14.
	"I started to think about adulthood when finishing a-levels. I thought about how I can benefit myself in the future and what might help getting a job." – Autistic young adult	36. Planning for the transition to adulthood should start when young people are preparing to finish compulsory education.

	"Young people may not be following the transition to adulthood pathway at the same chronological age as their peers and this needs to be factored into supporting them so that they do not feel that they are failing if they are not progressing at the exact same age as others." - Parent	37. Planning for the transition to adulthood should start when young people have reached an appropriate level of maturity to manage adult tasks, meaning the decision should not be based on age.
How to plan	"I feel that acknowledging and seeing this transition as a process and learning curve, rather than a sudden step is helpful." - Clinician	38. When planning for transition, making sure the process happens gradually and not suddenly is crucial.
	"Generally I'm okay with transitions as long as I have a chance to mentally prepare." – Autistic young adult	39. When planning for transition, ensuring young people have enough time to process information and change is crucial.
	"Improving clarity on my goals and the steps to achieve them [is important]." – Autistic young adult	40. When planning for transition, having clear goals and breaking down the steps to achieve them is crucial.
Theme 7: Helpful tools and processes		
Sub-themes	**Example quotes**	**Statements**
Early diagnosis and intervention	"Diagnosis as early as possible [is needed]. I feel like I wasn't told about adulthood growing up. Like I feel I could have been told about growing up to understand it better, to understand myself and what I need." - Autistic young adult	41. It is critical for autism to be formally diagnosed early in childhood for young people to better understand themselves and receive early intervention.
Suggestions for resources	"[There needs to be] more information available across services to refer to and signpost people to." - Clinician	42. It is critical for families to be signposted to appropriate services and be provided with information leaflets.
	"[We need] Better understanding of transition support available in different areas - building a directory." - Clinician	50. A directory of local support services available to young people and their families should exist for each county/London borough.
Tools for transition	"We also have a "checklist" to work through in the teens to support transition." - Clinician	43. It is critical for families to have a transition checklist as a tool to help young people during the transition to adulthood.
Centralized support wanted	"I think it's important for all organisations that work with young people to have a plan in place for transition including practical aspects and linking in	44. It is critical for families to receive support for a broad range of needs in one centralized service.

	families with information and sources of support. A central hub that holds information of this nature that would be helpful to young people would be fantastic - a one-stop shop so to speak, but that would be very difficult to achieve.” - Clinician	
	“It [transition] should be a structured programme that is coordinated by a professional as a single point of contact who can liaise with both the young person and other professionals involved in their care and education.” - Parent	45. It is critical for families to have a single point of contact to coordinate support from different services.
Collaborative approach needed	“A team of adults who work together rather than in isolation [is important]. Ideally this would involve parents/carers, school, health care and social care.” – Clinician	46. It is critical for all different adults caring for a young person (e.g. family, teachers, social workers, doctors) to be involved in planning discussions.
	“I am regularly involved in supporting families to consider next steps and liaising with schools and universities for example about the kind of support a young person might need.” - Clinician	47. Regular liaison between education and healthcare professionals is a key factor in supporting young people.
Helpful transition support	“Make support more available, especially the governmental help, like financial help, that’s the hardest to access.” – Autistic young adult	48. Financial support from the government is a key factor in supporting young people in transition.
	“[In future I would like to see] more transition workers to support in mental health services” - Clinician	49. Having a dedicated transition worker or access to a specialist transition team is a critical factor for young people.
Support improvements	“I would say someone like a mentor would help, but this is often a difficult relationship to establish.” – Autistic young adult	51. It would be helpful to implement more mentor schemes for young people to access for support.
	“[In future I would like to see] tailored workshops and more mental health support” – Autistic young adult	52. Services should offer workshops for young people and their families on topics voted for by service users e.g. Daily living skills, Relationships, Jobs.

Round 2

Results that reached overall strong consensus in R2Q are presented in tables 5-11, organised by theme. In R2Q 29/52 statements achieved strong consensus. Here, 'consensus' refers to agreement as no disagreement was observed. Levels of agreement and disagreement are displayed within and between participants, with between-group differences shown in bold. Quotes are presented to aid understanding of participants' perspectives. No significant difference was found between expert group ratings following a Kruskal-Wallis one-way analysis of variance with an alpha level of .01 due to the high number of comparisons (appendix P).

Theme 1: Personal qualities and relationships

Four of eight statements reached strong consensus. Participants agreed that building self-esteem, understanding oneself and needs, and the ability to manage difficult emotions are critical factors for a successful transition. It was also agreed that talking to trusted adults is a key form of support during transition.

> *"Unmasking and developing their identity as an autistic person and learning to recognise needs and how to get them met is essential for a 'successful' adult life."* – Clinician

Table 6

R2Q consensus for statements relating to personal qualities and relationships

Statements achieving strong consensus		Agree (%)	Disagree (%)
1. Young people need to build up their self-esteem to be successful in adulthood.	Autistic young adults	76	0
	Parents	**73**	0
	Healthcare Clinicians	93	0
	Overall	81	0
2. Being able to manage difficult emotions is a critical factor for young people.	Autistic young adults	82	6
	Parents	100	0

	Healthcare Clinicians	93	7
	Overall	90	5
3. Understanding themselves and their needs is a critical factor for young people.	Autistic young adults	100	0
	Parents	100	0
	Healthcare Clinicians	93	0
	Overall	98	0
8. Talking to trusted adults, such as professionals or mentors, is critical support for youth transitioning to adulthood.	Autistic young adults	82	0
	Parents	82	0
	Healthcare Clinicians	79	0
	Overall	81	0

Theme 2: Goals for daily living

Four of eight statements reached strong consensus. Participants agreed that practising daily living skills, staying physically healthy and safe, and engaging in meaningful activities are critical factors for a successful transition. It was agreed that daily living skills should be taught within secondary schools.

> *"I believe that learning skills of independence away from family is really important*."
>
> - Autistic young adult

Table 7

R2Q consensus for statements relating to goals for daily living

Statements achieving strong consensus		Agree (%)	Disagree (%)
10. Practicing daily living skills (e.g. hygiene, shopping, cooking, managing finances) is a critical factor for young people.	Autistic young adults	88	0
	Parents	100	0
	Healthcare Clinicians	93	7
	Overall	93	2
11. Daily living skills should be taught as part of the curriculum in secondary school.	Autistic young adults	88	0
	Parents	91	0
	Healthcare Clinicians	79	14

	Overall	86	5
12. Keeping physically healthy and safe is a critical factor for young people.	Autistic young adults	94	6
	Parents	100	0
	Healthcare Clinicians	93	0
	Overall	95	2
13. Engaging in meaningful activities and hobbies is a critical factor for young people.	Autistic young adults	88	0
	Parents	91	0
	Healthcare Clinicians	93	0
	Overall	90	0

Theme 3: Inclusivity

Four of five statements reached consensus. Participants agreed that encouragement and advocacy in decision making is critical for a successful transition. It was also agreed that more needs to be done to ensure AYP without a learning disability receive equal opportunities to non-autistic people, such as education and training on autism within organizations and initiatives to improve awareness and understanding of autism in society.

"The classification of autism is not well understood. On the one hand, it is a disability and a possible 'mental defect'. On the other hand, equal but different. The mental illness stigma lives on." -Parent

Table 8

R2Q consensus for statements relating to inclusivity

Statements achieving strong consensus		Agree (%)	Disagree (%)
17. Enabling and encouraging young people to make decisions and advocate for themselves is a critical factor for successful transition.	Autistic young adults	94	0
	Parents	82	0
	Healthcare Clinicians	93	0
	Overall	90	0
19. More needs to be done to ensure autistic people receive equal opportunities to non-autistic people.	Autistic young adults	88	0
	Parents	82	0

	Healthcare Clinicians	100	0
	Overall	90	0
20. Training and education regarding autism should be delivered routinely within organizations.	Autistic young adults	82	0
	Parents	**73**	0
	Healthcare Clinicians	79	0
	Overall	79	0
21. There should be more initiatives to improve awareness and understanding of autism in society.	Autistic young adults	88	0
	Parents	82	0
	Healthcare Clinicians	93	0
	Overall	88	0

Theme 4: Areas of development for mental health services

Six of seven statements reached consensus. Participants agreed that mental health services need to ensure families are aware of existing adult services, provide individualized support catering to all demographics, and help AYP without a learning disability to know when and how to seek support for themselves. It was also agreed that NHS services need greater investment, more specialist autism services should be established, and transfer from child to adult mental health services should happen routinely instead of requiring a referral.

> *"With a general improvement of mental health services, there would be less need for specialist support, and the more niche we get, the more money would be needed."*
>
> -Autistic young adult

Table 9

R2Q consensus for statements relating to areas of development for mental health services

Statements achieving strong consensus		**Agree (%)**	**Disagree (%)**
22. Services need to ensure families are aware of existing adult mental health services.	Autistic young adults	82	0
	Parents	**73**	0
	Healthcare Clinicians	100	0
	Overall	86	0

24. More specialist adult autism services need to be created.	Autistic young adults	94	0
	Parents	91	0
	Healthcare Clinicians	79	14
	Overall	88	5
25. Transfer from child to adult services should happen routinely for all young people instead of needing to seek a referral for support from mental health services.	Autistic young adults	88	6
	Parents	**73**	18
	Healthcare Clinicians	**64**	7
	Overall	76	10
26. Providing individualized support for all demographics of autistic people (e.g. autistic females, black and minority ethnic autistic people, autistic people without learning disability, autistic adults) is a critical area of support needed.	Autistic young adults	82	0
	Parents	82	0
	Healthcare Clinicians	**71**	0
	Overall	79	0
27. Helping young people to know when and how to actively seek support for themselves is a critical area of support needed.	Autistic young adults	88	0
	Parents	91	0
	Healthcare Clinicians	79	0
	Overall	86	0
28. There needs to be more investment into NHS services to improve access to services and availability of resources.	Autistic young adults	94	0
	Parents	91	0
	Healthcare Clinicians	100	0
	Overall	95	0

Theme 5: Other sources of support

Every statement reached strong consensus. Overall, participants agreed that easy access to non-statutory organisations, educational support, holistic support at university and employment support are all crucial forms of support outside of mental health services. It was also agreed that universally accessible resources, such as online information and advice, are essential for AYP without a learning disability during transition.

"An additional benefit of online support is that it can be shared, discussed, and openly dissected by many people leading to clearer directions for improvement. However, this is

definitely not going to be accessible for all autistic people, especially those who do not have unrestricted internet access." -Autistic young adult.

Table 10

R2Q consensus for statements relating to other sources of support

Statements achieving strong consensus		Agree (%)	Disagree (%)
29. Having universally accessible resources (e.g. online information and advice) is a critical support for young people.	Autistic young adults	76	0
	Parents	**64**	0
	Healthcare Clinicians	93	7
	Overall	79	2
30. Having easy access to non-statutory organisations (e.g. community groups, charities, youth groups) is a critical support for young people.	Autistic young adults	76	0
	Parents	**64**	0
	Healthcare Clinicians	93	7
	Overall	79	2
31. Having easy access to educational support (e.g. special educational needs coordinator, tutors, autism champion positions) is a critical support for young people.	Autistic young adults	88	0
	Parents	**64**	0
	Healthcare Clinicians	100	0
	Overall	86	0
32. Having easy access to support at university (e.g. career support, mental well-being, mentors, educational accommodations) is a critical support for young people.	Autistic young adults	88	0
	Parents	**73**	0
	Healthcare Clinicians	93	0
	Overall	86	0
33. Having easy access to employment support (e.g. job interview preparation, liaison with managers, general employment skills) is a critical support for young people.	Autistic young adults	88	0
	Parents	**73**	0
	Healthcare Clinicians	100	0
	Overall	88	0

Theme 6: Views on transition planning

Three of seven statements reached strong consensus. Participants agreed that transition planning should be a gradual process with adequate time for AYP without a learning disability to process information and include clear goals alongside instructions to achieve them.

> *"Gradual transition plans often make sense to neurotypical staff but in my practical experience many people with ASC dislike them in that they like changes to be clear and boundaried. A graduated programme means tolerance of repeated changes to routine and schedules. Having supported quite a few people with ASC through this process they seem to prefer to reach a point when they feel they are ready and make a substantial change in one larger step."* - Clinician

Table 11

R2Q consensus for statements relating to views on transition planning

Statements achieving strong consensus		**Agree (%)**	**Disagree (%)**
38. When planning for transition, making sure the process happens gradually and not suddenly is crucial.	Autistic young adults	**71**	6
	Parents	**73**	0
	Healthcare Clinicians	93	7
	Overall	79	5
39. When planning for transition, ensuring young people have enough time to process information and change is crucial.	Autistic young adults	82	6
	Parents	82	0
	Healthcare Clinicians	100	0
	Overall	88	2
40. When planning for transition, having clear goals and breaking down the steps to achieve them is crucial.	Autistic young adults	88	6
	Parents	82	0
	Healthcare Clinicians	100	0
	Overall	90	2

Theme 7: Helpful tools and processes

Three of 12 statements reached strong consensus. Participants agreed that a directory of local services would be a useful resource. Overall, stakeholders agreed that AYP without a learning disability and their families would benefit from signposting and information about appropriate services, and for services to offer workshops on subjects decided by service users.

"I would really like a mentor for my young person. It all feels on me. And while I do feel I have relevant skills I would like to share the role." - Parent

Table 12

R2Q consensus for statements relating to helpful tools and processes

Statements achieving strong consensus		Agree (%)	Disagree (%)
42. It is critical for families to be signposted to appropriate services and be provided with information leaflets.	Autistic young adults	76	6
	Parents	**64**	0
	Healthcare Clinicians	93	7
	Overall	79	5
50. A directory of local support services available to young people and their families should exist for each county/London borough.	Autistic young adults	76	0
	Parents	82	0
	Healthcare Clinicians	79	0
	Overall	79	0
52. Services should offer workshops for young people and their families on topics voted for by service users e.g. Daily living skills, Relationships, Jobs.	Autistic young adults	82	0
	Parents	**73**	0
	Healthcare Clinicians	86	0
	Overall	81	0

Round 3

Participants who completed R2Q were sent R3Q, which comprised 23 statements that had not reached consensus. A response rate of 81% was achieved. Of the 34 participants who completed R3Q, 32 changed at least one of their responses (mean changes per participant =5.2, range 1-11). Every statement was rated differently by at least four participants (statements 6, 34, 46 and 47), ranging to 13 participants changing their response (statement 18). On average 7.5 participants changed their response per statement.

Only the data of participants who completed both R2Q and R3Q was included in the analysis due to the high level response change in R3Q, meaning participants may have changed their responses as many others had. Consequently, data from 8 participants was lost. R3Q results are presented in Tables 13-18, organised by theme and level of consensus. Strong consensus was achieved on 11/23 statements. Percentage agreement and disagreement are displayed within and between participants, with between-group differences shown in bold and any divergence described. Quotes are shown to illustrate participants' perspectives.

A Kruskal–Wallis one-way analysis of variance compared expert groups ratings from the Likert scale. The alpha was set to .01 due to the high number of comparison tests conducted. No comparisons reached statistical significance (appendix Q).

Theme 1: Personal qualities and relationships

Two of the four statements reached strong consensus, two did not achieve consensus. Participants agreed that maintaining positive peer relationships is key for successful transition and the well-being of family members requires consideration. Clinicians and autistic adults showed some agreement that family members are best positioned to support AYP without a learning disability during transition, however this was not observed among parents. Statement four resulted in divergence between groups. Parents and clinicians showed some agreement that imagining the future is helpful for AYP without a learning disability, however this was not seen among autistic adults.

"For the second question I changed my response… my original position was that maintaining friendships and positive peer relationships was good, but not the only critical factor and certainly not the most important. But thinking it through a bit more and looking back at my own experiences, if I had more positive relationships in school growing up I likely would have

performed better academically and it would've taught me important social skills that I'm currently having to learn as an adult." – Autistic young adult.

Table 13

R3Q consensus for statements relating to personal qualities and relationships

Statements achieving strong consensus		**Agree (%)**	**Disagree (%)**
5. Being able to maintain friendships and positive peer relationships is a critical factor for young people.	Autistic young adults	82	9
	Parents	90	0
	Healthcare Clinicians	**67**	0
	Overall	79	3
7. The well-being of other family members is important to consider when young people transition to adulthood.	Autistic young adults	82	0
	Parents	82	0
	Healthcare Clinicians	100	0
	Overall	88	0
Statements achieving no consensus		**Agree (%)**	**Disagree (%)**
4. It is a helpful exercise for young people to imagine themselves in the future as adults.	Autistic young adults	18	0
	Parents	**55**	9
	Healthcare Clinicians	**67**	8
	Overall	47	6
6. Family members are the best people to provide emotional support and support with daily living skills to young people.	Autistic young adults	**55**	9
	Parents	27	0
	Healthcare Clinicians	**58**	0
	Overall	47	3

Theme 2: Goals for daily living

One of four statements reached moderate consensus whilst three did not reach consensus. Stakeholders reached moderate agreement that learning organisational skills is key for a successful transition, with strong consensus seen among autistic adults. Parents and autistic adults reached weak agreement that maintaining employment is a critical factor for transition, however this was not seen among clinicians. No consensus was found regarding whether moving out of the family home and attending higher education are critical factors.

> "*To differentiate I think employment is most important, university could help with life skill development and moving out would be good but it's not totally necessary.*" – Parent.

Table 14

R3Q consensus for statements relating to goals for daily living

Statements achieving moderate consensus		**Agree (%)**	**Disagree (%)**
9. Learning organisational skills and how to balance multiple demands is a critical factor for young people.	Autistic young adults	**82**	0
	Parents	73	0
	Healthcare Clinicians	67	8
	Overall	74	3
Statements achieving no consensus		**Agree (%)**	**Disagree (%)**
14. Attending and succeeding in higher education is a critical factor for young people.	Autistic young adults	27	18
	Parents	9	18
	Healthcare Clinicians	25	25
	Overall	21	21
15. Obtaining and maintaining employment is a critical factor for young people.	Autistic young adults	**55**	0
	Parents	**55**	9
	Healthcare Clinicians	33	8
	Overall	47	6
16. Moving out of the family home and living independently is a critical factor for young people.	Autistic young adults	36	0
	Parents	18	9
	Healthcare Clinicians	17	8
	Overall	24	6

Theme 3: Inclusivity

The remaining statement reached strong consensus. Stakeholders agreed that social inequalities and stigma are the biggest barriers preventing successful transition.

"*With an autistic teacher, and now social worker, for a parent she sees and works with the social inequality every day.*" – Autistic young adult.

Table 15

R3Q consensus for statements relating to inclusivity

Statements achieving strong consensus		**Agree (%)**	**Disagree (%)**
18. Social inequalities and stigma are the biggest barriers preventing young people from successfully transitioning to adulthood.	Autistic young adults	100	0
	Parents	82	0
	Healthcare Clinicians	83	8
	Overall	88	3

Theme 4: Areas of development for mental health services

The remaining statement reached strong consensus. Parents and clinicians reached moderate agreement that helping parents to step back and AYP to take more responsibility is a critical area of support needed, although this reached strong agreement among autistic adults.

"*I agree with the comment [but] it's not necessarily for mental health services. My autistic young person does not have mental health difficulties*" – Parent.

Table 16

R3Q consensus for statements relating to areas of development for mental health services

Statements achieving strong consensus		**Agree (%)**	**Disagree (%)**
23. Helping parents to step back and young people to take more responsibility is a critical area of support needed.	Autistic young adults	91	0
	Parents	**73**	0
	Healthcare Clinicians	**67**	17
	Overall	76	6

Theme 6: Views on transition planning

One of four statements reached strong consensus, another reached weak consensus, and two did not achieve consensus. Participants agreed that transition planning should begin when AYP without a learning disability reach an appropriate level of maturity to manage adult tasks. Clinicians reached weak agreement that transition planning should begin when AYP without a learning disability reach the age of 14, although no consensus was seen among autistic adults or parents. Finally, no consensus was achieved regarding transition planning starting when AYP without a learning disability are preparing to finish compulsory education.

Divergence between groups was seen in statement 34. Participants reached weak agreement regarding transition planning beginning when AYP without a learning disability start secondary school, which reflected strong agreement among autistic adults and moderate agreement among parents, whilst no consensus was seen among clinicians.

"*I attempted to learn how to transition to adulthood from age 14 and it kind of freaked me out."* – Autistic young adult.

Table 17

R3Q consensus for statements relating to views on transition planning

Statements achieving strong consensus		**Agree (%)**	**Disagree (%)**
37. Planning for the transition to adulthood should start when young people have reached an appropriate level of maturity to manage adult tasks, meaning the decision should not be based on age.	Autistic young adults	91	0
	Parents	82	0
	Healthcare Clinicians	83	0
	Overall	85	0
Statements achieving weak consensus		**Agree (%)**	**Disagree (%)**
34. Planning for the transition to adulthood should start when young people begin secondary school.	Autistic young adults	55	18
	Parents	**73**	0
	Healthcare Clinicians	**33**	8
	Overall	53	9

Statements achieving no consensus		**Agree (%)**	**Disagree (%)**
35. Planning for the transition to adulthood should start when young people turn 14.	Autistic young adults	27	18
	Parents	45	18
	Healthcare Clinicians	**50**	8
	Overall	41	15
36. Planning for the transition to adulthood should start when young people are preparing to finish compulsory education.	Autistic young adults	27	36
	Parents	36	45
	Healthcare Clinicians	33	8
	Overall	32	29

Theme 7: Helpful tools and processes

Six of nine statements achieved strong consensus and three reached moderate consensus. Statements 43, 46, 48 and 49 observed a divergence between groups.

Participants agreed that families should have a single contact to coordinate support, that regular liaison between education and healthcare professionals is key, and more mentor schemes should be implemented to support AYP without a learning disability. Clinicians reached strong agreement that early diagnosis is needed for AYP without a learning disability to better understand themselves, with moderate agreement among autistic adults and parents. Clinicians and parents reached strong agreement that families should receive a range of support from one centralised service, with moderate agreement among autistic adults. Furthermore, autistic adults and parents reached strong agreement that a dedicated transition workers/teams are key supports for a successful transition, however this received weak agreement among clinicians.

Whilst parents reached strong agreement that transition checklists are a useful tool, weak agreement was observed among autistic adults and clinicians. Parents and clinicians reached strong agreement that all adults involved in an individuals' care should be involved in planning for transition, however this reached weak agreement among autistic adults.

Finally, although autistic adults achieved strong agreement that financial support is a key during transition, this reached moderate agreement among parents and weak agreement among clinicians.

> *"One centralised service is a fantastic idea but only if they are a superb service. This is why I can't select 'strongly' agree and why a choice of services is currently better."* – Parent.

Table 18

R3Q consensus for statements relating to helpful tools and processes

Statements achieving strong consensus		**Agree (%)**	**Disagree (%)**
41. It is critical for autism to be formally diagnosed early in childhood for young people to better understand themselves and receive early intervention.	Autistic young adults	**73**	0
	Parents	**73**	9
	Healthcare Clinicians	92	0
	Overall	79	3
44. It is critical for families to receive support for a broad range of needs in one centralized service.	Autistic young adults	**64**	**0**
	Parents	100	0
	Healthcare Clinicians	83	8
	Overall	82	3
45. It is critical for families to have a single point of contact to coordinate support from different services.	Autistic young adults	82	0
	Parents	91	0
	Healthcare Clinicians	83	0
	Overall	85	0
47. Regular liaison between education and healthcare professionals is a key factor in supporting young people.	Autistic young adults	82	0
	Parents	91	0
	Healthcare Clinicians	75	0
	Overall	82	0
49. Having a dedicated transition worker or access to a specialist transition team is a critical factor for young people.	Autistic young adults	91	0
	Parents	100	0
	Healthcare Clinicians	**58**	0
	Overall	82	0
51. It would be helpful to implement more mentor schemes for young people to access for support.	Autistic young adults	91	0
	Parents	82	0

	Healthcare Clinicians	83	0
	Overall	85	0
Statements achieving moderate consensus		**Agree (%)**	**Disagree (%)**
43. It is critical for families to have a transition checklist as a tool to help young people during the transition to adulthood.	Autistic young adults	**55**	9
	Parents	**82**	0
	Healthcare Clinicians	**58**	8
	Overall	65	6
46. It is critical for all different adults caring for a young person (e.g. family, teachers, social workers, doctors) to be involved in planning discussions.	Autistic young adults	**55**	0
	Parents	**82**	0
	Healthcare Clinicians	**75**	0
	Overall	71	0
48. Financial support from the government is a key factor in supporting young people in transition.	Autistic young adults	**82**	0
	Parents	73	0
	Healthcare Clinicians	**58**	0
	Overall	71	0

Importance ratings

Twenty participants noted their three most important statements. A total of 24/52 statements received at least one vote of importance. The three most frequently voted statements remained consistent between R2Q-R3Q, with eight participants (40%) changing at least one of their answers, ranging from one vote changed (n=3) to two votes changed (n=5). Table 20 displays the three ‘most important’ statements. See Appendix R for full details of frequencies per statement per round.

Overall, participants indicated that understanding oneself and needs is an important factor for a successful transition, that helping AYP without a learning disability to know when and how to seek support for themselves is an important form of support, and a directory of local services would be an important tool to support families.

Table 19

The three most important statements voted by participants

Statement	**Autistic young adults** (n= 7)	**Parents/ Carers** (n= 4)	**Healthcare Clinicians** (n= 9)	**Overall** (n= 20)
3. Understanding themselves and their needs is a critical factor for young people.	3 (43%)	3 (75%)	4 (44%)	10 (50%)
27. Helping young people to know when and how to actively seek support for themselves is a critical area of support needed.	3 (43%)	1 (25%)	2 (22%)	6 (30%)
50. A directory of local support services available to young people and their families should exist for each county/London borough.	2 (29%)	1 (25%)	2 (22%)	5 (25%)

Discussion

This Delphi study gained an understanding of stakeholders' views regarding the transition to adulthood for AYP without a learning disability in the UK, including what factors constitute a successful transition and what support and resources enable this. Findings are discussed in relation to areas of overall stakeholder consensus or divergence, and linked to relevant literature. Strengths and limitations of the study are considered alongside implications for clinical practice and future research.

Overall, 40/52 statements achieved a strong consensus, 4/52 reached moderate consensus, 1/52 reached weak consensus and 7/52 reached no consensus. Every statement reaching consensus demonstrated agreement across stakeholders. Whilst divergence between stakeholders was seen in six statements, no statistically significant difference was found between expert groups, meaning these may be chance fluctuations. The agreement seen between expert groups likely reflects shared priorities on what support is required.

What are the key factors for 'successful' transition?

Overall, participants agreed a successful transition involves keeping physically healthy and safe, the ability to manage one's emotions, and developing confidence in one's abilities and judgements (self-esteem); factors which align with Maslow's hierarchy (1943). Lower self-regulation and subjective quality of life has been found in AYP without a learning disability than the general population (Dijkhuis et al., 2017). Current findings suggest the psychological needs of AYP without a learning disability require development during transition, the absence of which may result in lower subjective quality of life. Significant positive predictors of quality of life for autistic adults in the UK included employment and relationship status' (Mason et al., 2018). Conversely, in this study maintaining employment, attending higher education or moving out of the family home were not found to be key factors for successful transition. Stakeholders did however reach consensus that ‘engagement in meaningful activities’ and ‘maintaining positive peer relationships’ were key factors, implying that hobbies and friendships are at least equally as important as employment and romantic relationships.

Divergence was seen between autistic adults and clinicians regarding imagining the future being a helpful exercise. In young adults with no co-occurring difficulties other than depression or anxiety, visual imagery strongly correlates with the clarity of goal directed imagination, assisting the attainment of goals (Gamble, 2020). Healthcare clinicians may understand this and assume visualisation is a helpful exercise for AYP without a learning disability. However, many autistic individuals share a common difficulty in generalising and self-projection into the future (Terrett et al., 2013; Lind et al., 2014), which may explain the divergence between these groups.

Stakeholders agreed that understanding oneself and one’s needs is a key factor for a successful transition, and considered this the most important factor. Additionally, stakeholders agreed the ability to make decisions and advocate for themselves is a key factor for transition. To self-advocate effectively, people with disabilities need an accurate and realistic understanding of themselves (Downing et al., 2007). Research has shown the integration of "autism" into AYP’s identities was influenced by their social environments, as AYP believed they deviated from "normality", a benchmark against which they measured themselves (Mesa & Hamilton, 2022). Perceiving oneself as 'different' can fuel social inequality via internal mechanisms like the self-fulfilling prophecy (Merton, 1948) prompting self-exclusion, and external mechanisms such as social stigma and discrimination resulting in limited opportunities for those deemed 'different' (Turnock et al., 2022). This was acknowledged by stakeholders, who agreed that having equal-opportunities to non-autistic people and increased support for minoritised autistic groups are key factors for a successful transition.

What support is needed from systems for a successful transition?

Stakeholders agreed AYP without a learning disability need trusted adults to speak with openly about their experiences and that a single point of contact (e.g. care coordinator) was beneficial. Trust within relationships is significantly positively associated with psychological health (Giordano & Lindström, 2011). Most importantly, stakeholders agreed that services should help AYP without a learning disability to know when/how to seek support for themselves. Prior research indicated that just 32% of AYP were confident in recognizing mental health issues in themselves and fewer felt comfortable disclosing this to healthcare/education professionals (Crane et al., 2017). Intentions to seek support are predicted by better knowledge of mental health (Rüsch et al., 2011). This suggests that healthcare clinicians supporting transition-age AYP must build trusting relationships and provide individualised psychoeducation regarding mental health.

Stakeholders agreed practical support relating to daily living skills, education (e.g. SEN coordinators, mentor, autism champions) and employment (e.g. careers advice, job interview preparation, workplace liaison) was needed. This could be provided within healthcare or education systems; the overlap of which was acknowledged as stakeholders agreed regular liaison between healthcare and education professionals is key. Nonetheless, participants suggested that life skills be taught within secondary school. Practical ‘life skills’ classes are offered in SEN schools, which may deviate from the national curriculum within state-funded mainstream education (Department of Education, 2014, 2015). However, the ‘life skill’ classes and careers advice consistently offered within SEN schools would benefit all young people, and ought to be offered within mainstream education also.

Participants agreed that families need to be aware of existing adult mental health services and transfer to adult services should be routine for AYP without a learning disability. The role of family members during transition was acknowledged across stakeholders, with agreement that the well-being of other family members should be considered, and that parents need to be supported to shift responsibility onto AYP without a learning disability. One framework emphasising the needs of entire family units when providing support is the Think Family approach, which aims to improve outcomes through collaboration between young people, parents and practitioners; it embodies the value ‘nothing about you without you’ (Bexley Safeguarding Partnership, 2024).

What resources are most important to achieve a successful transition?

Participants agreed that AYP without a learning disability and their families need freely accessible information, such as online resources. ChatAutism is the first and only messaging service offering healthcare support to AYP and their families, however this is exclusive to Leicestershire NHS Trust (n.d.). Stakeholders also agreed that a centralized service offering support for a broad range of needs would help facilitate transition. ActuallyHaringey Autism Hub offers a range of support (information and advice, therapy, social events and careers support) in one location with flexible appointment formats. This relatively novel service model provided by the council supports local autistic people. Services vary greatly between local authorities, with expenditures per 0-25 year old ranging from £274-£1057 (Local Government Association, 2019). Stakeholders agreed a directory of support services should exist per area/local authority so autistic people, their families, and clinicians are aware of available support; this was considered the most important resource for transition.

According to stakeholders, transition planning should be gradual, allow AYP without a learning disability time to process information and outline clear goals with steps on how to achieve them. These findings support previous literature regarding educational transition planning for AYP and healthcare transition planning for youth with medical complexity (Cumming et al., 2020; Snell-Rood et al., 2020; Li et al., 2022). Parent (moderate consensus) and clinician (no consensus) groups diverged on whether transition planning should begin when AYP without a learning disability start secondary school. However, stakeholders agreed that transition planning should begin based on individual 'maturity', although which factors demonstrate adequate maturity is unclear. Research investigating the optimal time and developmental readiness required to begin transition planning would be beneficial. Overall, stakeholders agreed that transition workers are a useful resource during transition, however a weak consensus was found among clinicians. This divergence could be explained by healthcare clinicians lived experience of the healthcare system and acknowledgement that whilst potentially beneficial, resources rarely exist to support such implementations (Chun et al., 2023).

Stakeholders agreed that greater investment in the NHS is required to improve access to and availability of services. Lack of financial resource inhibits the implementation of specialist services and initiatives such as mentor schemes or skills based workshops, all of which were considered helpful transition supports. Stakeholders also agreed that early diagnosis is important to aid self-understanding and receive support from an early age. The NHS long-term plan (2019) emphasizes early intervention in supporting children's mental health, yet autism assessment waiting times averaged over 10 months in 2023 (Royal College of Psychiatrists, 2023), highlighting resource limitations in meeting targets.

Finally, stakeholders agreed that training and education to improve understanding of autism is required for staff in organisations and society in general, supporting existing research (Turnock et al., 2022; Han et al., 2023). Misconceptions regarding autism are common, although online training has been found to be a cost-effective method to help increase understanding and acceptance of autism among university students (Gillespie-Lynch et al., 201; Someki et al., 2018).

Strengths and limitations

This appears to be the first study to focus on the factors constituting and facilitators to a successful transition to adulthood for AYP without a learning disability agreed across stakeholders. Consultation with an EbE improved the accessibility of research materials. The varied expertise of participants contributed to comprehensive and pertinent conclusions, enhancing the validity of group consensus while mitigating the risk of conformity bias (Jorm, 2015). The high response rate maintained between rounds strengthened the validity of findings (Hsu & Sandford, 2007). The online format of this study meant participation was not limited by geographical location. Consensus across stakeholders was attained for 77% of statements, indicating a unified understanding across stakeholders (Townsend, 2020).

Nonetheless, there is a clear limitation in the lack of diversity within the sample which is predominantly female, white British and professionally skewed towards psychologists. Subsequently, the findings may not be applicable to broader populations and an opportunity to explore variations in responses across different demographic and professional groups was not possible. Additionally, despite extensive recruitment attempts only three parents completed R1Q, meaning there was an underrepresentation of caregiver perspectives in the statements developed for subsequent rounds. These factors limit the generalizability of the current findings. A larger sample would also have increased statistical power in exploring group differences, although this was not a main aim of the study.

Clinical Implications

The findings of this study have numerous implications for clinical practice, embodying the NHS values of ‘improving lives’ and ‘commitment to quality of care’ (NHS, 2023). The factors that stakeholders agree are key to a successful transition should be considered within transition planning. For example, exploring identity and what autism means to individuals could foster greater self-understanding and awareness of needs. Furthermore, several suggestions for support have been outlined: support that can be readily implemented with clinical practice includes building trusting relationships with AYP without a learning disability, offering practical skills based guidance, and adopting the ‘think family’ approach when working with AYP without a learning disability and their families.

Findings indicated that helping AYP without a learning disability to know when and how to seek support is the most important support needed during transition. Safety planning is a common intervention in child and adolescent mental health services aimed at suicide prevention (Abbot-Smith et al., 2023). These plans outline an individual’s ‘warning signs’, coping strategies, things other people can do to help and contact information for support (NHS, 2018), information that is helpful for general emotional well-being. A form of ‘safety planning’ with all AYP without a learning disability during transition could be a universally useful intervention.

Finally, stakeholders agreed that local directories to provide information regarding all services accessible to AYP without a learning disability and their families, are important resources for transition. Developing local directories would require extensive liaison and collaboration between healthcare, education, social care, charities and local authorities. However, this could be a cost-effective method to alleviate the barrier of limited and inconsistent information reported in previous transition research (Anderson & Butt, 2018; Shanahan et al., 2020).

Research Implications

The presented evidence indicated a variety of methods to improve transition for AYP without a learning disability. Research investigating ways to operationalise these methods and evaluate their effectiveness is now needed.

Participants varied in opinion of when transition planning should begin, with the only statement reaching strong consensus suggesting this should be based on 'maturity' of the individual. Future research looking at the optimal time to begin transition planning and what factors stakeholders believe indicates 'maturity' would be beneficial.

Finally, the present and previous research indicated a need for improved awareness and understanding of autism, particularly in places of work and wider society. One participant in this study took it upon themselves to offer training in their workplace and advocated for EbE led initiatives. Few initiatives are currently implemented, for example the National Autism Trainer Programme (NHS England, 2020) and the Autism at Work programme which aims to improve employers awareness of autistic talent (NAS, n.d.). Future research is required to investigate the long-term impact of autism training initiatives, determine which aspects of society are not being reached and co-produce initiatives accordingly with the autistic community.

Conclusion

This study offered an original attempt to explore the key factors of a successful transition to adulthood and its facilitators (i.e. support and resources) with autistic young adults without a learning disability, caregivers and healthcare clinicians supporting this population. The most important factor of a successful transition agreed across stakeholders was for AYP without a learning disability to ‘understand themselves and their needs’, with the most important support agreed being ‘helping young people to know when and how to actively seek support for themselves’. Stakeholders also agreed the most important resource to achieve a successful transition is a directory of local support services; no participant knew of any such resource currently existing. Despite efforts to conduct a national research project, the study was limited by a lack of diversity in the recruited sample. However, the findings offer implications for future clinical practice. Further research is required to operationalise and evaluate key facilitators of a successful transition to adulthood for AYP.

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Section C: Appendices of supporting material contents

Appendix A: Detailed quality appraisal using the adapted CASP tool (Long et al., 2020)

CASP Criteria	**Cheak-Zamora & Teti, 2015**	**Schwartz et al., 2020**	**Crane et al., 2019**	**Berg et al., 2023**	**Culnane et al., 2020**	**Merrick et al., 2020**	**Shanahan et al., 2020**	**Cheak-Zamora et al., 2017**	**Ghanouni & · Seaker, 2022**	**McMinn et al., 2019**	**Ames et al., 2023**	**Kuhlthau et al., 2015**	**Anderson & Butt, 2018**
Clear aims?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Appropriate methodology?	Yes - to explore group norms and commonly shared participant experiences	Yes – to examine lived healthcare experiences	Yes – explored experiences and perspectives	Yes – seeking perspectives and advice	Yes – perspectives of stakeholders sought	Yes – to understand the experience of transition	Yes - to explore the experiences of transition	Yes – to explore and compare perspectives	Yes – to collect general views and perspectives about services	Yes - to explore the experiences of transition	Yes – to capture perspectives and experiences	Yes – to identify current strategies	Yes – to know more about families lived experiences
Design appropriate to address aims?	Yes – justification for qualitative approach and focus groups specifically given	Yes – reason for qualitative approach given	Somewhat – methods “jointly decided” but not explained	Somewhat – reason for using interviews specifically not explained	Somewhat – explanation for using surveys and interviews with different groups not given	Somewhat – rationale for mixed methods unclear	Yes – multiple reasons for use of interviews given	Yes – explanation for interviews and focus groups given and evidenced	Yes – reason for interviews briefly described	Somewhat – reason for interviews specifically not explained	Somewhat – rationale for use of interviews not explained	Yes – rationale for qualitative approach and interviews given	Somewhat – rationale for interviews specifically unclear
Theoretical underpinnings described?	Not described	Yes – rooted in grounded theory	Yes – essentialist framework	Not described	Not described	Not described	Not described	Not described	Yes - social constructionist epistemology	Not described	Somewhat – analysis through “the lens of a social model” of disability	Not described	Yes – a grounded theory approach
Recruitment strategy appropriate?	Yes – convenience sampling; rationale given; advertising described; volunteers	Somewhat - convenience sample; recruitment described; approached participants; rationale for sample not explicit	Yes – rationale for sample given; recruitment process described; volunteers	Yes – rationale given; recruitment process described; participants referred; reason(s) for not taking part given	Somewhat – recruitment process outlined; participants invited; rationale and discussion are limited	Somewhat – referred to participate; recruitment process described; vague rationale in introduction	Yes – rationale for sample given; recruitment process clear; volunteers	Yes – rationale for participants and description of selection given; volunteers; reason(s) for not taking part given	Yes – snowball sample; process of recruitment described; volunteers	Yes – self-selected sample; rationale given; recruitment process outlined	Yes –rationale given; participants invited; recruitment process outlined	Yes – rationale given; participants invited; recruitment process outlined	Somewhat – recruitment described but unclear if sample were invited or volunteered

Data collection addresses the issue?	Yes – focus groups with semi structured guides; example questions provided; “recordings”	Yes – semi structured interviews; interview guide presented; audio recordings and notes used	Somewhat – online survey and/or semi structured interviews; digitally recorded; areas of enquiry stated; reason for different methods not explained	Yes – semi structured interviews; questions stated; written notes recorded; saturation described	Somewhat – surveys and semi structured interviews; guide questions not shared; methods unclear	Somewhat – questionnaires case notes and “discussions”; method choice not explained	Yes – semi structured interviews; strong rationale; schedule used and described; audio recorded data	Somewhat – focus groups and interviews; saturation discussed; interview guide used but not described; form of raw data unclear	Yes – semi-structured interviews; saturation mentioned; guide example questions provided; audio recorded data	Yes – semi-structured interviews; guide questions shared; “recorded” data	Yes – semi-structured interviews; interview guide provided; audio recorded data	Yes – semi structured interviews; interview guide topics shared; phone interviews “recorded”	Somewhat – unstructured interviews; form of raw data unclear; initial questions provided
Researcher-participant relationship considered?	Not critically examined	Yes – research assistants used with no established relationship to participants	Not critically examined	Yes – efforts to reflexively engage with data and analysis described	Not critically examined	Not critically examined	Somewhat – ensured that researchers had not worked with participants before	Not critically examined	Yes – used reflexivity to reflect upon their own assumptions	Not critically examined	Somewhat – 2/3 researchers purposely not involved in interviews	Not critically examined	Not critically examined
Ethical issues considered?	Somewhat – ethics review not mentioned; consent and right to withdraw outlined	Somewhat - approved ethics review; confidentiality considered; consent process unclear	Somewhat – approved ethics review; consent mentioned but process unclear	Somewhat – approved ethics review; consent not mentioned	Yes – approved ethics review; informed written consent obtained; voluntary participation	Yes – approved ethics review; informed written consent obtained	Yes – approved ethics review; capacity and consent process clear	Somewhat – ethics review not mentioned; consent and adaptations outlined	Yes – approved ethics review; consent process clear; confidentiality considered	Yes – approved ethics review; consent process stated	Yes – approved ethics review; informed consent process clear; adaptations considered	Somewhat – approved ethics review; consent process unclear	Yes – approved ethics review; informed consent obtained
Data analysis rigorous?	Somewhat – analysis process clear; researcher influence not noted; verbatim quotations used	Somewhat - analysis process clear; researcher influence not noted; quotations used	Yes – researcher preconceptions considered; analysis process clear; verbatim quotations used	Yes – researcher assumptions considered; analysis process clear; quotations used	No - analysis approach was stated but not described	Somewhat – analysis described briefly; data examples in appendix; researcher influence not noted	Somewhat - process described; verbatim quotations used; researcher influence not noted	Somewhat – analysis process clear; researcher influence not noted; example data demonstrated	Yes – analysis process described; researcher role considered; quotes used	Somewhat – analysis process described; researcher influence not noted; verbatim quotations used	Somewhat – analysis process described; researcher influence not noted; verbatim quotations used	Somewhat – analysis described; researcher influence not noted; quotations used	Yes – analysis process described; trustworthiness considered in analysis; quotes used

Clear findings?	Yes – key findings clear and discussed; related to aim; credibility discussed	Yes – clear findings discussed; related to aim; credibility discussed	Somewhat – findings stated and discussed; not related to aim; credibility not explicitly discussed	Yes – clear findings discussed; credibility addressed; vaguely related to research aim	Somewhat – findings stated and discussed; credibility not discussed; not related to aim(s)	Yes – main findings are clear and discussed; vague relation to research aim; double coding and consensus mentioned	Yes – main findings are clear and discussed; credibility sought through member checking	Yes – clear findings in relation to research aim discussed; double coding consensus described	Yes – clear findings in relation to aim; in-depth discussion; double coding, triangulation and member checking applied for credibility	Yes – clear findings in relation to aims discussed; triangulation and member checking utilized	Somewhat – clear findings discussed; three researchers involved in coding mentioned; not explicitly linked back to aim(s)	Yes – findings are clear and discussed in relation to research aim; each researcher coded independently to ensure rigour	Yes – clear findings discussed in relation to aim; rigor discussed extensively including member checking
Is the research valuable?	Yes – contributions clear; transferability limitations discussed; future research suggested	Yes – clear contribution; limitations including transferability considered; implications and future research outlined	Yes – clear contribution; future research suggested; limitation in diversity considered	Yes – clear contributions discussed; limitations discussed including transferability; future research suggested	Yes – contributions discussed; transferability limitations acknowledged; one implication for future research	Yes – contribution of research and implications discussed	Yes – clear contributions; limitations discussed; future research opportunities stated	Yes – clear contributions; future research suggested; transferability limitations addressed	Yes – clear contributions; limitations including transferability discussed; clinical implications discussed; future research suggested	Yes – clear contributions; limitations including transferability considered; future research suggested	Yes – contributions clear; limitations of representativeness discussed; clinical implications described	Yes – clear contributions; limitations and implications discussed; future area of research named	Yes – clear contributions; implications discussed; limitations addressed including sample diversity

Appendix B: Sample of coded data for thematic synthesis

Schwartz et al., 2020	Coding
The participants discussed the difficulty of finding health-care providers to serve their family members with ASD	Struggling to find services
The adults with ASD required multispecialty care for multiple medical conditions seeing a variety of health-care providers such as primary care providers, specialists (neurologist, psychiatrist, gerontologist, pulmonologist, etc.), therapists (applied behavioural analysis, occupational, physical and speech and language), as well as other health professionals (such as dentists and optometrists).	Multispecialty needs
Despite having insurance, caregivers reported that they had significant difficulty finding providers who would accept their health insurance.	Limitations of health insurance
Participant 7 reported "I went through 20 dentists before I found the one that was able to do his surgery."	Struggling to find services; Accessing support is hard
Caregivers also reported that their family member with ASD often needed special services, such as sedation during dental visits, but many providers did not offer that level of care.	Different needs per individual
Participant 6 reported: And this particular dentist that I told you that I like, he does it in the office. It's not general anesthesia like the other guy. And the other ones, they have like this twilight anesthesia and it's not enough. So most dentists that do take Medicaid or the Medicaid waiver, whatever it is, they turn me down.	Being turned away; Limitations of health insurance; Different needs per individual; Accessing support is hard
After successfully finding a health-care provider, family members with ASD who would demonstrate challenging behaviours, such as inability to comply with medical	Being turned away

examinations, eloping and hitting, would be refused subsequent treatment.	
Parents reported that after these incidences the health-care providers would dismiss the adult with ASD from the practice.	Being turned away
Participant 7 reported: When he was 15, the last visit, she said she found some cavities, two of them. They were too deep in order for her to make work on them without numbing him. So then we scheduled it, went to the office, she numbed his mouth, and it took a while. And then after his mouth was numb, just with the instruments and stuff, she could not work on him in a safe way without putting him in jeopardy, putting her staff and us in jeopardy. She did do everything she could. She looked at me, she goes, “Listen, we had a good run.”	Being turned away; Ineffective care
Participants also reported that they liked their family member’s childhood health-care providers, but clinic or payor policy often resulted in 18-22 year olds “aging out” of their pediatric provider and needing to find a new adult health-care provider.	Ageing out of paediatrics
Participant 1 reports: The big change was when she turned 18, we had to switch from a pediatrician to find an adult doctor care, because of the change in the pediatrician definition. And our pediatrician, there was a name for it, I forget if it’s called progressive health. Like somebody believes in more natural holistic pediatrician. And then I can’t find any adult holistic, but it’s not pediatrician anymore, the doctor who’s familiar with autism.	Ageing out of paediatrics; Struggling to find services
The lack of ability to find health-care providers led many families to go without services.	Struggling to find services; Going without formal support
Of participants interviewed all reported delaying health-care visits or going without care because of lack of availability of health-care providers.	Low availability; Going without formal support

The participants also spent much of the time discussing the quality of care received. Many caregivers identified medical personnel that provided high quality services.	Professional attunement

Appendix C: Ethics committee approval

This has been removed from the electronic copy.

Appendix D: Health Research Authority ethics approval documents

This has been removed from the electronic copy.

Appendix E: Research and Development Office approval

This has been removed from the electronic copy.

Appendix F: Participant information sheet

Participant Information Sheet:

Supporting the transition to adulthood for autistic people* without a learning disability

You are being invited to take part in a research project being completed by Hannah Bowman for educational purposes. This project is sponsored by Canterbury Christ Church University and organised through [NHS Trust]. This study has been reviewed and agreed by Hampshire A Research Ethics Committee.

Before you decide, it is important to understand why the research is being done and what you would need to do. Please read the following information carefully. You might want to talk to someone you trust about it or if you want to ask questions please contact Hannah at hb592@canterbury.ac.uk. Take time to decide if you would like to take part and thank you for reading.

What is the project's purpose?

The transition to adulthood refers to the period of life where children grow into adults. This is a process that often includes new experiences and the development of independence. During the transition to adulthood autistic young people, including those without a learning disability, may experience challenges within mental health, developing new relationships, independence, further education and employment. We want to find out how autistic young people without a learning disability can be best supported to meet their needs and achieve their goals beyond the age of 18.

We aim:

- **To understand what "successful" transition support means to autistic young adults without a learning disability, as well as the parents/carers and healthcare professionals that care for autistic young people without a learning disability. These people are called stakeholders.**
- **To find out what support stakeholders agree is needed to achieve a successful transition.**
- **To identify what resources stakeholders agree are most important for a successful transition.**

The questions will cover a range of topics such as what needs to happen for transition to adulthood to be considered 'successful', what support is helpful to achieve this and who is important to involve in this process. We understand that some people may become anxious when thinking about these topics. Please note you may take breaks -or stop entirely- when completing the questionnaires should you feel the need.

Why me?

We are inviting you because you have expert knowledge of the issues we are studying through lived experience. You also need to be willing and able to take part. This means having the time to complete the study and being able to communicate your thoughts, views and experiences effectively. We will have a quick conversation to check the study is right for you and answer any questions you have. Between 30 and 45 people will be recruited for the project.

You can decide whether or not to take part. If you decide to take part, you can keep this information sheet and you will be asked to sign a consent form.

What will happen if I take part?

- We will ask you to fill out a total of **3 questionnaires**. The distribution of all 3 questionnaires may **take up to 10 months.**
- We ask that you **please complete the questionnaires online**, which you can access through a link we will share with you via email. If required, you could complete the questionnaires with the assistance of a researcher via Microsoft Teams or by attending an appointment at [NHS site]. This can be arranged with Hannah.
- The first questionnaire will ask you to provide written responses to a number of questions, we expect this will take **up to an hour** to complete.
- All answers from the first questionnaire will be analysed to determine important themes and create the second questionnaire.
- The second questionnaire will ask you to **rate your agreement with a number of statements** with space to explain your answer. This should take **less than 30 minutes** to complete.
- In the third questionnaire you will be shown how statements were rated across participants and reasons given, and will show you again your previous responses from the second questionnaire. **You will then be asked to re-rate the statements**. This should take **less than 30 minutes** to complete.
- We ask that each questionnaire please be returned **within 3 weeks** of receiving it.
- Whilst there are no immediate benefits for those people participating in the project, it is hoped that this work will help autistic young people in the future.

Will my taking part in this project be kept confidential?

- **The answers you provide to questionnaires will be used to create the subsequent questionnaires.** We will therefore link your questionnaires with an ID number which we can track to your email, as the last questionnaire will be personalised to you. Any identifying information in your data will be changed so **you will not be identifiable** to other participants.
- All the information that we collect during the course of the research will be **confidential**. Confidentiality will be broken if we are worried about potential harm to yourself or others and we may be obliged to share information with other services.
- Your data will be anonymised, encrypted and stored on password-protected computers during the course of the project.
- **You will not be able to be identified in any reports or publications**.

How will we use information about you?

We will need to use information from you for this research project. This information will include your:

- Name
- Email address

The research team will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

- **You can stop being part of the study at any time, without giving a reason, but we may keep the data that we have already collected.**
- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we collect about you.
- If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study.
- When this study is finished, data will be kept in password-protected and encrypted files to be stored in a locked cabinet within the Salomons Institute for Applied Psychology for 10 years and then destroyed.

Where can you find out more about how your information is used?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- our leaflet available from www.hra.nhs.uk/patientdataandresearch
- by asking one of the research team on hb592@canterbury.ac.uk
- by sending an email to Salomons data protection lead on fergal.jones@canterbury.ac.uk

What will happen to the results of the research project?

The results will be used for educational submission and could be submitted for publication in appropriate academic journals. Should this project be published, we will tell you how to obtain a copy of the published results. **You can choose to be sent a summary of the results by email**.

Complaints procedure

If you have a concern about any aspect of this study, you can contact Hannah by email on hb592@canterbury.ac.uk and she will try her best to address your concerns. If you remain dissatisfied and wish to complain formally, you can do this by contacting:

Dr Fergal Jones (Clinical Psychology Programme Research Director)
fergal.jones@canterbury.ac.uk
01227 927 110
Salomon's Institute for Applied Psychology, 1 Meadow Road, Tunbridge Wells, TN1 2YG

Contact for further information

Should you have any questions or require further information, please contact Hannah Bowman (Trainee Clinical Psychologist and Student Researcher) via hb592@canterbury.ac.uk

Should you choose to participate, please contact Hannah on hb592@canterbury.ac.uk **and you will be provided with a consent form shortly.** Thank you for taking the time to read this information sheet, which you can keep.

Appendix G : Blank round one consent form

Canterbury
Christ Church
University

Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG

Ethics code: 23/SC/0079
Version number: 1.1
Participant Identification number for this study:

CONSENT FORM

Title of Project: Supporting the Transition to Adulthood for Autistic People* Without Intellectual Disability

If you agree, please initial box

I confirm that I have read and understand the information sheet (version: 1.1) dated 05/04/2023 for this study. I have considered the information and had any questions answered satisfactorily.	
I understand that my participation is voluntary and that I am free to withdraw at any time before 01/01/2024. I do not need to give a reason and there will be no adverse consequences if I choose to withdraw.	
I agree to take part in the study named above. I understand that taking part in the study means completing 3 online questionnaires which will require up to 120 minutes of my time in total. The time between receiving the first questionnaire and returning the third may be up to 10 months.	
I understand my personal details such as name and email address will not be revealed to anyone outside the research team.	
I understand and agree that researchers will have access to my data only if they agree to preserve my confidentiality.	
I understand and agree to my anonymised data being stored on password protected computers during the project. After the study, data will be kept in password protected and encrypted file(s) to be stored in a locked cabinet within the grounds of the Salomons Institute for 10 years and then destroyed.	
I understand and agree to my anonymised quotes being used in published reports of the study findings.	
I understand and agree that researchers may use my data in publications, reports, web pages, and other research outputs, only if they agree to preserve my confidentiality.	

[Optional] I give permission for my anonymous data to be used in further research studies.	
[Optional] I agree to be contacted by the research team should they require more detail regarding the answers I have provided. I would prefer to be contacted by (please check the box): Videocall ☐ Email ☐ via this email address: ________________________________	

Reasonable Adaptations (for autistic adult participants):
Please use this space to consider what will help you to feel comfortable participating in the study. Please note how you would like to complete the questionnaires. If you do not feel comfortable completing questionnaires online via Gorilla you could meet with a researcher via a MS Teams video call or in person at [NHS site].

- Please provide us with an email address that you are happy for us to contact you on and send the questionnaires to:

____

- Please indicate if you would like to receive a summary of the results:

Yes ☐

No ☐

_______________________ ____________
Name of Participant (printed) Date

____
Participant signature

_______________________ ____________ ______________________
Name of Researcher (printed) Date Signature

Project contact details for further information:
Hannah Bowman (Student Researcher) hb592@canterbury.ac.uk

Appendix H: Summary report for participants

Dear participant,

Thank you for taking part in this study sponsored by Canterbury Christ Church University which explored the views of autistic young adults, caregivers and healthcare clinicians on the transition to adulthood for autistic young people without a learning disability and how to effectively support young people and their families. I appreciate this topic may have been difficult to think about, especially for those who have found this to be a difficult stage of life. I would like to offer my sincere thanks for volunteering your time and sharing your experiences with me. Without your valuable contribution this study would not have been completed. The study has now ended and I am pleased to share the following summary with you.

Title

Transition to adulthood: Developing a consensus on support for autistic young people without learning disability in the UK

Aims

We wanted to find out what experts agreed the key factors for a successful transition to adulthood are. We also wanted to find out what support and resources experts agreed were needed to achieve this.

Data Collection

In total 46 participants took part in this study. We defined experts on this subject as autistic young adults, caregivers of autistic young people and healthcare clinicians who work with autistic young people.

Participants completed either two or three online questionnaires. One questionnaire collected detailed information about the transition to adulthood. The other two questionnaires asked participants to rate their agreement with a series of statements. Data collection took 10 months in total.

Summary of Findings

The key findings of this study are the statements that reached a strong consensus across experts. Consensus can be thought of as the majority opinion. For example, when a group of friends decide which restaurant to eat in and most of them choose the same restaurant – that's consensus. Consensus was graded as strong, moderate, weak or no consensus, depending on how many experts agreed or disagreed with a statement.

Overall, 40/52 statements reached a strong consensus across experts, 4/52 reached moderate consensus, 1/52 reached weak consensus and 7/52 did not reach a consensus. All of the consensus found reflected experts agreeing with each statement. The statements that reached agreement across experts are listed on the next pages.

The most important factor of a successful transition agreed across experts was for autistic young people to 'understand themselves and their needs', with the most important support agreed being 'helping young people to know when and how to actively seek support for themselves'. Experts also agreed the most important resource to achieve a successful transition is a directory of local support services. It is believed that the findings of this study will help services to improve the support offered to autistic young people and their families during the transition to adulthood in the future.

If you would like to read more about this study this research may be published in a journal. Your anonymous responses may be quoted to illustrate important points, as you were informed before participating. If the research is published you will be provided with details of the publication.

Ideas that reached strong consensus across expert groups

Critical factors related to Personal Qualities and Relationships:

- Young people need to build up their self-esteem to be successful in adulthood.
- Being able to manage difficult emotions.
- Understanding themselves and their needs.
- Being able to maintain friendships and positive peer relationships.
- The well-being of other family members is important to consider when young people transition to adulthood.
- Talking to trusted adults, such as professionals or mentors.

Critical factors related to Goals for Daily Living:

- Practicing daily living skills (e.g. hygiene, shopping, cooking, managing finances).
- Daily living skills should be taught as part of the curriculum in secondary school.
- Keeping physically healthy and safe.
- Engaging in meaningful activities and hobbies.
- Enabling and encouraging young people to make decisions and advocate for themselves.

Critical factors related to Inclusivity:

- Social inequalities and stigma are the biggest barriers preventing young people from successfully transitioning to adulthood.
- More needs to be done to ensure autistic people receive equal opportunities to non-autistic people.
- Training and education regarding autism should be delivered routinely within organizations.
- There should be more initiatives to improve awareness and understanding of autism in society.

Critical factors relating to Areas of Development for Mental Health Services:

- Services need to ensure families are aware of existing adult mental health services.
- Helping parents to step back and young people to take more responsibility.
- More specialist adult autism services need to be created.
- Transfer from child to adult services should happen routinely for all young people instead of needing to seek a referral for support from mental health services.
- Providing individualized support for all demographics of autistic people (e.g. autistic females, black and minority ethnic autistic people, autistic people without a learning disability, autistic adults).
- Helping young people to know when and how to actively seek support for themselves.
- There needs to be more investment into NHS services to improve access to services and availability resources.

Critical factors relating to Other Sources of Support:

- Having universally accessible resources (e.g. online information and advice).
- Having easy access to non-statutory organisations (e.g. community groups, charities, youth groups).
- Having easy access to educational support (e.g. special educational needs coordinator, tutors, autism champion positions).
- Having easy access to support at university (e.g. career support, mental well-being, mentors, educational accommodations).
- Having easy access to employment support (e.g. job interview preparation, liaison with managers, general employment skills).

Critical factors relating to Views on Transition Planning:

- Planning for the transition to adulthood should start when young people have reached an appropriate level of maturity to manage adult tasks, meaning the decision should not be based on age.
- When planning for transition, making sure the process happens gradually and not suddenly.
- When planning for transition, ensuring young people have enough time to process information and change.
- When planning for transition, having clear goals and breaking down the steps to achieve them.

Critical factors relating to Helpful Tools and Processes:

- For autism to be formally diagnosed early in childhood for young people to better understand themselves and receive early intervention.
- For families to be signposted to appropriate services and be provided with information leaflets.
- For families to receive support for a broad range of needs in one centralized service.
- For families to have a single point of contact to coordinate support from different services.
- Regular liaison between education and healthcare professionals.
- Having a dedicated transition worker or access to a specialist transition team.
- A directory of local support services available to young people and their families should exist for each county/London borough.
- It would be helpful to implement more mentor schemes for young people to access for support.
- Services should offer workshops for young people and their families on topics voted for by service users e.g. Daily living skills, Relationships, Jobs.

Best wishes,

Hannah Bowman
Trainee Clinical Psychologist
Salomons Institute for Applied Psychology

Appendix I : Round one questionnaire

Page 1

Transition to adulthood: Support for autistic young people without intellectual disability in the UK

Thinking about transition to adulthood could be distressing for some. Do remember that you can take breaks or stop answering questions completely if you need to. We are happy to offer a follow-up conversation if you want and can signpost you to free services that might be able to provide further support.

Please note that any reference to "young people" in this questionnaire refers to autistic young people without a learning disability.

Please allow yourself time to consider the following questions and **answer with as much detail as possible**. Please complete within **two weeks.**

I have read and understood the above and hereby give my consent to take part in this study in full knowledge that data is being recorded:

I agree

I do not agree

Page 2

Please enter your participant ID here:

Page 3

1. **What do you think “successful” transition to adulthood is?**

Page 4

2. **When did you begin to think about the transition to adulthood for either yourself as an autistic person or for a young person as a caregiver/professional?**

Page 5

3. **Has it been difficult to think or talk about adulthood, either for yourself or with a young person? If so, what made this difficult and what would have helped?**

Page 6

4. **What is your experience of transition(s) to date? This may be professional experience or personal experience as a young adult or a relative of a young person.**

Page 7

5. **What is your experience of transition support and planning to date? This may be professional experience or personal experience as a young adult or a relative of a young person.**

Page 8

6. **What support do you know of that currently exists to help young autistic people in their transition to adulthood?**

Page 9

7. **What resources do you have access to now that can help you support transition (as a clinician or carer)? / What resources did you access that helped support your transition?**

Page 10

8. **Who has been/do you anticipate being important to an autistic young person's transition journey?**

Page 11

9. **What would you change or like in the future to usefully inform transition support?**

Page 12

10. **Do you have any other comments you would like to share regarding the transition to adulthood for autistic young people without a learning disability?**

Page 13

Please tell us your age:

Please tell us your ethnicity:

Please tell us your gender:

Please tell us your current occupation:

Page 14

Thank you for participating

Please take a moment to note how you are feeling and consider your usual forms of support if needed.

If participation in this research has raised any concerns about the wellbeing of yourself or others, please make use of the resources below for help and support. You can also contact Hannah by email at hb592@canterbury.ac.uk for enquiries or more specific help or resources.

If you would like further support, you can contact:

- Your GP or call NHS 111.
- Mind Infoline: 0300 123 3393 for information and signposting (9am-6pm, Mon-Fri).
- National Autistic Society: https://www.autism.org.uk/what-we-do/help-and-support
- The Mix: https://www.themix.org.uk/get-support/speak-to-our-team for 11 to 25 year olds.
- Young Minds: https://www.youngminds.org.uk/parent/parents-helpline-and-webchat/ for parents/carers
- SANEline: 0300 304 7000 for anyone experiencing a mental health problem or supporting someone else (4.30pm-10.30pm, every day)

Appendix J: Research diary extract as example of coding reflexivity

December 2023

I feel defeated and exhausted at the moment, which is a shame as the run up to Christmas is usually my favourite time of year. It feels like one step forward, two steps back. I made every possible effort to get the notoriously long ethics process done as soon as possible, thinking that was the hard bit, but recruitment has been much harder than expected. [supervisor] and I keep agreeing to push back the deadline for round 1 further and further to try and get more caregivers involved but nothing has worked like I'd hoped. I actually cannot think of what more we could have done. It's been 6 months! I'm stuck in my own negative thinking at the minute but when I hypothesise reasons why parents may not have signed up I don't feel surprised. I can empathise with how busy they might be, recruitment was live over summer and the start of a new school year, and we are asking people to volunteer without financial incentive which isn't ideal. I think we need to push on now, but I'm disappointed, it's an important perspective and I wonder about missed opportunities. That said, I am pleased with how many autistic individuals have participated, at the end of the day they're the heart of this study.

*

So [charity] has agreed to advertise the study which feels pretty huge! It will have to be for round two at this point but I have hope again for recruitment. I made a timetable of sorts for the coming months and research tasks. I have three weeks to do the round one analysis and every day counts. I'm happy to immerse myself in it though, and [supervisor] has already agreed meetings to check my coding and themes which I'm super grateful for. I'm not going to rush despite feeling the pressure to. I want to get this right and I know how valuable it can be to sleep on my work and come back to it with fresh eyes the next day.

*

On first look at the data I'm really pleased. There's lots of detail although it was all conducted online, and it seems people have been really thoughtful in their answers. I can already see some similarities across participants [responses], which I didn't expect to be evident so early. Mainly about the not knowing what support is out there, which I guess isn't a shock based on all the reading I've done.

There's a striking tone when reading these responses which I can only name as care, you can really tell how much everyone cares about this topic. That's been motivating for me, I feel much more connected to the participants than expected despite never having met. It's been really nice actually, how that tone and connection has come through in an online study. I wondered if that nuance might get lost without conducting interviews but no. I've decided to code question-by-question instead of person-by-person like I originally planned. I feel like coding by question helps me hold in mind the context of peoples answers, which feels important when I'm interpreting meaning from their text.

*

Wow, has this been a long old process. I have a decent framework though. I've enjoyed it in a strange stress fuelled way, it's a bit like a jigsaw puzzle. Starting with this mess of data and as I sort through my codes and groupings and themes I can start to see a picture forming. I'm happy with where I'm at and I'm glad I took the time to keep refining with fresh eyes. There's a fair amount of instinct involved, in grouping codes and then deciding what you name the subtheme based on what those codes capture as a whole. I guess that's where I need to really think about personal bias, why do I feel X and Y are linked? I think the best example is probably in the theme relating to relationships. As someone who has strong family values I might assume family to be the dominant form of interpersonal support, so I needed to be careful I didn't give more weight to the importance of family relationships than what was coming from the text. For some people it was clear their friendships felt more supportive.

That's where meeting with [supervisor] has really paid off too. We didn't disagree on much but she suggested some tweaks that I agreed with, mainly in my wording rather than meaning or how I've grouped things, which was promising. I'm a week behind where I wanted to be but I'm actually okay with that - realistically who was going to fill it [round 2] out over Christmas and new years anyway?

Appendix K: Sample of coded data for thematic analysis

Participant responses to question nine	**Code(s)**
I think this is difficult for me to give a good answer. I believe if I was diagnosed earlier my experience would be completely different. I think a guide of exactly what adulthood entails would be useful, covering things like laundry and hygiene, finances and savings, the importance of communication (i.e. phoning work if you are sick). Maybe written in a way that is more explanatory instead of didactic, with useful diagrams. Emphasizing the importance of routines and structures for autistic adults.	Early diagnosis/intervention Informative books Daily life skills Social skills Accessibility Healthy habits and routine; Need for structure
The development of a transition team to support young people leaving CAMHS to link [to] the support care leavers require. For appropriate young people this could support them up to the age of twenty five dependent of resources.	Specialist transition team/worker Improve awareness of support Support beyond 18; Limited resources
I'm not sure, I can't think of what would have helped because I didn't get any help.	No known support
Early planning is essential, links to resources to help find out about the art of the possible. A professional to coordinate all aspects of transition.	Early transition planning; Improve awareness of support Single point of coordination
Something organised and systematic, I feel the support is probably there if I search for it and if there was a crisis, but there's no provision as a matter of course.	Need for structure No routine support
More joined-up services, more SEN placements for young people until the age of 25, transparent information, equal access across counties, easier access to advocates, more transition workers to support in mental health services	Liaison/Integration; Support beyond 18 Clear information Equal opportunities; Advocacy Specialist transition team/worker
Tailored workshops and more mental health support	Workshops
Diagnosis as early as possible. I feel like I wasn't told about adulthood growing up. Like I feel I could have been told about growing up to understand it better, to understand myself and what I need. But I guess it seems obvious to people, but it's not. The best form of support would have been understanding myself better and the tools to even seek support. If you don't understand your own needs how do you get help for them. A clearer indication of what support is actually available would be good, I'm in my mid-twenties and I know of barely anything -like one [county] charity and the GP. I've mentioned schools a lot, I think they need to educate children better. To prepare for adulthood but also about disabilities. Children are horrible to each other. Sometimes I feel schools encourage a bullying culture, even from teachers, they try to discipline out your difference and punish traits rather than help them. Screening to raise	Early diagnosis/intervention Understanding self and autism Society needs to understand autism Understanding self and autism; Seeking support for self Improve awareness of support No known support Life skills in schools Training and educating about autism Stigma and discrimination

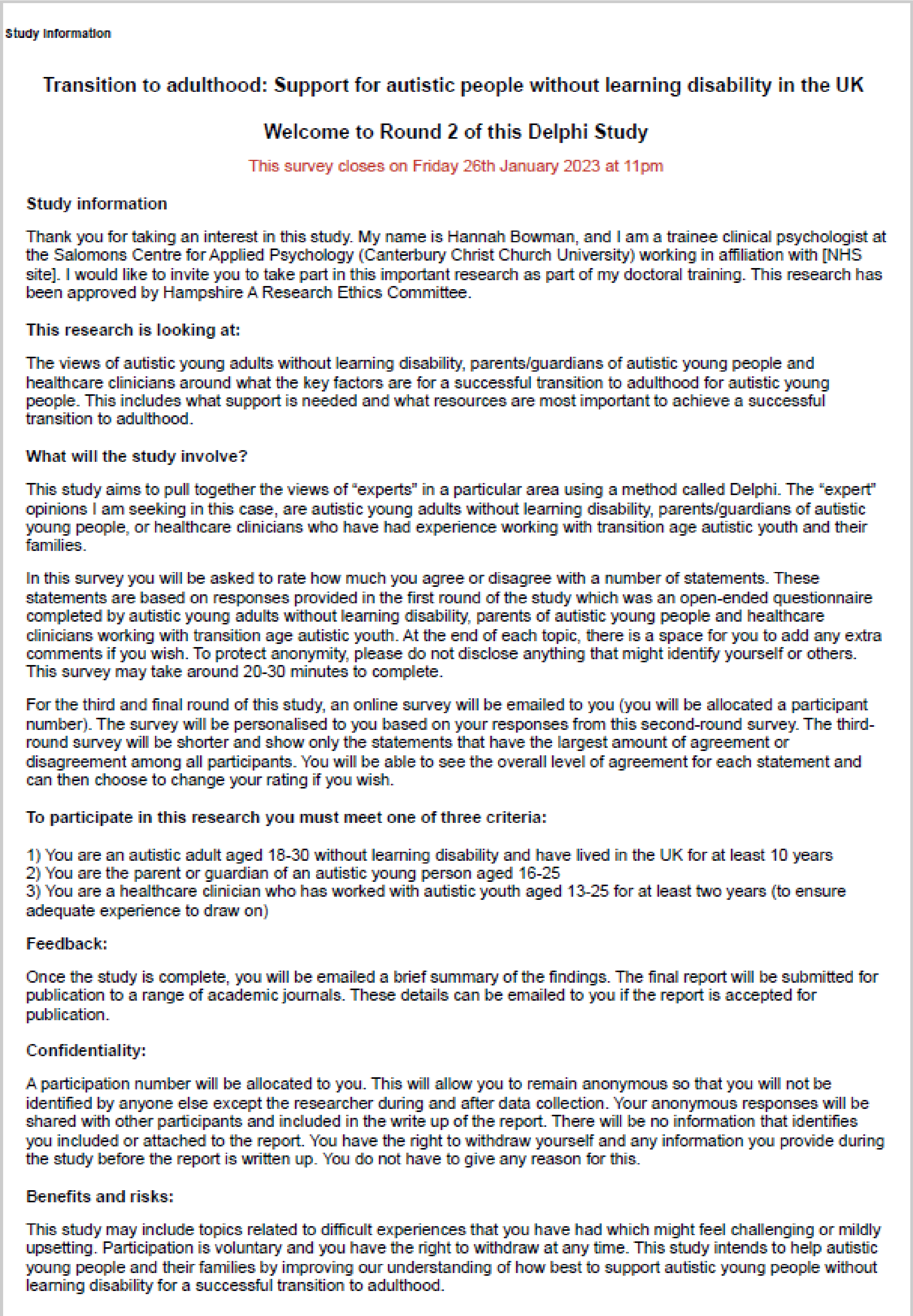
awareness and signpost to support services should be in schools, it's the place you spend most time as a kid.	Improve awareness of support; Signposting and advice
more information available across services to refer to and signpost young people to. More multi-agency work.	Clear information; Liaison/Integration
I think it's important for all organisations that work with young people to have a plan in place for transition including practical aspects and linking in families with information and sources of support. A central hub that holds information of this nature that would be helpful to young people would be fantastic - a one stop shop so to speak, but that would be very difficult to achieve.	Goal based transition planning Signposting and advice; Improving awareness of support Centralised support
More structured approach to transition planning, similar to the STEP programme for secondary school transition. Better understanding of transition support available in different areas - building a directory. Better funding for local CAMHS and education services to provide the support we recommend. Ongoing developments in awareness of colleges, universities and employers about how to collaborate and work with young people with autism to design environments for working, learning and living, that help them flourish.	Need for structure Improving awareness of support; Directory as a resource Government funding Society needs to understand autism; Training and educating about autism; Co-production
More easily accessible and standardised adult services.	Improve service access
I really wouldn't know. I'm no specialist nor do I have imagination to pull it from my head right now or remember what needs changing/improving. My only recommendation is for the Diagnosis itself, that being more clinics and staff with the support post-assessment mentioned prior; otherwise, it's just ensuring Universities' support systems are working effectively and Employers furthering disability support/assistance to more niche and less obvious disorders.	Early diagnosis/intervention Wellbeing at university Employment support
I would like child services and adult services to have more communication. There was no communication or transfer of my files between services and I had to repeat everything multiple times between services. There should be some form of introduction to adult services before deciding if you need them or not, rather than being dropped and self-referring afterwards. There should also be more information available regarding local charities or organisations that specialise in these areas.	Liaison/Integration Information sharing Opt-out process not opt-in Improve awareness of support; Directory as a resource

Increased coordinated co- and joint working amongst the professionals and families I mentioned in my previous responses. Increased awareness raising and information/ training for these agencies about autism and the challenges faced by young autistic adults, whilst also recognising their strengths. More support for autistic young people to have their voice heard and flexibility in the support that is available.	Liaison/Integration Training and educating about autism Advocacy; Accessibility
I would like to see people learning to respect and welcome autism from being children. Autistic kids get bullied and struggle as a social outcast. I have tics so got bullied for that. Kids and teenagers need to understand that everyone is different in their own unique ways, understanding what autism is with presentations, talks, like me talking about my own authentic experience. As an adult trying to push forward with a career, I think all companies in the world should be more inclusive with diversity. I'm sick of discrimination for being different, it needs to change. Every company needs to be aware of autism, what it's like and how hard work it can be. I am constantly trying to push the boundaries with autism awareness. I asked to give an awareness presentation at work. More people need to do this. I'm passionate about diversity and inclusivity. I've got two friends from uni who also face discrimination. Every human has value they can bring, especially autistic people. I want to specialize in autism awareness.	Society needs to understand autism Stigma and discrimination Training and educating about autism Promoting neurodiversity; Training and educating about autism; Stigma and discrimination Society needs to understand autism Training and educating about autism Promoting neurodiversity Stigma and discrimination Promoting neurodiversity
I don't think I would change anything. There is a lot of support out there available. but if I was being picky, I would like to change the cost of the student gym to make it easier for anyone to have access to it. As an autistic person, I have found that exercise really helps my mental health but I find it hard in the winter because I am scared to go out when it is dark, but if I had the opportunity to use the gym instead of running in the dark, I would find it easier to get outside!	Feeling well supported Financial support Physical health and safety; Healthy habits and routine
For there to be some kind of national support mechanism that can be accessed. For the careers and benefits service to be more understanding and supportive. For more opportunities for being able to live independently without having to buy a home.	Centralised support; Directory as a resource Society needs to understand autism Living independently
I would like people to get diagnosed and recognised quicker because I have seen people I know struggle because they have not had the help and support that they need.	Early diagnosis/intervention Going without support
Tell people that the support exists	Improve awareness of support

Appendix L: Example of themes developed from codes in Excel

B	C	D	E	F
	CODE GROUPINGS	**SUB THEMES**	**SUB THEME GROUPINGS**	**THEMES**
	Employment as success; Higher education as success; Sense of achievement; Exploring new hobbies; Community engagement; Volunteering; Pet care	**Engagement in meaningful activities**	Daily living skills; Health and safety; Engagement in meaningful activities; Living independently	**Goals for daily living**
	Life skills; Hygiene; Daily tasks; Practicing activities of daily living; Organizational skills; Balancing multiple demands; Managing finances; Becoming independent	**Daily living skills**		
	Physical health; Feeling safe; 'street smarts'; Exercise routine; Receiving support as needed	**Health and safety**		
	Moving out; Housing support; Affordable housing needed; Financial independence; Government financial aid; Becoming independent; Leaving family	**Living Independently**		
	Understanding strengths and difficulties; Understanding autism; Self-understanding; Going your own pace; Identity development; Stop compairing self; Time to process; Feeling prepared for challenges; Values; Work ethic	**Internal development**	Internal developent; Self-esteem; Managing emotions; Future thinking	**Personal qualities and relationships**
	Self-satisfaction; Achieving goals/hopes; Quality of life; Learning to trust yourself; Taking responsibility; Making own choices; Feeling confident	**Self-Esteem**		
	Managing change; Anxiety; Embarrassed to be 'different'; Fear of transitions; Feeling alone; Feeling overwhelmed; Talking causing upset; Coping skills; Being happy; Feeling underprepared; Scared of responsibility; Time to process; Feeling let down	**Managing emotions**		
	Struggle to imagine the future; Ideas of adulthood; Imagining future self helpful	**Future thinking**		
	Friends as support; Boundaries in relationships; Scheduling communication; Reciprocal relationships; Changing friend group; Peer support groups	**Maintaining peer support**	Intensive family support; Support from trusted individuals; Maintaining peer support	
	Family biggest support; Emotional support from parent; Family teaching skills; Parental support preferred; Easy access to family; Parental wellbeing neglected	**Intensive family support**		
	Trusted adults; Support network crucial; Mentors helpful; Mental helath professionals; Role Models; Teachers; Social workers; Tutors/Counsellors at university; Need a strong social network	**Support from trusted individuals**		

Appendix M: Round two questionnaire



Study Information

Transition to adulthood: Support for autistic people without learning disability in the UK

Welcome to Round 2 of this Delphi Study

This survey closes on Friday 26th January 2023 at 11pm

Study information

Thank you for taking an interest in this study. My name is Hannah Bowman, and I am a trainee clinical psychologist at the Salomons Centre for Applied Psychology (Canterbury Christ Church University) working in affiliation with [NHS site]. I would like to invite you to take part in this important research as part of my doctoral training. This research has been approved by Hampshire A Research Ethics Committee.

This research is looking at:

The views of autistic young adults without learning disability, parents/guardians of autistic young people and healthcare clinicians around what the key factors are for a successful transition to adulthood for autistic young people. This includes what support is needed and what resources are most important to achieve a successful transition to adulthood.

What will the study involve?

This study aims to pull together the views of "experts" in a particular area using a method called Delphi. The "expert" opinions I am seeking in this case, are autistic young adults without learning disability, parents/guardians of autistic young people, or healthcare clinicians who have had experience working with transition age autistic youth and their families.

In this survey you will be asked to rate how much you agree or disagree with a number of statements. These statements are based on responses provided in the first round of the study which was an open-ended questionnaire completed by autistic young adults without learning disability, parents of autistic young people and healthcare clinicians working with transition age autistic youth. At the end of each topic, there is a space for you to add any extra comments if you wish. To protect anonymity, please do not disclose anything that might identify yourself or others. This survey may take around 20-30 minutes to complete.

For the third and final round of this study, an online survey will be emailed to you (you will be allocated a participant number). The survey will be personalised to you based on your responses from this second-round survey. The third-round survey will be shorter and show only the statements that have the largest amount of agreement or disagreement among all participants. You will be able to see the overall level of agreement for each statement and can then choose to change your rating if you wish.

To participate in this research you must meet one of three criteria:

1) You are an autistic adult aged 18-30 without learning disability and have lived in the UK for at least 10 years
2) You are the parent or guardian of an autistic young person aged 16-25
3) You are a healthcare clinician who has worked with autistic youth aged 13-25 for at least two years (to ensure adequate experience to draw on)

Feedback:

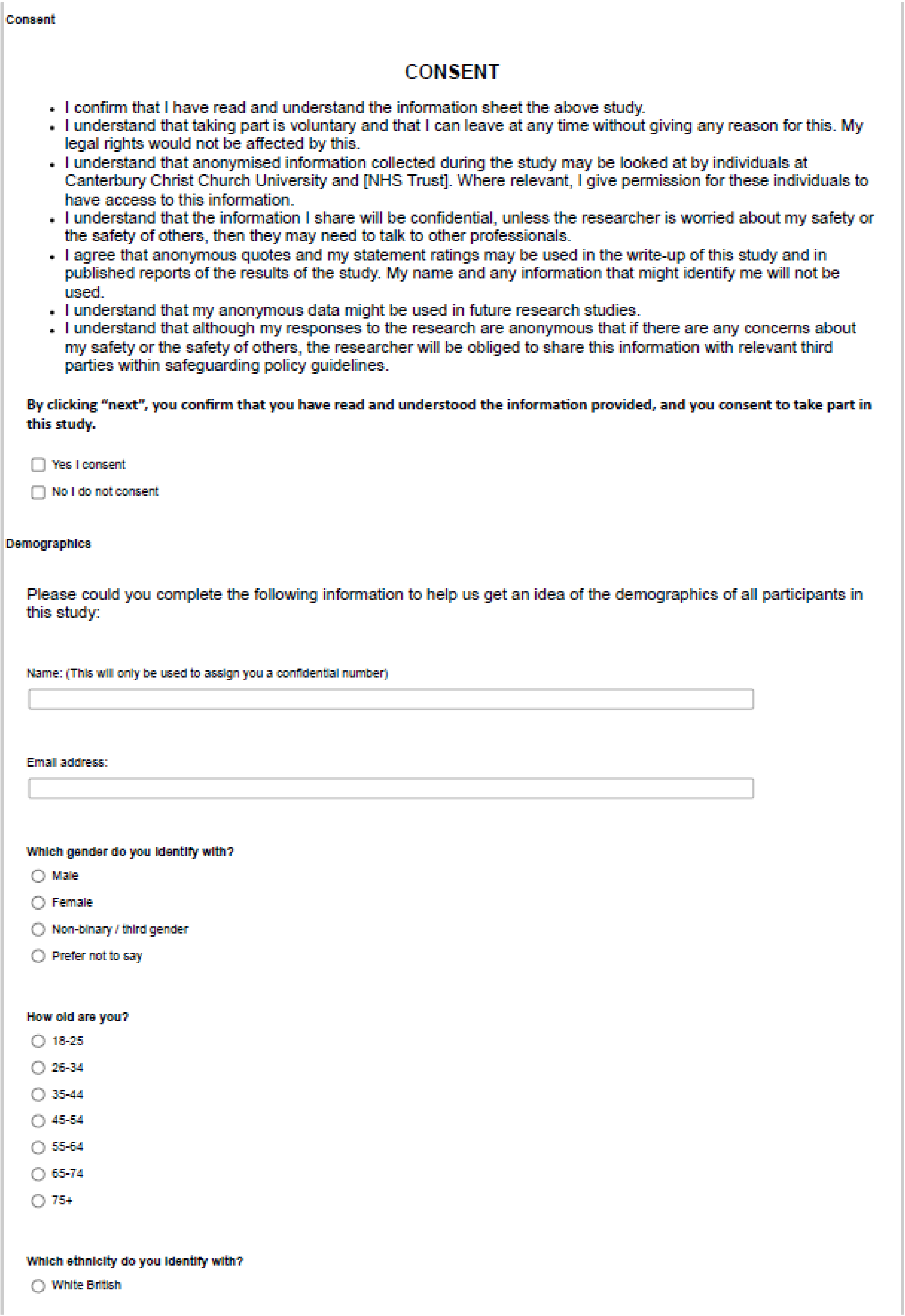
Once the study is complete, you will be emailed a brief summary of the findings. The final report will be submitted for publication to a range of academic journals. These details can be emailed to you if the report is accepted for publication.

Confidentiality:

A participation number will be allocated to you. This will allow you to remain anonymous so that you will not be identified by anyone else except the researcher during and after data collection. Your anonymous responses will be shared with other participants and included in the write up of the report. There will be no information that identifies you included or attached to the report. You have the right to withdraw yourself and any information you provide during the study before the report is written up. You do not have to give any reason for this.

Benefits and risks:

This study may include topics related to difficult experiences that you have had which might feel challenging or mildly upsetting. Participation is voluntary and you have the right to withdraw at any time. This study intends to help autistic young people and their families by improving our understanding of how best to support autistic young people without learning disability for a successful transition to adulthood.



Consent

CONSENT

- I confirm that I have read and understand the information sheet the above study.
- I understand that taking part is voluntary and that I can leave at any time without giving any reason for this. My legal rights would not be affected by this.
- I understand that anonymised information collected during the study may be looked at by individuals at Canterbury Christ Church University and [NHS Trust]. Where relevant, I give permission for these individuals to have access to this information.
- I understand that the information I share will be confidential, unless the researcher is worried about my safety or the safety of others, then they may need to talk to other professionals.
- I agree that anonymous quotes and my statement ratings may be used in the write-up of this study and in published reports of the results of the study. My name and any information that might identify me will not be used.
- I understand that my anonymous data might be used in future research studies.
- I understand that although my responses to the research are anonymous that if there are any concerns about my safety or the safety of others, the researcher will be obliged to share this information with relevant third parties within safeguarding policy guidelines.

By clicking "next", you confirm that you have read and understood the information provided, and you consent to take part in this study.

☐ Yes I consent

☐ No I do not consent

Demographics

Please could you complete the following information to help us get an idea of the demographics of all participants in this study:

Name: (This will only be used to assign you a confidential number)

Email address:

Which gender do you identify with?

○ Male

○ Female

○ Non-binary / third gender

○ Prefer not to say

How old are you?

○ 18-25

○ 26-34

○ 35-44

○ 45-54

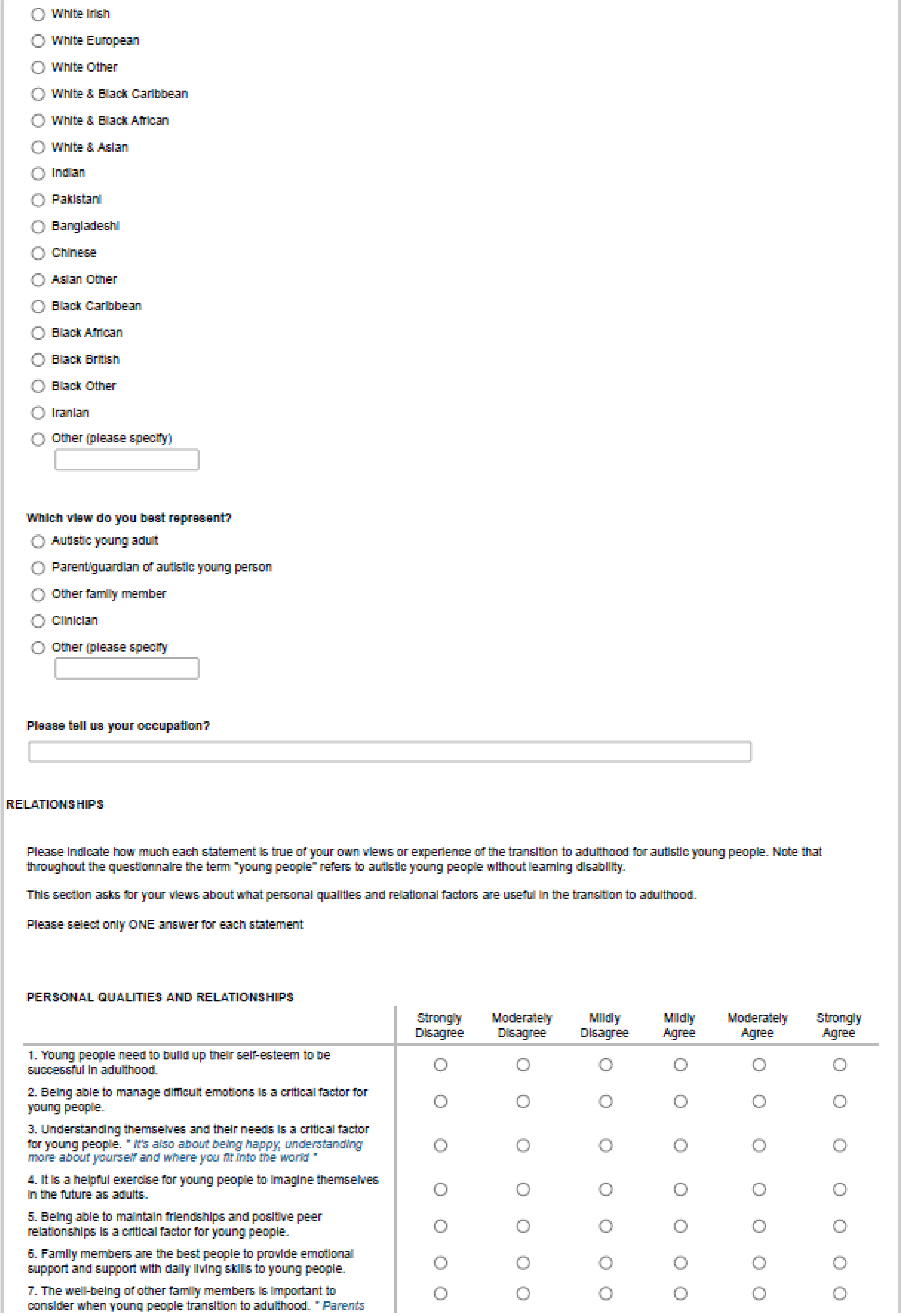
○ 55-64

○ 65-74

○ 75+

Which ethnicity do you identify with?

○ White British



○ White Irish
○ White European
○ White Other
○ White & Black Caribbean
○ White & Black African
○ White & Asian
○ Indian
○ Pakistani
○ Bangladeshi
○ Chinese
○ Asian Other
○ Black Caribbean
○ Black African
○ Black British
○ Black Other
○ Iranian
○ Other (please specify)

Which view do you best represent?

○ Autistic young adult
○ Parent/guardian of autistic young person
○ Other family member
○ Clinician
○ Other (please specify

Please tell us your occupation?

RELATIONSHIPS

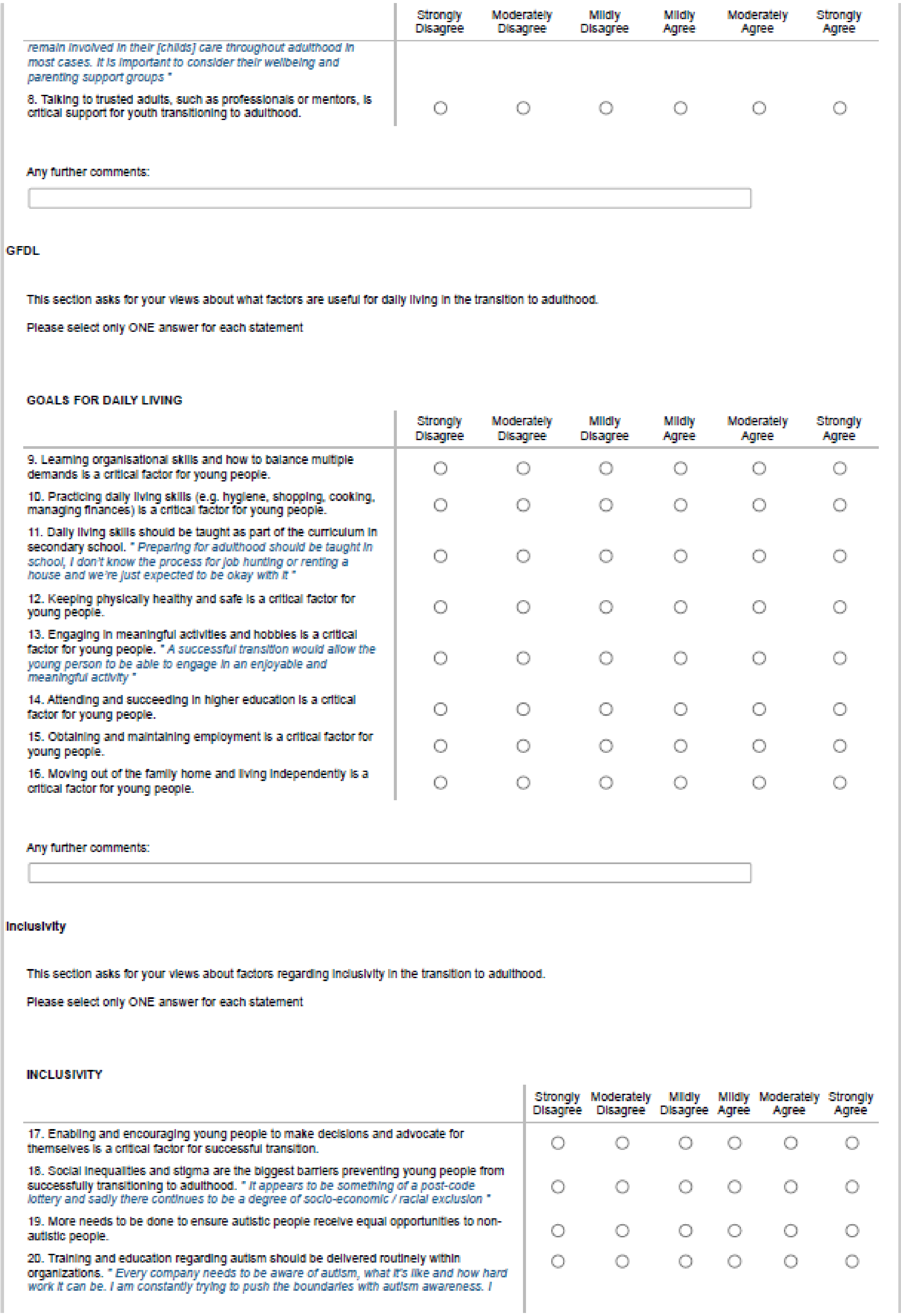
Please indicate how much each statement is true of your own views or experience of the transition to adulthood for autistic young people. Note that throughout the questionnaire the term "young people" refers to autistic young people without learning disability.

This section asks for your views about what personal qualities and relational factors are useful in the transition to adulthood.

Please select only ONE answer for each statement

PERSONAL QUALITIES AND RELATIONSHIPS

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	Moderately Agree	Strongly Agree
1. Young people need to build up their self-esteem to be successful in adulthood.	○	○	○	○	○	○
2. Being able to manage difficult emotions is a critical factor for young people.	○	○	○	○	○	○
3. Understanding themselves and their needs is a critical factor for young people. " *It's also about being happy, understanding more about yourself and where you fit into the world* "	○	○	○	○	○	○
4. It is a helpful exercise for young people to imagine themselves in the future as adults.	○	○	○	○	○	○
5. Being able to maintain friendships and positive peer relationships is a critical factor for young people.	○	○	○	○	○	○
6. Family members are the best people to provide emotional support and support with daily living skills to young people.	○	○	○	○	○	○
7. The well-being of other family members is important to consider when young people transition to adulthood. " *Parents*	○	○	○	○	○	○



	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	Moderately Agree	Strongly Agree
remain involved in their [childs] care throughout adulthood in most cases. It is important to consider their wellbeing and parenting support groups "						
8. Talking to trusted adults, such as professionals or mentors, is critical support for youth transitioning to adulthood.	○	○	○	○	○	○

Any further comments:

GFDL

This section asks for your views about what factors are useful for daily living in the transition to adulthood.

Please select only ONE answer for each statement

GOALS FOR DAILY LIVING

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	Moderately Agree	Strongly Agree
9. Learning organisational skills and how to balance multiple demands is a critical factor for young people.	○	○	○	○	○	○
10. Practicing daily living skills (e.g. hygiene, shopping, cooking, managing finances) is a critical factor for young people.	○	○	○	○	○	○
11. Daily living skills should be taught as part of the curriculum in secondary school. " *Preparing for adulthood should be taught in school, I don't know the process for job hunting or renting a house and we're just expected to be okay with it "*	○	○	○	○	○	○
12. Keeping physically healthy and safe is a critical factor for young people.	○	○	○	○	○	○
13. Engaging in meaningful activities and hobbies is a critical factor for young people. " *A successful transition would allow the young person to be able to engage in an enjoyable and meaningful activity "*	○	○	○	○	○	○
14. Attending and succeeding in higher education is a critical factor for young people.	○	○	○	○	○	○
15. Obtaining and maintaining employment is a critical factor for young people.	○	○	○	○	○	○
16. Moving out of the family home and living independently is a critical factor for young people.	○	○	○	○	○	○

Any further comments:

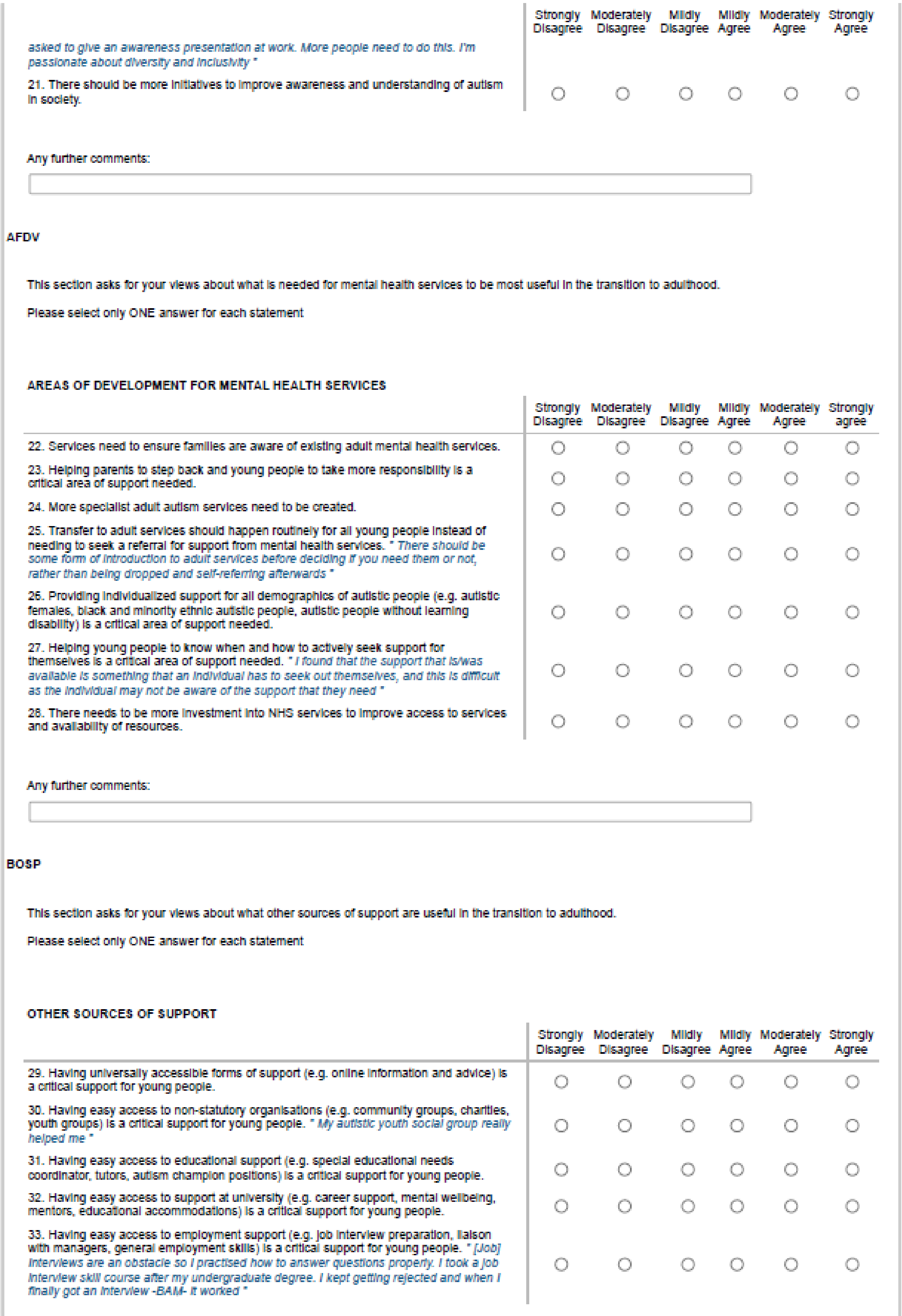
Inclusivity

This section asks for your views about factors regarding inclusivity in the transition to adulthood.

Please select only ONE answer for each statement

INCLUSIVITY

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	Moderately Agree	Strongly Agree
17. Enabling and encouraging young people to make decisions and advocate for themselves is a critical factor for successful transition.	○	○	○	○	○	○
18. Social inequalities and stigma are the biggest barriers preventing young people from successfully transitioning to adulthood. " *It appears to be something of a post-code lottery and sadly there continues to be a degree of socio-economic / racial exclusion "*	○	○	○	○	○	○
19. More needs to be done to ensure autistic people receive equal opportunities to non-autistic people.	○	○	○	○	○	○
20. Training and education regarding autism should be delivered routinely within organizations. " *Every company needs to be aware of autism, what it's like and how hard work it can be. I am constantly trying to push the boundaries with autism awareness. I*	○	○	○	○	○	○



	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	Moderately Agree	Strongly Agree
asked to give an awareness presentation at work. More people need to do this. I'm passionate about diversity and inclusivity "						
21. There should be more initiatives to improve awareness and understanding of autism in society.	○	○	○	○	○	○

Any further comments:

AFDV

This section asks for your views about what is needed for mental health services to be most useful in the transition to adulthood.

Please select only ONE answer for each statement

AREAS OF DEVELOPMENT FOR MENTAL HEALTH SERVICES

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	Moderately Agree	Strongly agree
22. Services need to ensure families are aware of existing adult mental health services.	○	○	○	○	○	○
23. Helping parents to step back and young people to take more responsibility is a critical area of support needed.	○	○	○	○	○	○
24. More specialist adult autism services need to be created.	○	○	○	○	○	○
25. Transfer to adult services should happen routinely for all young people instead of needing to seek a referral for support from mental health services. *" There should be some form of introduction to adult services before deciding if you need them or not, rather than being dropped and self-referring afterwards "*	○	○	○	○	○	○
26. Providing individualized support for all demographics of autistic people (e.g. autistic females, black and minority ethnic autistic people, autistic people without learning disability) is a critical area of support needed.	○	○	○	○	○	○
27. Helping young people to know when and how to actively seek support for themselves is a critical area of support needed. *" I found that the support that is/was available is something that an individual has to seek out themselves, and this is difficult as the individual may not be aware of the support that they need "*	○	○	○	○	○	○
28. There needs to be more investment into NHS services to improve access to services and availability of resources.	○	○	○	○	○	○

Any further comments:

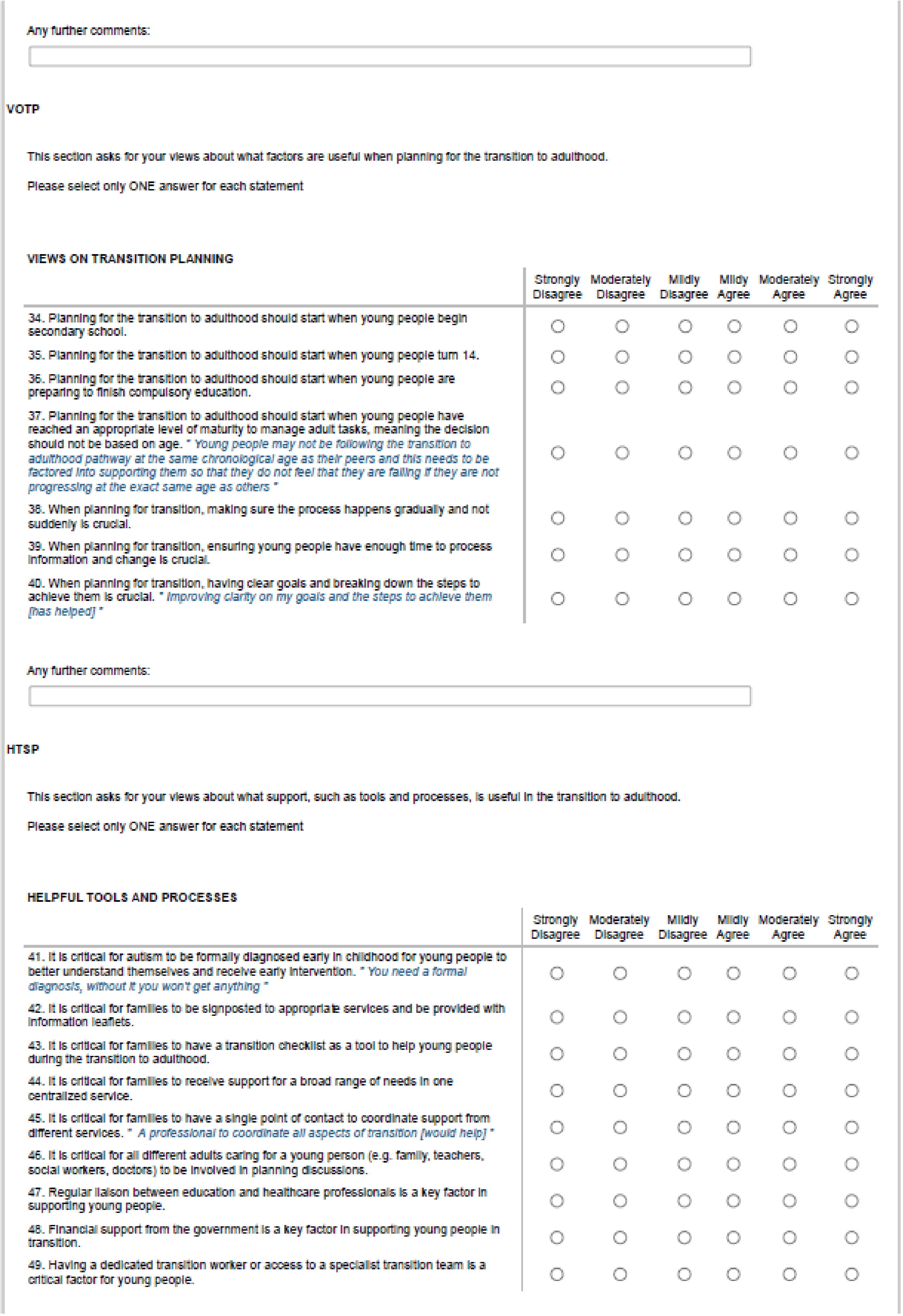
BOSP

This section asks for your views about what other sources of support are useful in the transition to adulthood.

Please select only ONE answer for each statement

OTHER SOURCES OF SUPPORT

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	Moderately Agree	Strongly Agree
29. Having universally accessible forms of support (e.g. online information and advice) is a critical support for young people.	○	○	○	○	○	○
30. Having easy access to non-statutory organisations (e.g. community groups, charities, youth groups) is a critical support for young people. *" My autistic youth social group really helped me "*	○	○	○	○	○	○
31. Having easy access to educational support (e.g. special educational needs coordinator, tutors, autism champion positions) is a critical support for young people.	○	○	○	○	○	○
32. Having easy access to support at university (e.g. career support, mental wellbeing, mentors, educational accommodations) is a critical support for young people.	○	○	○	○	○	○
33. Having easy access to employment support (e.g. job interview preparation, liaison with managers, general employment skills) is a critical support for young people. *" [Job] interviews are an obstacle so I practised how to answer questions properly. I took a job interview skill course after my undergraduate degree. I kept getting rejected and when I finally got an interview -BAM- it worked "*	○	○	○	○	○	○



Any further comments:

VOTP

This section asks for your views about what factors are useful when planning for the transition to adulthood.

Please select only ONE answer for each statement

VIEWS ON TRANSITION PLANNING

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildy Agree	Moderately Agree	Strongly Agree
34. Planning for the transition to adulthood should start when young people begin secondary school.	○	○	○	○	○	○
35. Planning for the transition to adulthood should start when young people turn 14.	○	○	○	○	○	○
36. Planning for the transition to adulthood should start when young people are preparing to finish compulsory education.	○	○	○	○	○	○
37. Planning for the transition to adulthood should start when young people have reached an appropriate level of maturity to manage adult tasks, meaning the decision should not be based on age. " *Young people may not be following the transition to adulthood pathway at the same chronological age as their peers and this needs to be factored into supporting them so that they do not feel that they are failing if they are not progressing at the exact same age as others* "	○	○	○	○	○	○
38. When planning for transition, making sure the process happens gradually and not suddenly is crucial.	○	○	○	○	○	○
39. When planning for transition, ensuring young people have enough time to process information and change is crucial.	○	○	○	○	○	○
40. When planning for transition, having clear goals and breaking down the steps to achieve them is crucial. " *Improving clarity on my goals and the steps to achieve them [has helped]* "	○	○	○	○	○	○

Any further comments:

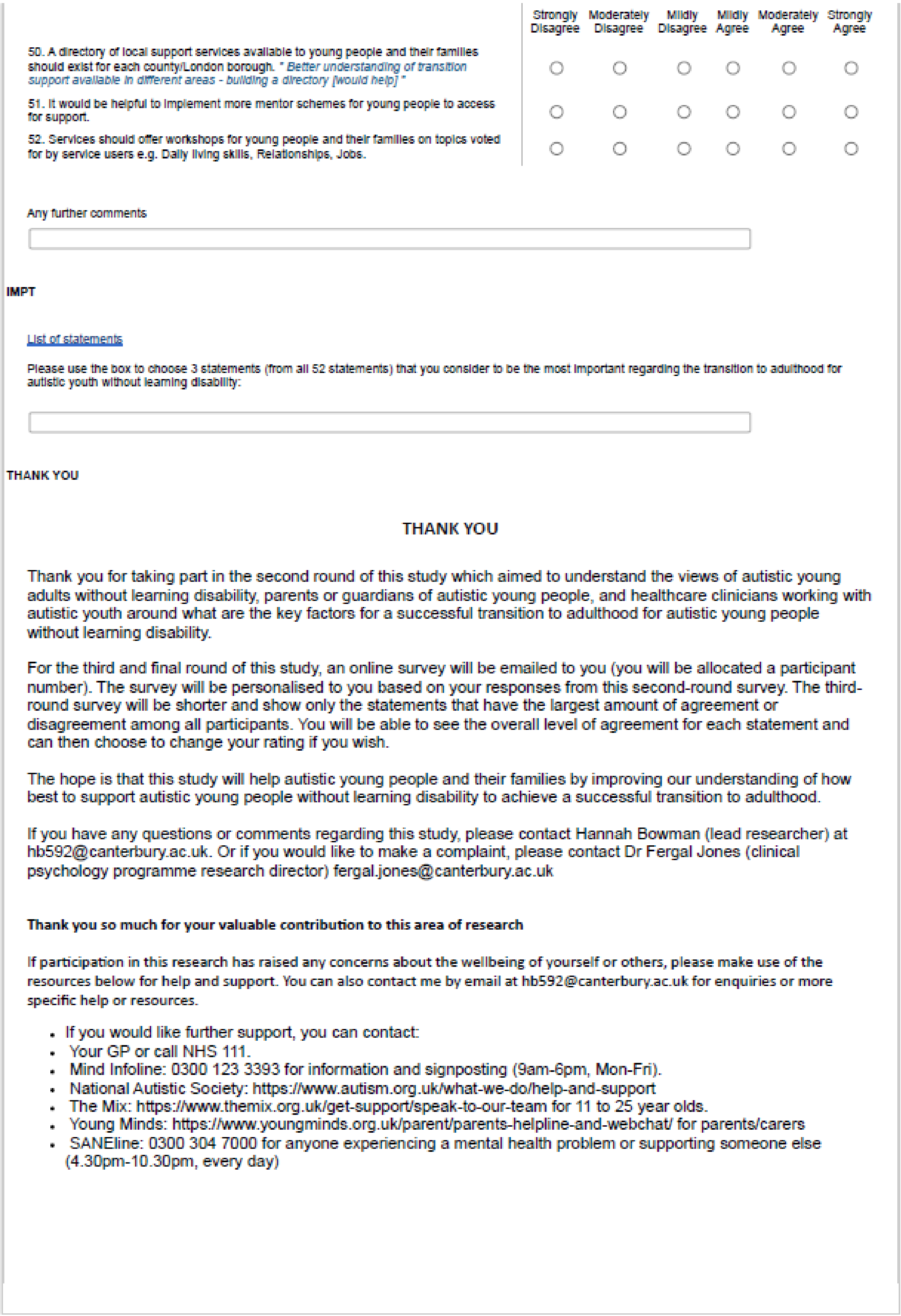
HTSP

This section asks for your views about what support, such as tools and processes, is useful in the transition to adulthood.

Please select only ONE answer for each statement

HELPFUL TOOLS AND PROCESSES

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	Moderately Agree	Strongly Agree
41. It is critical for autism to be formally diagnosed early in childhood for young people to better understand themselves and receive early intervention. " *You need a formal diagnosis, without it you won't get anything* "	○	○	○	○	○	○
42. It is critical for families to be signposted to appropriate services and be provided with information leaflets.	○	○	○	○	○	○
43. It is critical for families to have a transition checklist as a tool to help young people during the transition to adulthood.	○	○	○	○	○	○
44. It is critical for families to receive support for a broad range of needs in one centralized service.	○	○	○	○	○	○
45. It is critical for families to have a single point of contact to coordinate support from different services. " *A professional to coordinate all aspects of transition [would help]* "	○	○	○	○	○	○
46. It is critical for all different adults caring for a young person (e.g. family, teachers, social workers, doctors) to be involved in planning discussions.	○	○	○	○	○	○
47. Regular liaison between education and healthcare professionals is a key factor in supporting young people.	○	○	○	○	○	○
48. Financial support from the government is a key factor in supporting young people in transition.	○	○	○	○	○	○
49. Having a dedicated transition worker or access to a specialist transition team is a critical factor for young people.	○	○	○	○	○	○



	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	Moderately Agree	Strongly Agree
50. A directory of local support services available to young people and their families should exist for each county/London borough. *" Better understanding of transition support available in different areas - building a directory [would help] "*	○	○	○	○	○	○
51. It would be helpful to implement more mentor schemes for young people to access for support.	○	○	○	○	○	○
52. Services should offer workshops for young people and their families on topics voted for by service users e.g. Daily living skills, Relationships, Jobs.	○	○	○	○	○	○

Any further comments

IMPT

List of statements

Please use the box to choose 3 statements (from all 52 statements) that you consider to be the most important regarding the transition to adulthood for autistic youth without learning disability:

THANK YOU

THANK YOU

Thank you for taking part in the second round of this study which aimed to understand the views of autistic young adults without learning disability, parents or guardians of autistic young people, and healthcare clinicians working with autistic youth around what are the key factors for a successful transition to adulthood for autistic young people without learning disability.

For the third and final round of this study, an online survey will be emailed to you (you will be allocated a participant number). The survey will be personalised to you based on your responses from this second-round survey. The third-round survey will be shorter and show only the statements that have the largest amount of agreement or disagreement among all participants. You will be able to see the overall level of agreement for each statement and can then choose to change your rating if you wish.

The hope is that this study will help autistic young people and their families by improving our understanding of how best to support autistic young people without learning disability to achieve a successful transition to adulthood.

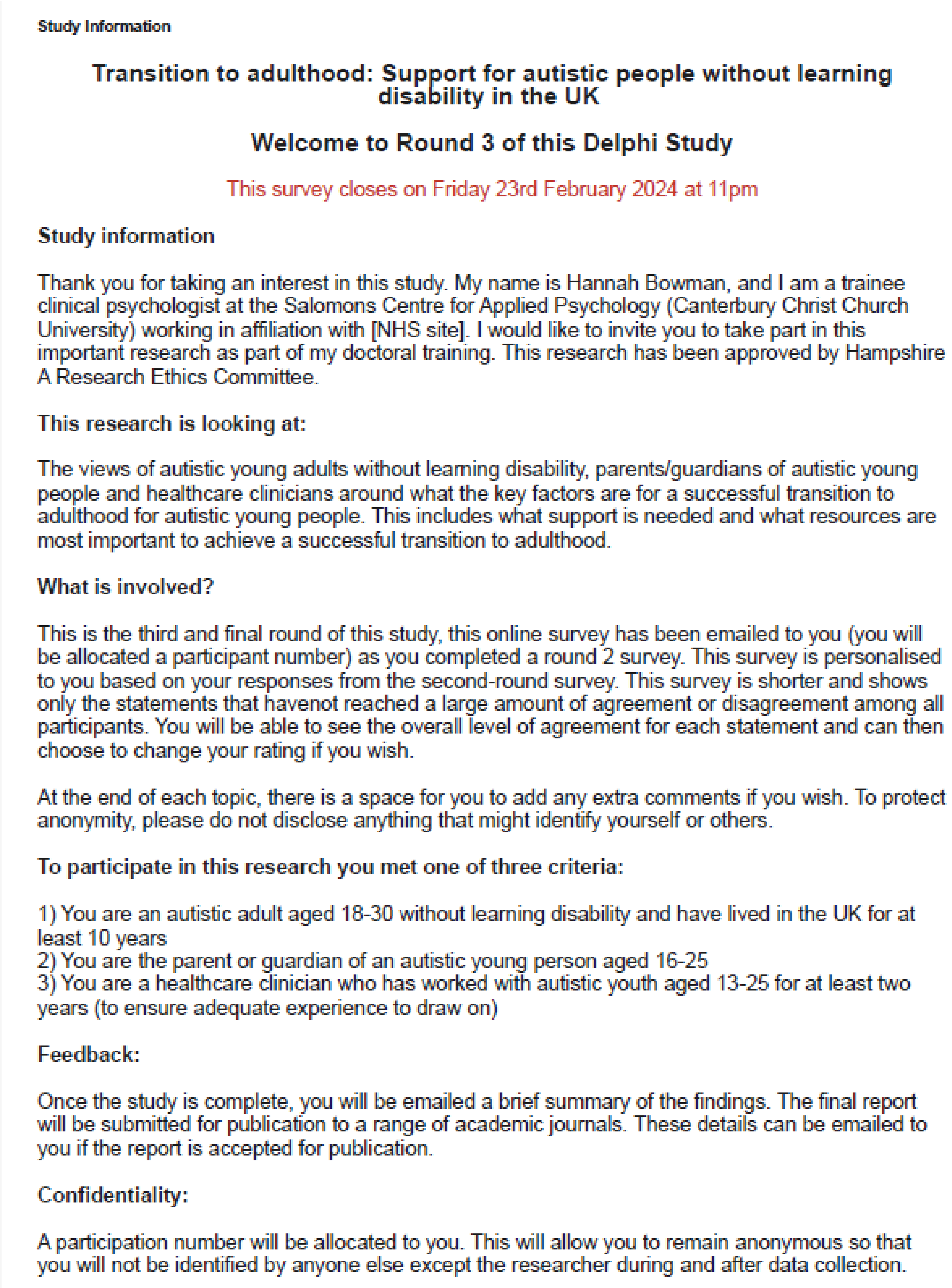
If you have any questions or comments regarding this study, please contact Hannah Bowman (lead researcher) at hb592@canterbury.ac.uk. Or if you would like to make a complaint, please contact Dr Fergal Jones (clinical psychology programme research director) fergal.jones@canterbury.ac.uk

Thank you so much for your valuable contribution to this area of research

If participation in this research has raised any concerns about the wellbeing of yourself or others, please make use of the resources below for help and support. You can also contact me by email at hb592@canterbury.ac.uk for enquiries or more specific help or resources.

- If you would like further support, you can contact:
- Your GP or call NHS 111.
- Mind Infoline: 0300 123 3393 for information and signposting (9am-6pm, Mon-Fri).
- National Autistic Society: https://www.autism.org.uk/what-we-do/help-and-support
- The Mix: https://www.themix.org.uk/get-support/speak-to-our-team for 11 to 25 year olds.
- Young Minds: https://www.youngminds.org.uk/parent/parents-helpline-and-webchat/ for parents/carers
- SANEline: 0300 304 7000 for anyone experiencing a mental health problem or supporting someone else (4.30pm-10.30pm, every day)

Appendix N : Round three questionnaire (clinician example)



Study Information

Transition to adulthood: Support for autistic people without learning disability in the UK

Welcome to Round 3 of this Delphi Study

This survey closes on Friday 23rd February 2024 at 11pm

Study information

Thank you for taking an interest in this study. My name is Hannah Bowman, and I am a trainee clinical psychologist at the Salomons Centre for Applied Psychology (Canterbury Christ Church University) working in affiliation with [NHS site]. I would like to invite you to take part in this important research as part of my doctoral training. This research has been approved by Hampshire A Research Ethics Committee.

This research is looking at:

The views of autistic young adults without learning disability, parents/guardians of autistic young people and healthcare clinicians around what the key factors are for a successful transition to adulthood for autistic young people. This includes what support is needed and what resources are most important to achieve a successful transition to adulthood.

What is involved?

This is the third and final round of this study, this online survey has been emailed to you (you will be allocated a participant number) as you completed a round 2 survey. This survey is personalised to you based on your responses from the second-round survey. This survey is shorter and shows only the statements that havenot reached a large amount of agreement or disagreement among all participants. You will be able to see the overall level of agreement for each statement and can then choose to change your rating if you wish.

At the end of each topic, there is a space for you to add any extra comments if you wish. To protect anonymity, please do not disclose anything that might identify yourself or others.

To participate in this research you met one of three criteria:

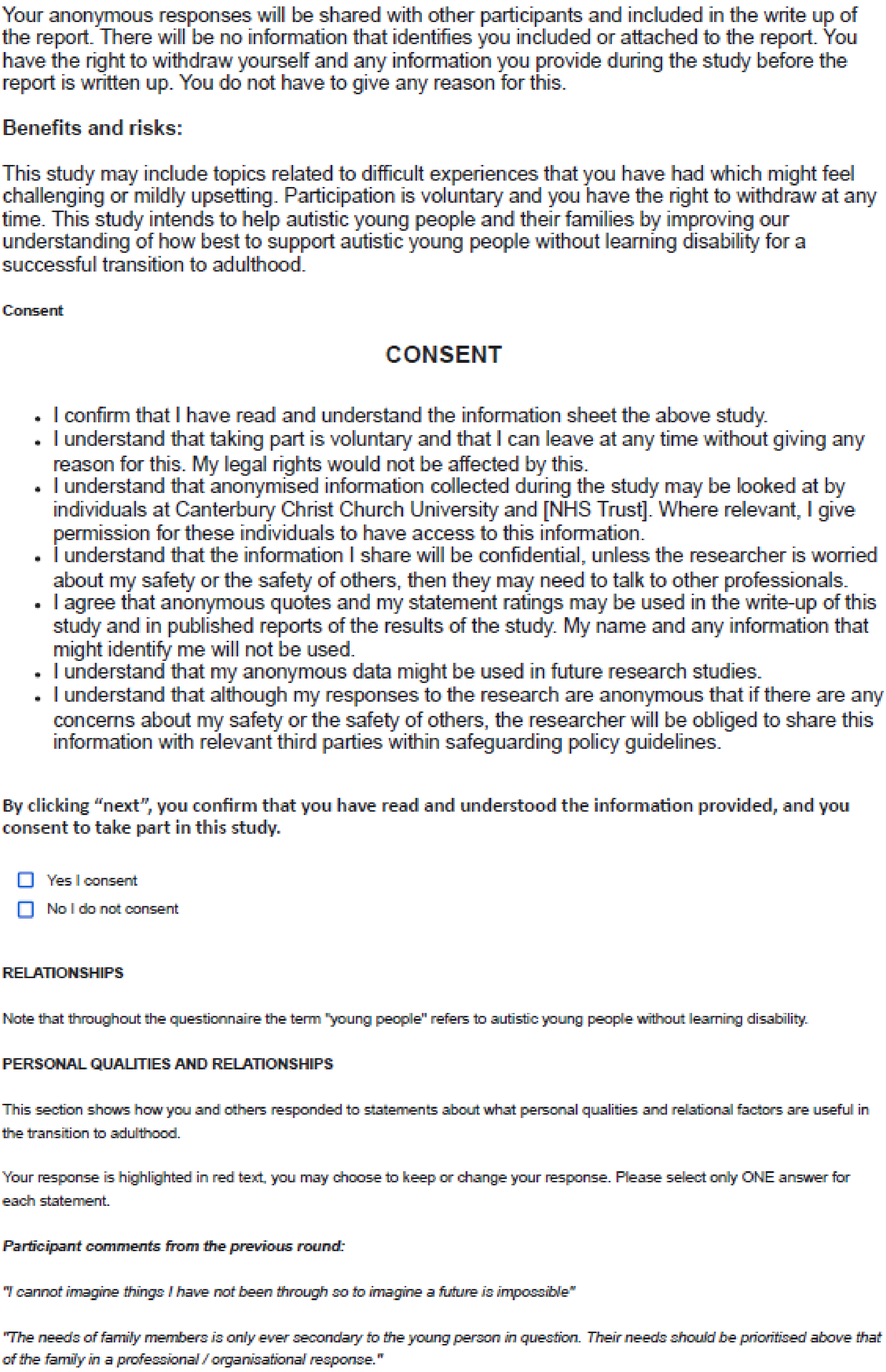
1) You are an autistic adult aged 18-30 without learning disability and have lived in the UK for at least 10 years
2) You are the parent or guardian of an autistic young person aged 16-25
3) You are a healthcare clinician who has worked with autistic youth aged 13-25 for at least two years (to ensure adequate experience to draw on)

Feedback:

Once the study is complete, you will be emailed a brief summary of the findings. The final report will be submitted for publication to a range of academic journals. These details can be emailed to you if the report is accepted for publication.

Confidentiality:

A participation number will be allocated to you. This will allow you to remain anonymous so that you will not be identified by anyone else except the researcher during and after data collection.



Your anonymous responses will be shared with other participants and included in the write up of the report. There will be no information that identifies you included or attached to the report. You have the right to withdraw yourself and any information you provide during the study before the report is written up. You do not have to give any reason for this.

Benefits and risks:

This study may include topics related to difficult experiences that you have had which might feel challenging or mildly upsetting. Participation is voluntary and you have the right to withdraw at any time. This study intends to help autistic young people and their families by improving our understanding of how best to support autistic young people without learning disability for a successful transition to adulthood.

Consent

CONSENT

- I confirm that I have read and understand the information sheet the above study.
- I understand that taking part is voluntary and that I can leave at any time without giving any reason for this. My legal rights would not be affected by this.
- I understand that anonymised information collected during the study may be looked at by individuals at Canterbury Christ Church University and [NHS Trust]. Where relevant, I give permission for these individuals to have access to this information.
- I understand that the information I share will be confidential, unless the researcher is worried about my safety or the safety of others, then they may need to talk to other professionals.
- I agree that anonymous quotes and my statement ratings may be used in the write-up of this study and in published reports of the results of the study. My name and any information that might identify me will not be used.
- I understand that my anonymous data might be used in future research studies.
- I understand that although my responses to the research are anonymous that if there are any concerns about my safety or the safety of others, the researcher will be obliged to share this information with relevant third parties within safeguarding policy guidelines.

By clicking "next", you confirm that you have read and understood the information provided, and you consent to take part in this study.

☐ Yes I consent
☐ No I do not consent

RELATIONSHIPS

Note that throughout the questionnaire the term "young people" refers to autistic young people without learning disability.

PERSONAL QUALITIES AND RELATIONSHIPS

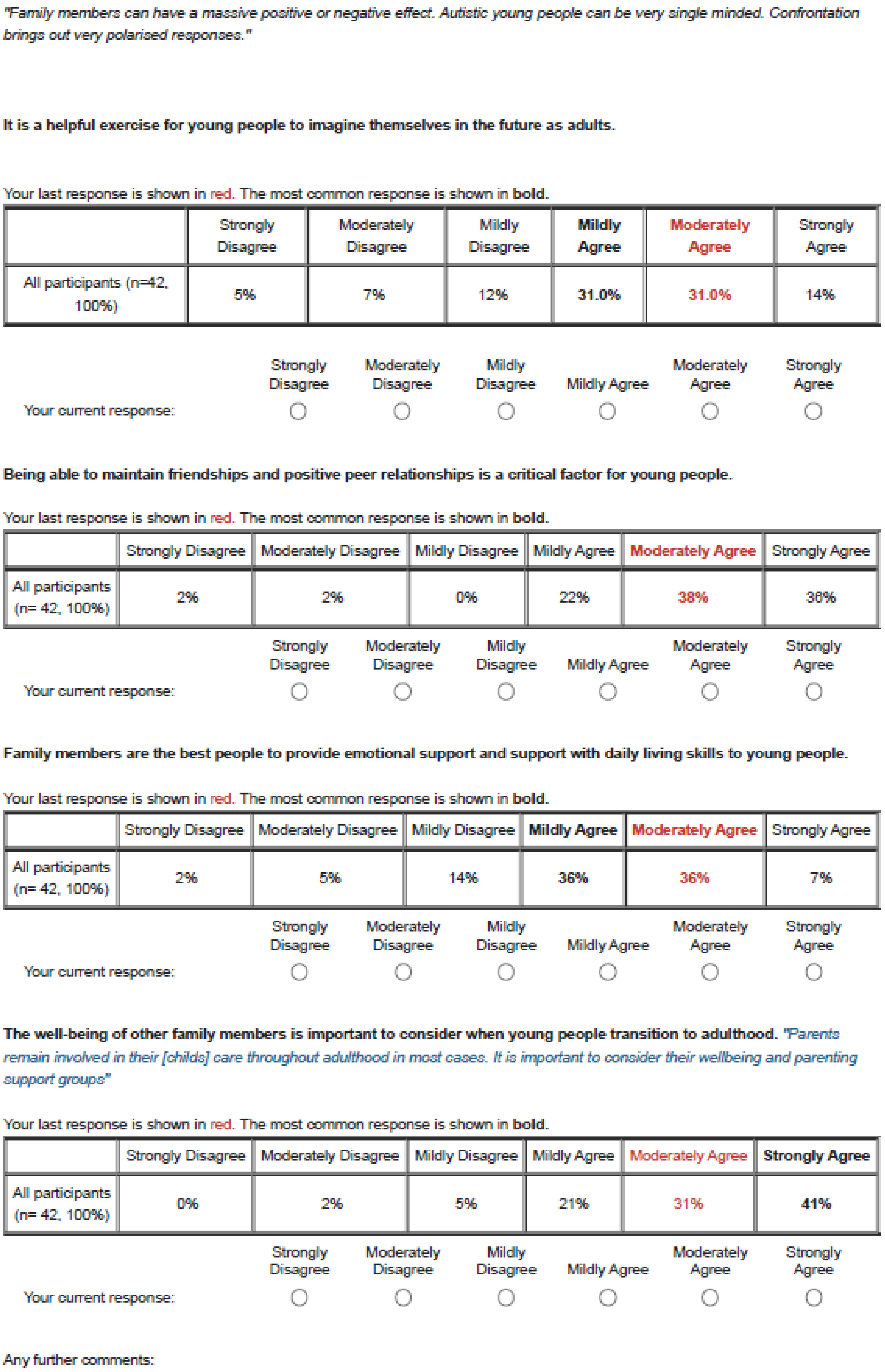
This section shows how you and others responded to statements about what personal qualities and relational factors are useful in the transition to adulthood.

Your response is highlighted in red text, you may choose to keep or change your response. Please select only ONE answer for each statement.

Participant comments from the previous round:

"I cannot imagine things I have not been through so to imagine a future is impossible"

"The needs of family members is only ever secondary to the young person in question. Their needs should be prioritised above that of the family in a professional / organisational response."



"Family members can have a massive positive or negative effect. Autistic young people can be very single minded. Confrontation brings out very polarised responses."

It is a helpful exercise for young people to imagine themselves in the future as adults.

Your last response is shown in red. The most common response is shown in **bold.**

	Strongly Disagree	Moderately Disagree	Mildly Disagree	**Mildly Agree**	**Moderately Agree**	Strongly Agree
All participants (n=42, 100%)	5%	7%	12%	**31.0%**	**31.0%**	14%

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	Moderately Agree	Strongly Agree
Your current response:	○	○	○	○	○	○

Being able to maintain friendships and positive peer relationships is a critical factor for young people.

Your last response is shown in red. The most common response is shown in **bold.**

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	**Moderately Agree**	Strongly Agree
All participants (n= 42, 100%)	2%	2%	0%	22%	**38%**	36%

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	Moderately Agree	Strongly Agree
Your current response:	○	○	○	○	○	○

Family members are the best people to provide emotional support and support with daily living skills to young people.

Your last response is shown in red. The most common response is shown in **bold.**

	Strongly Disagree	Moderately Disagree	Mildly Disagree	**Mildly Agree**	**Moderately Agree**	Strongly Agree
All participants (n= 42, 100%)	2%	5%	14%	**36%**	**36%**	7%

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	Moderately Agree	Strongly Agree
Your current response:	○	○	○	○	○	○

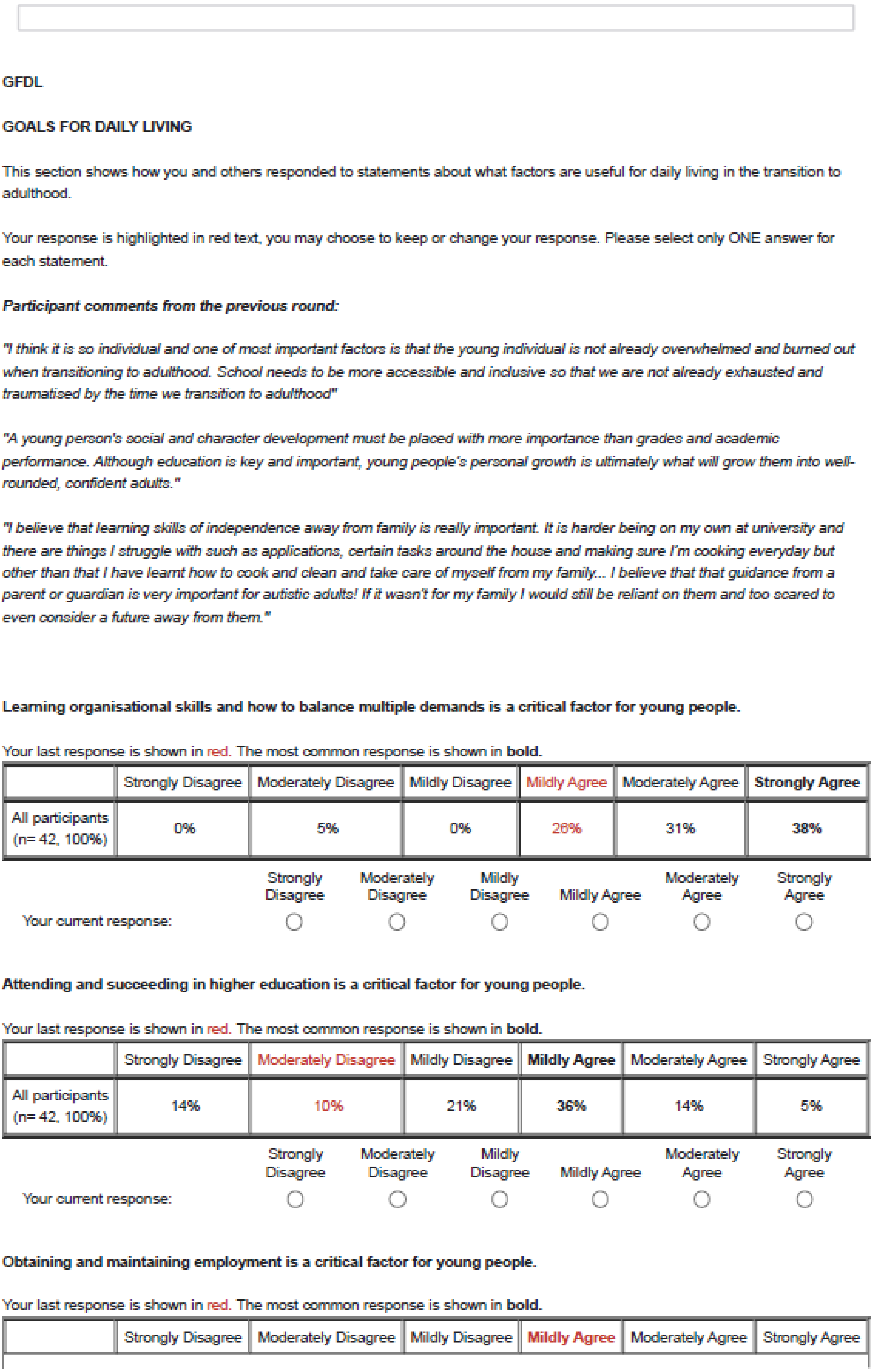
The well-being of other family members is important to consider when young people transition to adulthood. *"Parents remain involved in their [childs] care throughout adulthood in most cases. It is important to consider their wellbeing and parenting support groups"*

Your last response is shown in red. The most common response is shown in **bold.**

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	Moderately Agree	**Strongly Agree**
All participants (n= 42, 100%)	0%	2%	5%	21%	31%	**41%**

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	Moderately Agree	Strongly Agree
Your current response:	○	○	○	○	○	○

Any further comments:



GFDL

GOALS FOR DAILY LIVING

This section shows how you and others responded to statements about what factors are useful for daily living in the transition to adulthood.

Your response is highlighted in red text, you may choose to keep or change your response. Please select only ONE answer for each statement.

Participant comments from the previous round:

"I think it is so individual and one of most important factors is that the young individual is not already overwhelmed and burned out when transitioning to adulthood. School needs to be more accessible and inclusive so that we are not already exhausted and traumatised by the time we transition to adulthood"

"A young person's social and character development must be placed with more importance than grades and academic performance. Although education is key and important, young people's personal growth is ultimately what will grow them into well-rounded, confident adults."

"I believe that learning skills of independence away from family is really important. It is harder being on my own at university and there are things I struggle with such as applications, certain tasks around the house and making sure I'm cooking everyday but other than that I have learnt how to cook and clean and take care of myself from my family... I believe that that guidance from a parent or guardian is very important for autistic adults! If it wasn't for my family I would still be reliant on them and too scared to even consider a future away from them."

Learning organisational skills and how to balance multiple demands is a critical factor for young people.

Your last response is shown in red. The most common response is shown in **bold.**

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	Moderately Agree	**Strongly Agree**
All participants (n= 42, 100%)	0%	5%	0%	26%	31%	**38%**

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	Moderately Agree	Strongly Agree
Your current response:	○	○	○	○	○	○

Attending and succeeding in higher education is a critical factor for young people.

Your last response is shown in red. The most common response is shown in **bold.**

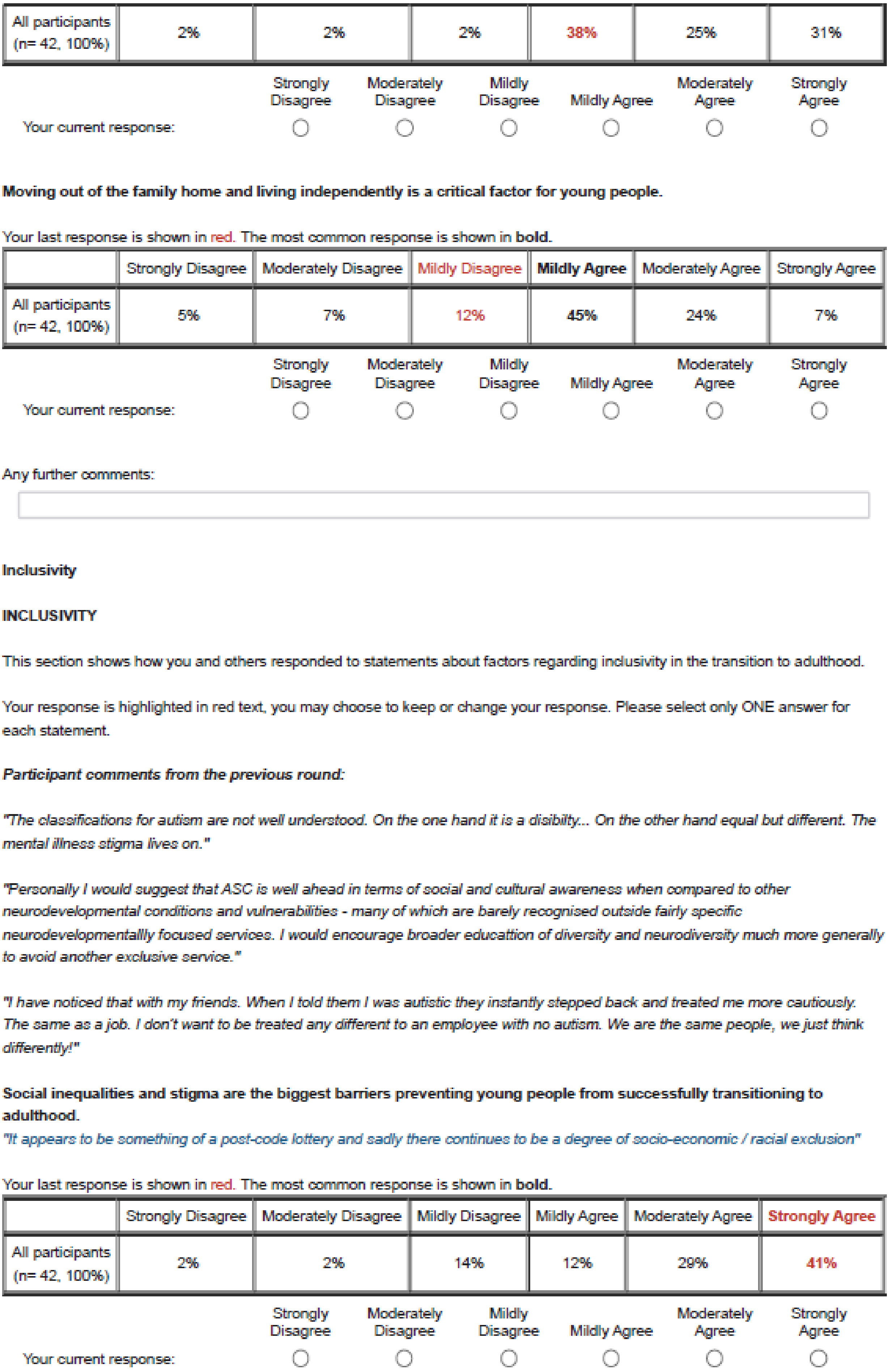
	Strongly Disagree	Moderately Disagree	Mildly Disagree	**Mildly Agree**	Moderately Agree	Strongly Agree
All participants (n= 42, 100%)	14%	10%	21%	**36%**	14%	5%

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	Moderately Agree	Strongly Agree
Your current response:	○	○	○	○	○	○

Obtaining and maintaining employment is a critical factor for young people.

Your last response is shown in red. The most common response is shown in **bold.**

	Strongly Disagree	Moderately Disagree	Mildly Disagree	**Mildly Agree**	Moderately Agree	Strongly Agree



All participants (n= 42, 100%)	2%	2%	2%	38%	25%	31%

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	Moderately Agree	Strongly Agree
Your current response:	○	○	○	○	○	○

Moving out of the family home and living independently is a critical factor for young people.

Your last response is shown in red. The most common response is shown in **bold**.

	Strongly Disagree	Moderately Disagree	Mildly Disagree	**Mildly Agree**	Moderately Agree	Strongly Agree
All participants (n= 42, 100%)	5%	7%	12%	**45%**	24%	7%

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	Moderately Agree	Strongly Agree
Your current response:	○	○	○	○	○	○

Any further comments:

Inclusivity

INCLUSIVITY

This section shows how you and others responded to statements about factors regarding inclusivity in the transition to adulthood.

Your response is highlighted in red text, you may choose to keep or change your response. Please select only ONE answer for each statement.

Participant comments from the previous round:

"The classifications for autism are not well understood. On the one hand it is a disibilty... On the other hand equal but different. The mental illness stigma lives on."

"Personally I would suggest that ASC is well ahead in terms of social and cultural awareness when compared to other neurodevelopmental conditions and vulnerabilities - many of which are barely recognised outside fairly specific neurodevelopmentallly focused services. I would encourage broader educattion of diversity and neurodiversity much more generally to avoid another exclusive service."

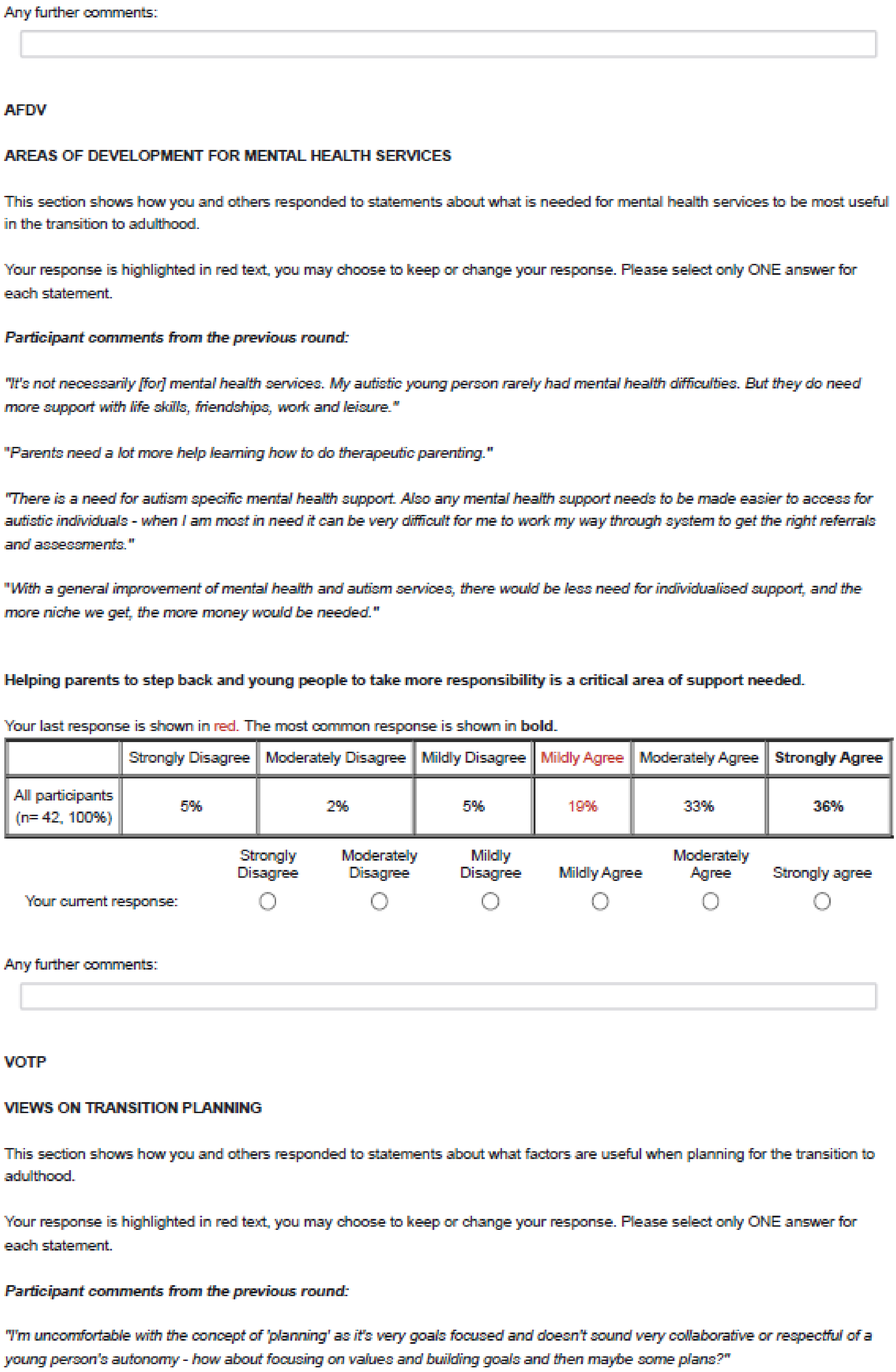
"I have noticed that with my friends. When I told them I was autistic they instantly stepped back and treated me more cautiously. The same as a job. I don't want to be treated any different to an employee with no autism. We are the same people, we just think differently!"

Social inequalities and stigma are the biggest barriers preventing young people from successfully transitioning to adulthood.
"It appears to be something of a post-code lottery and sadly there continues to be a degree of socio-economic / racial exclusion"

Your last response is shown in red. The most common response is shown in **bold**.

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	Moderately Agree	**Strongly Agree**
All participants (n= 42, 100%)	2%	2%	14%	12%	29%	**41%**

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	Moderately Agree	Strongly Agree
Your current response:	○	○	○	○	○	○



Any further comments:

AFDV

AREAS OF DEVELOPMENT FOR MENTAL HEALTH SERVICES

This section shows how you and others responded to statements about what is needed for mental health services to be most useful in the transition to adulthood.

Your response is highlighted in red text, you may choose to keep or change your response. Please select only ONE answer for each statement.

Participant comments from the previous round:

"It's not necessarily [for] mental health services. My autistic young person rarely had mental health difficulties. But they do need more support with life skills, friendships, work and leisure."

"Parents need a lot more help learning how to do therapeutic parenting."

"There is a need for autism specific mental health support. Also any mental health support needs to be made easier to access for autistic individuals - when I am most in need it can be very difficult for me to work my way through system to get the right referrals and assessments."

"With a general improvement of mental health and autism services, there would be less need for individualised support, and the more niche we get, the more money would be needed."

Helping parents to step back and young people to take more responsibility is a critical area of support needed.

Your last response is shown in red. The most common response is shown in **bold**.

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	Moderately Agree	**Strongly Agree**
All participants (n= 42, 100%)	5%	2%	5%	19%	33%	**36%**

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	Moderately Agree	Strongly agree
Your current response:	○	○	○	○	○	○

Any further comments:

VOTP

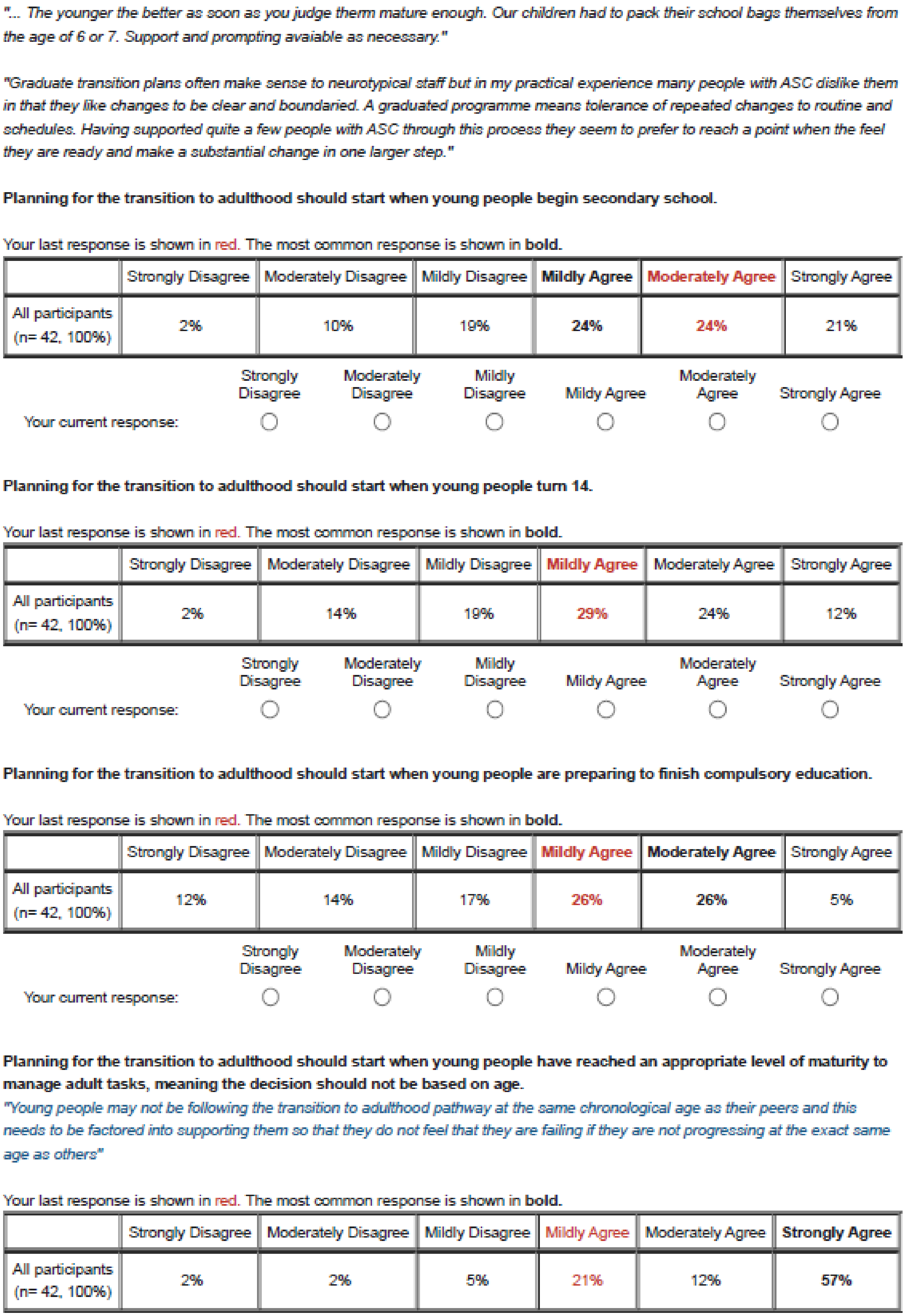
VIEWS ON TRANSITION PLANNING

This section shows how you and others responded to statements about what factors are useful when planning for the transition to adulthood.

Your response is highlighted in red text, you may choose to keep or change your response. Please select only ONE answer for each statement.

Participant comments from the previous round:

"I'm uncomfortable with the concept of 'planning' as it's very goals focused and doesn't sound very collaborative or respectful of a young person's autonomy - how about focusing on values and building goals and then maybe some plans?"



"... The younger the better as soon as you judge therm mature enough. Our children had to pack their school bags themselves from the age of 6 or 7. Support and prompting avaiable as necessary."

"Graduate transition plans often make sense to neurotypical staff but in my practical experience many people with ASC dislike them in that they like changes to be clear and boundaried. A graduated programme means tolerance of repeated changes to routine and schedules. Having supported quite a few people with ASC through this process they seem to prefer to reach a point when the feel they are ready and make a substantial change in one larger step."

Planning for the transition to adulthood should start when young people begin secondary school.

Your last response is shown in red. The most common response is shown in **bold**.

	Strongly Disagree	Moderately Disagree	Mildly Disagree	**Mildly Agree**	Moderately Agree	Strongly Agree
All participants (n= 42, 100%)	2%	10%	19%	**24%**	24%	21%

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildy Agree	Moderately Agree	Strongly Agree
Your current response:	○	○	○	○	○	○

Planning for the transition to adulthood should start when young people turn 14.

Your last response is shown in red. The most common response is shown in **bold**.

	Strongly Disagree	Moderately Disagree	Mildly Disagree	**Mildly Agree**	Moderately Agree	Strongly Agree
All participants (n= 42, 100%)	2%	14%	19%	**29%**	24%	12%

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildy Agree	Moderately Agree	Strongly Agree
Your current response:	○	○	○	○	○	○

Planning for the transition to adulthood should start when young people are preparing to finish compulsory education.

Your last response is shown in red. The most common response is shown in **bold**.

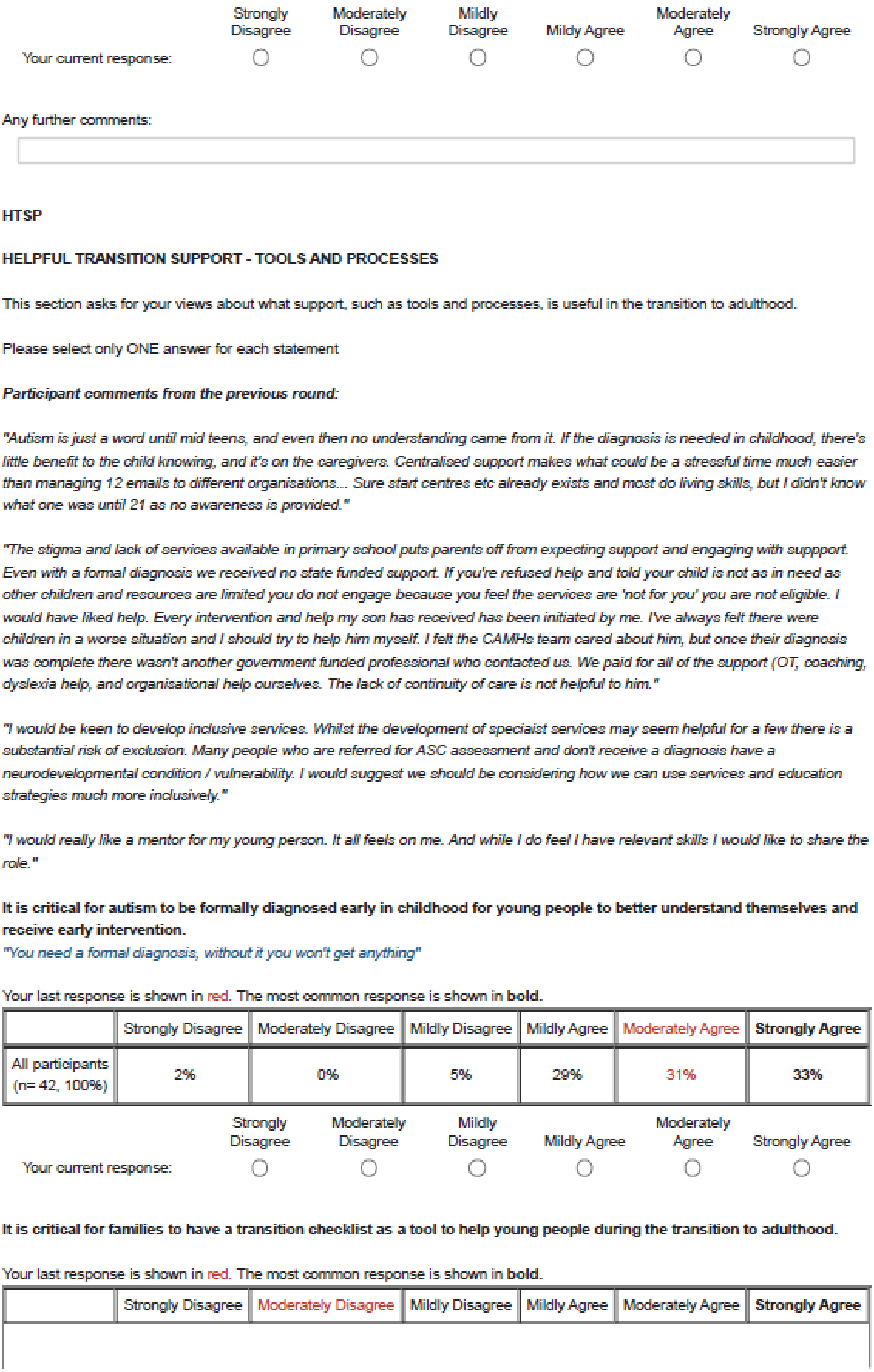
	Strongly Disagree	Moderately Disagree	Mildly Disagree	**Mildly Agree**	**Moderately Agree**	Strongly Agree
All participants (n= 42, 100%)	12%	14%	17%	**26%**	**26%**	5%

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildy Agree	Moderately Agree	Strongly Agree
Your current response:	○	○	○	○	○	○

Planning for the transition to adulthood should start when young people have reached an appropriate level of maturity to manage adult tasks, meaning the decision should not be based on age.
"Young people may not be following the transition to adulthood pathway at the same chronological age as their peers and this needs to be factored into supporting them so that they do not feel that they are failing if they are not progressing at the exact same age as others"

Your last response is shown in red. The most common response is shown in **bold**.

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	Moderately Agree	**Strongly Agree**
All participants (n= 42, 100%)	2%	2%	5%	21%	12%	**57%**



	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildy Agree	Moderately Agree	Strongly Agree
Your current response:	○	○	○	○	○	○

Any further comments:

HTSP

HELPFUL TRANSITION SUPPORT - TOOLS AND PROCESSES

This section asks for your views about what support, such as tools and processes, is useful in the transition to adulthood.

Please select only ONE answer for each statement

Participant comments from the previous round:

"Autism is just a word until mid teens, and even then no understanding came from it. If the diagnosis is needed in childhood, there's little benefit to the child knowing, and it's on the caregivers. Centralised support makes what could be a stressful time much easier than managing 12 emails to different organisations... Sure start centres etc already exists and most do living skills, but I didn't know what one was until 21 as no awareness is provided."

"The stigma and lack of services available in primary school puts parents off from expecting support and engaging with suppport. Even with a formal diagnosis we received no state funded support. If you're refused help and told your child is not as in need as other children and resources are limited you do not engage because you feel the services are 'not for you' you are not eligible. I would have liked help. Every intervention and help my son has received has been initiated by me. I've always felt there were children in a worse situation and I should try to help him myself. I felt the CAMHs team cared about him, but once their diagnosis was complete there wasn't another government funded professional who contacted us. We paid for all of the support (OT, coaching, dyslexia help, and organisational help ourselves. The lack of continuity of care is not helpful to him."

"I would be keen to develop inclusive services. Whilst the development of speciaist services may seem helpful for a few there is a substantial risk of exclusion. Many people who are referred for ASC assessment and don't receive a diagnosis have a neurodevelopmental condition / vulnerability. I would suggest we should be considering how we can use services and education strategies much more inclusively."

"I would really like a mentor for my young person. It all feels on me. And while I do feel I have relevant skills I would like to share the role."

It is critical for autism to be formally diagnosed early in childhood for young people to better understand themselves and receive early intervention.
"You need a formal diagnosis, without it you won't get anything"

Your last response is shown in red. The most common response is shown in **bold**.

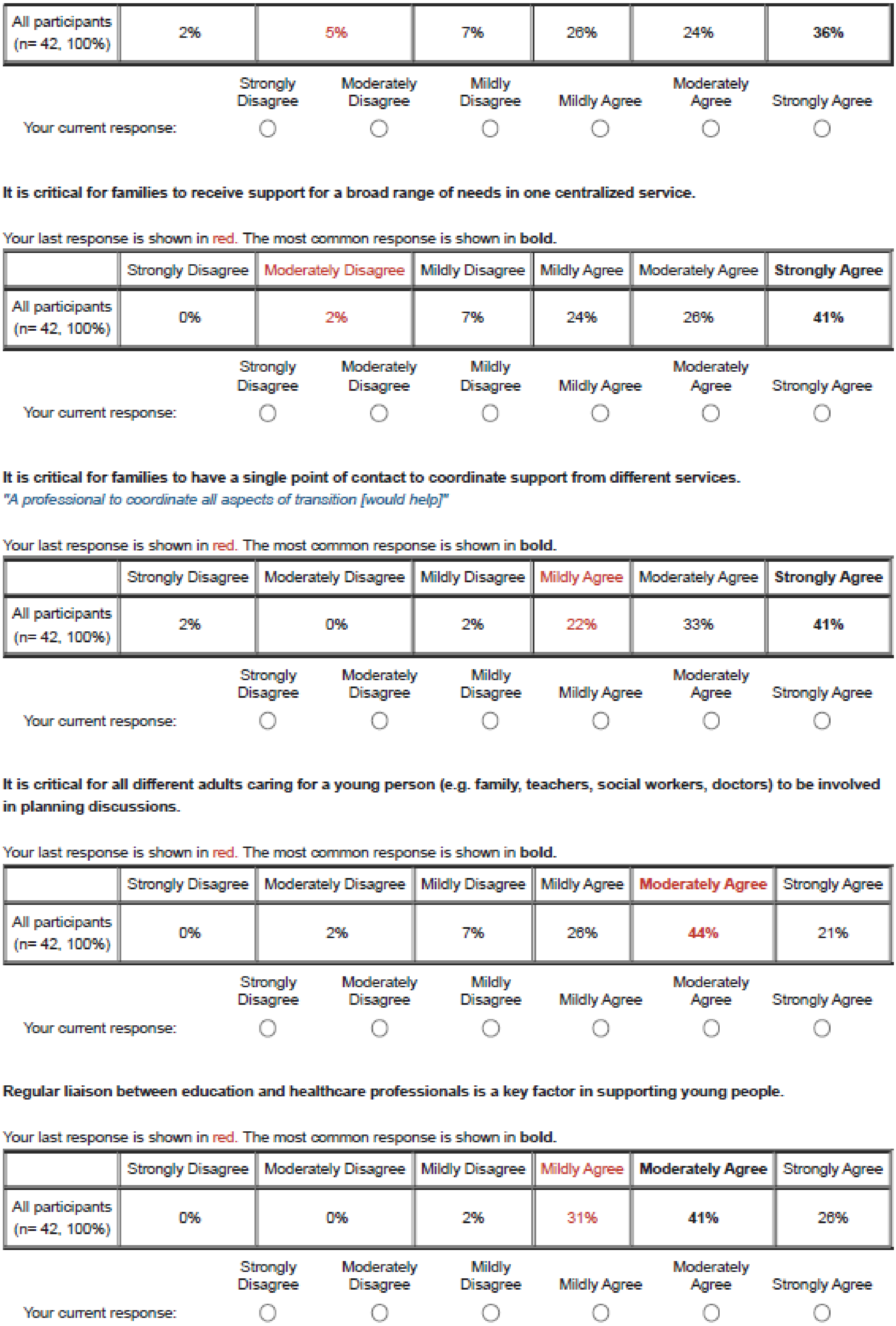
	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	Moderately Agree	**Strongly Agree**
All participants (n= 42, 100%)	2%	0%	5%	29%	31%	**33%**

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	Moderately Agree	Strongly Agree
Your current response:	○	○	○	○	○	○

It is critical for families to have a transition checklist as a tool to help young people during the transition to adulthood.

Your last response is shown in red. The most common response is shown in **bold**.

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	Moderately Agree	**Strongly Agree**



All participants (n= 42, 100%)	2%	5%	7%	26%	24%	**36%**

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	Moderately Agree	Strongly Agree
Your current response:	○	○	○	○	○	○

It is critical for families to receive support for a broad range of needs in one centralized service.

Your last response is shown in red. The most common response is shown in **bold.**

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	Moderately Agree	**Strongly Agree**
All participants (n= 42, 100%)	0%	2%	7%	24%	26%	**41%**

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	Moderately Agree	Strongly Agree
Your current response:	○	○	○	○	○	○

It is critical for families to have a single point of contact to coordinate support from different services.
"A professional to coordinate all aspects of transition [would help]"

Your last response is shown in red. The most common response is shown in **bold.**

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	Moderately Agree	**Strongly Agree**
All participants (n= 42, 100%)	2%	0%	2%	22%	33%	**41%**

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	Moderately Agree	Strongly Agree
Your current response:	○	○	○	○	○	○

It is critical for all different adults caring for a young person (e.g. family, teachers, social workers, doctors) to be involved in planning discussions.

Your last response is shown in red. The most common response is shown in **bold.**

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	**Moderately Agree**	Strongly Agree
All participants (n= 42, 100%)	0%	2%	7%	26%	**44%**	21%

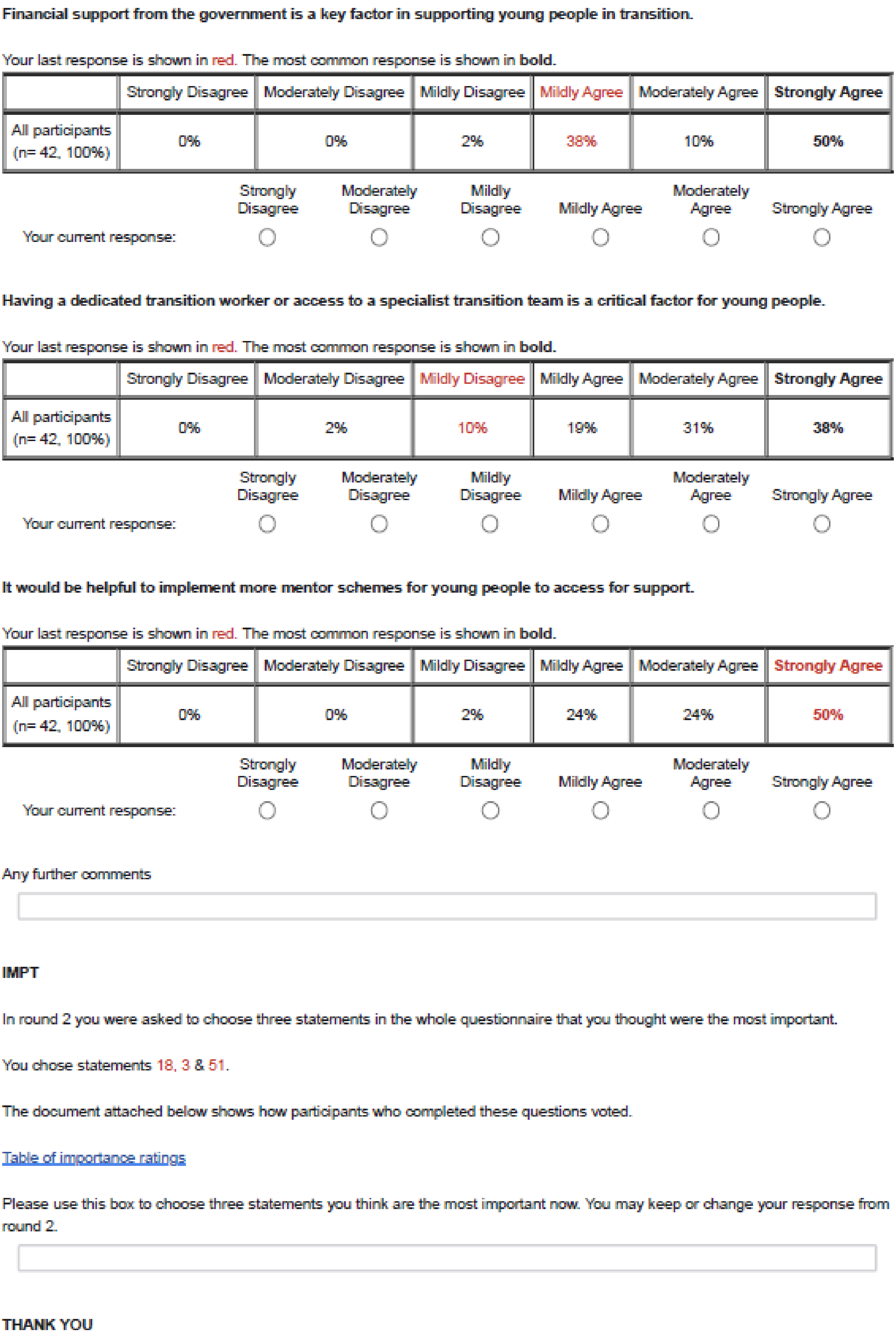
	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	Moderately Agree	Strongly Agree
Your current response:	○	○	○	○	○	○

Regular liaison between education and healthcare professionals is a key factor in supporting young people.

Your last response is shown in red. The most common response is shown in **bold.**

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	**Moderately Agree**	Strongly Agree
All participants (n= 42, 100%)	0%	0%	2%	31%	**41%**	26%

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	Moderately Agree	Strongly Agree
Your current response:	○	○	○	○	○	○



Financial support from the government is a key factor in supporting young people in transition.

Your last response is shown in red. The most common response is shown in **bold.**

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	Moderately Agree	**Strongly Agree**
All participants (n= 42, 100%)	0%	0%	2%	38%	10%	**50%**

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	Moderately Agree	Strongly Agree
Your current response:	○	○	○	○	○	○

Having a dedicated transition worker or access to a specialist transition team is a critical factor for young people.

Your last response is shown in red. The most common response is shown in **bold.**

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	Moderately Agree	**Strongly Agree**
All participants (n= 42, 100%)	0%	2%	10%	19%	31%	**38%**

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	Moderately Agree	Strongly Agree
Your current response:	○	○	○	○	○	○

It would be helpful to implement more mentor schemes for young people to access for support.

Your last response is shown in red. The most common response is shown in **bold.**

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	Moderately Agree	**Strongly Agree**
All participants (n= 42, 100%)	0%	0%	2%	24%	24%	**50%**

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	Moderately Agree	Strongly Agree
Your current response:	○	○	○	○	○	○

Any further comments

IMPT

In round 2 you were asked to choose three statements in the whole questionnaire that you thought were the most important.

You chose statements 18, 3 & 51.

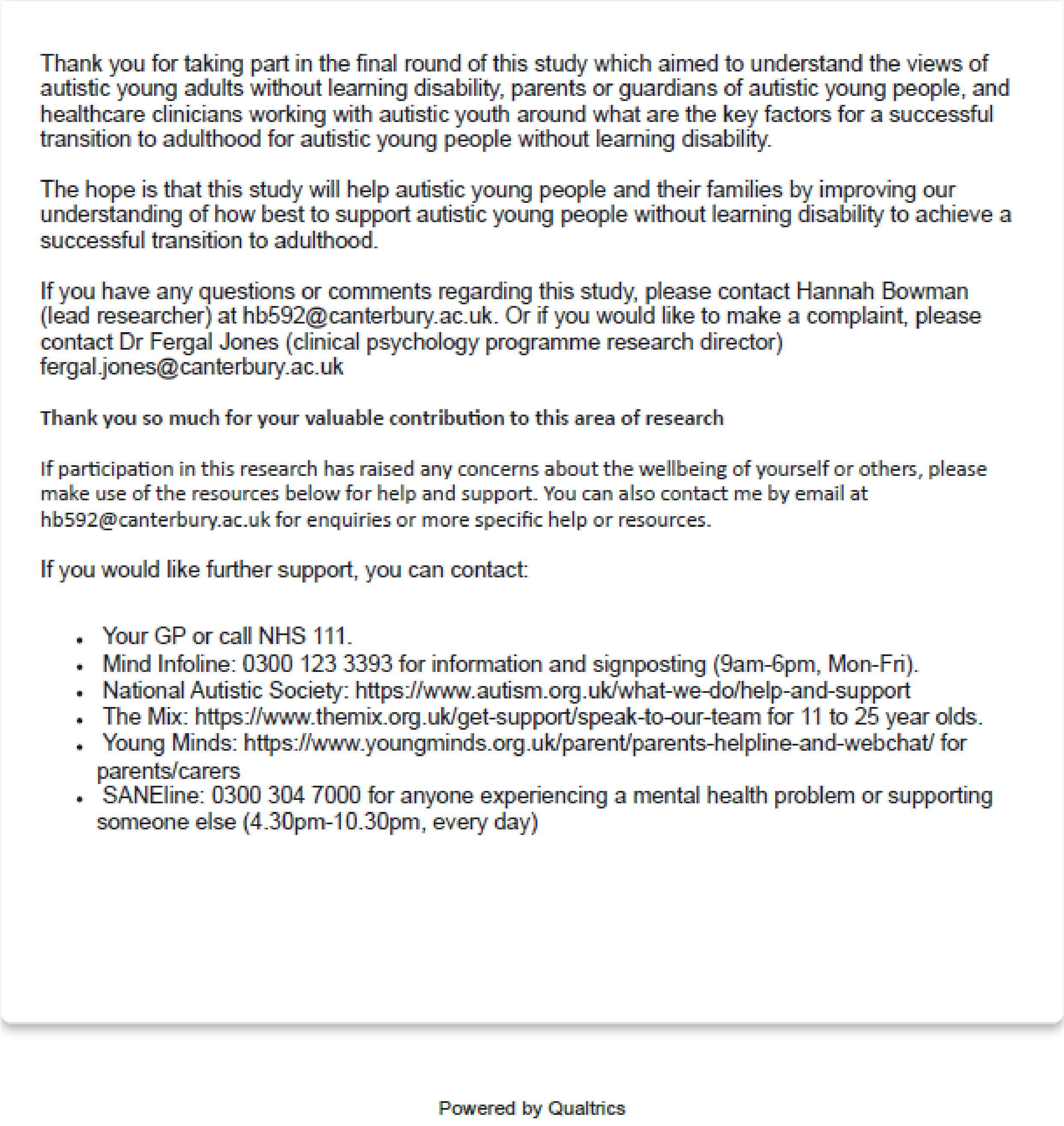
The document attached below shows how participants who completed these questions voted.

Table of importance ratings

Please use this box to choose three statements you think are the most important now. You may keep or change your response from round 2.

THANK YOU

THANK YOU



Thank you for taking part in the final round of this study which aimed to understand the views of autistic young adults without learning disability, parents or guardians of autistic young people, and healthcare clinicians working with autistic youth around what are the key factors for a successful transition to adulthood for autistic young people without learning disability.

The hope is that this study will help autistic young people and their families by improving our understanding of how best to support autistic young people without learning disability to achieve a successful transition to adulthood.

If you have any questions or comments regarding this study, please contact Hannah Bowman (lead researcher) at hb592@canterbury.ac.uk. Or if you would like to make a complaint, please contact Dr Fergal Jones (clinical psychology programme research director) fergal.jones@canterbury.ac.uk

Thank you so much for your valuable contribution to this area of research

If participation in this research has raised any concerns about the wellbeing of yourself or others, please make use of the resources below for help and support. You can also contact me by email at hb592@canterbury.ac.uk for enquiries or more specific help or resources.

If you would like further support, you can contact:

- Your GP or call NHS 111.
- Mind Infoline: 0300 123 3393 for information and signposting (9am-6pm, Mon-Fri).
- National Autistic Society: https://www.autism.org.uk/what-we-do/help-and-support
- The Mix: https://www.themix.org.uk/get-support/speak-to-our-team for 11 to 25 year olds.
- Young Minds: https://www.youngminds.org.uk/parent/parents-helpline-and-webchat/ for parents/carers
- SANEline: 0300 304 7000 for anyone experiencing a mental health problem or supporting someone else (4.30pm-10.30pm, every day)

Appendix O: Research diary extract of research design decision making

February 2022

- Issues regarding research budget, as NHS site have requested fee for honorary contract which was not anticipated and takes entire research budget. [supervisor] to look into options regarding this with Salomons as I would ideally want to offer incentive for participation and paid consultation with expert by experience.
- IRAS process has flagged that for GDPR reasons only direct member of clinical team at NHS site should access records, which means I cannot do this step myself. [external supervisor] agreed to check 'consent to be contacted about research' boxes on records which is on a form filled out as standard upon introduction to the service. Will cause slight delay but no alternative.

May 2022

- Research documents (PIS and consent) discussed and amended slightly to make more accessible for autistic people, and will check with expert consultant. Agreed the PowerPoint with key info is a nice idea and more accessible than the document alone.
- Agreed that round one questionnaire should be broad and general so participants can be free in their responses and answer with whatever comes to mind for them. Should round 1 be separate per expert group or one copy? The type of questions we are asking aren't exclusive to any one group i.e what's your experience so far, what helped, what would you like to see in future, who has been important… so one copy feels appropriate. Need to make sure questions are worded to be applicable to all experts participating.
- Autistic young people or autistic young adults? Autistic young people are the focus of the project, but this could be an anxiety provoking topic and we might be prompting young people to think about transition/adulthood before they are ready to– is this necessary? If not necessary, this is potentially unethical. Autistic young adults are either in the transition to adulthood currently (18-25?) or can reflect on transition (25-30?) so still very relevant. May also get more detailed answers from asking those who have had time to process the experience. Doesn't change focus of the project, so agreed autistic young adults will be the expert group. Age 18-30 should capture those with experience of transition nicely. Agreed not to recruit >30yrs to remain relevant to current policy and 'recent' experience.
- Acknowledge potential anxiety and have signposting to freely available support at the end of the questionnaire as well as own contact details.

October 2022

- Consider adaptations to enable access, maybe offer to complete with me via videocall or in person if preferred. This gives people the option to speak with cameras on/off, or use chat function if not wanting to speak, but also chance to check understanding or ask questions. Can also offer to send the questions in good time before the link goes live so there's adequate processing time.
- Consultation helped change the wording of research documents, particularly the PIS. Advised to highlight key text in colour so have done so. Feedback that it was a "boring" document so make an enticing advert with concise text and have contact details and be free to discuss with people. Suggested parents can be present if helps people feel comfortable but be clear in explaining they cannot answer for the autistic person. R1 to be piloted by consultant and [external supervisor].
- Order questions to try end on a positive note.

May 2023

- IRAS approved and R&D confirmed, can now start recruitment. Contingency plan for recruitment to advertise through appropriate online forums and parent support groups. Examples include [redacted].

Appendix P: Round two statistical analysis results

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.^{a,b}	Decision
1	The distribution of PERSONAL QUALITIES AND RELATIONSHIPS - 1. Young people need to build up their self-esteem to be successful in adulthood. is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.135	Retain the null hypothesis.
2	The distribution of PERSONAL QUALITIES AND RELATIONSHIPS - 2. Being able to manage difficult emotions is a critical factor for young people. is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.699	Retain the null hypothesis.
3	The distribution of PERSONAL QUALITIES AND RELATIONSHIPS - 3. Understanding themselves and their needs is a critical factor for young people. " It's also about being happy, understanding more about yourself and where you fit into the world " is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.650	Retain the null hypothesis.
4	The distribution of PERSONAL QUALITIES AND RELATIONSHIPS - 4. It is a helpful exercise for young people to imagine themselves in the future as adults. is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.115	Retain the null hypothesis.
5	The distribution of PERSONAL QUALITIES AND RELATIONSHIPS - 5. Being able to maintain friendships and positive peer relationships is a critical factor for young people. is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.297	Retain the null hypothesis.
6	The distribution of PERSONAL QUALITIES AND RELATIONSHIPS - 6. Family members are the best people to provide emotional support and support with daily living skills to young people. is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.080	Retain the null hypothesis.
7	The distribution of PERSONAL QUALITIES AND RELATIONSHIPS - 7. The well-being of other family members is important to consider when young people transition to adulthood. " Parents remain involved in their [childs] care throughout adulthood in most cases. It is important to consider their wellbeing and parenting support groups " is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.109	Retain the null hypothesis.
8	The distribution of PERSONAL QUALITIES AND RELATIONSHIPS - 8. Talking to trusted adults, such as professionals or mentors, is critical support for youth transitioning to adulthood. is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.877	Retain the null hypothesis.

9	The distribution of GOALS FOR DAILY LIVING - 9. Learning organisational skills and how to balance multiple demands is a critical factor for young people. is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.738	Retain the null hypothesis.
10	The distribution of GOALS FOR DAILY LIVING - 10. Practicing daily living skills (e.g. hygiene, shopping, cooking, managing finances) is a critical factor for young people. is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.807	Retain the null hypothesis.
11	The distribution of GOALS FOR DAILY LIVING - 11. Daily living skills should be taught as part of the curriculum in secondary school. " Preparing for adulthood should be taught in school, I don’t know the process for job hunting or renting a house and we’re just expected to be okay with it " is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.243	Retain the null hypothesis.
12	The distribution of GOALS FOR DAILY LIVING - 12. Keeping physically healthy and safe is a critical factor for young people. is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.316	Retain the null hypothesis.
13	The distribution of GOALS FOR DAILY LIVING - 13. Engaging in meaningful activities and hobbies is a critical factor for young people. " A successful transition would allow the young person to be able to engage in an enjoyable and meaningful activity " is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.851	Retain the null hypothesis.
14	The distribution of GOALS FOR DAILY LIVING - 14. Attending and succeeding in higher education is a critical factor for young people. is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.921	Retain the null hypothesis.
15	The distribution of GOALS FOR DAILY LIVING - 15. Obtaining and maintaining employment is a critical factor for young people. is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.507	Retain the null hypothesis.
16	The distribution of GOALS FOR DAILY LIVING - 16. Moving out of the family home and living independently is a critical factor for young people. is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.338	Retain the null hypothesis.
17	The distribution of INCLUSIVITY - 17. Enabling and encouraging young people to make decisions and advocate for themselves is a critical factor for successful transition. is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.902	Retain the null hypothesis.
18	The distribution of INCLUSIVITY - 18. Social inequalities and stigma are the biggest barriers preventing young people from successfully transitioning to adulthood. " It appears to be something of a post-code lottery and sadly there continues to be a degree of socio-economic / racial exclusion " is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.187	Retain the null hypothesis.

19	The distribution of INCLUSIVITY - 19. More needs to be done to ensure autistic people receive equal opportunities to non-autistic people. is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.954	Retain the null hypothesis.
20	The distribution of INCLUSIVITY - 20. Training and education regarding autism should be delivered routinely within organizations. " Every company needs to be aware of autism, what it's like and how hard work it can be. I am constantly trying to push the boundaries with autism awareness. I asked to give an awareness presentation at work. More people need to do this. I'm passionate about diversity and inclusivity " is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.521	Retain the null hypothesis.
21	The distribution of INCLUSIVITY - 21. There should be more initiatives to improve awareness and understanding of autism in society. is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.737	Retain the null hypothesis.
22	The distribution of AREAS OF DEVELOPMENT FOR MENTAL HEALTH SERVICES - 22. Services need to ensure families are aware of existing adult mental health services. is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.893	Retain the null hypothesis.
23	The distribution of AREAS OF DEVELOPMENT FOR MENTAL HEALTH SERVICES - 23. Helping parents to step back and young people to take more responsibility is a critical area of support needed. is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.050	Retain the null hypothesis.
24	The distribution of AREAS OF DEVELOPMENT FOR MENTAL HEALTH SERVICES - 24. More specialist adult autism services need to be created. is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.106	Retain the null hypothesis.
25	The distribution of AREAS OF DEVELOPMENT FOR MENTAL HEALTH SERVICES - 25. Transfer to adult services should happen routinely for all young people instead of needing to seek a referral for support from mental health services. " There should be some form of introduction to adult services before deciding if you need them or not, rather than being dropped and self-referring afterwards " is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.078	Retain the null hypothesis.
26	The distribution of AREAS OF DEVELOPMENT FOR MENTAL HEALTH SERVICES - 26. Providing individualized support for all demographics of autistic people (e.g. autistic females, black and minority ethnic autistic people, autistic people without learning disability) is a critical area of support needed. is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.509	Retain the null hypothesis.

27	The distribution of AREAS OF DEVELOPMENT FOR MENTAL HEALTH SERVICES - 27. Helping young people to know when and how to actively seek support for themselves is a critical area of support needed. " I found that the support that is/was available is something that an individual has to seek out themselves, and this is difficult as the individual may not be aware of the support that they need " is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.377	Retain the null hypothesis.
28	The distribution of AREAS OF DEVELOPMENT FOR MENTAL HEALTH SERVICES - 28. There needs to be more investment into NHS services to improve access to services and availability of resources. is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.596	Retain the null hypothesis.
29	The distribution of OTHER SOURCES OF SUPPORT - 29. Having universally accessible forms of support (e.g. online information and advice) is a critical support for young people. is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.567	Retain the null hypothesis.
30	The distribution of OTHER SOURCES OF SUPPORT - 30. Having easy access to non-statutory organisations (e.g. community groups, charities, youth groups) is a critical support for young people. " My autistic youth social group really helped me " is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.598	Retain the null hypothesis.
31	The distribution of OTHER SOURCES OF SUPPORT - 31. Having easy access to educational support (e.g. special educational needs coordinator, tutors, autism champion positions) is a critical support for young people. is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.678	Retain the null hypothesis.
32	The distribution of OTHER SOURCES OF SUPPORT - 32. Having easy access to support at university (e.g. career support, mental wellbeing, mentors, educational accommodations) is a critical support for young people. is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.967	Retain the null hypothesis.
33	The distribution of OTHER SOURCES OF SUPPORT - 33. Having easy access to employment support (e.g. job interview preparation, liaison with managers, general employment skills) is a critical support for young people. " [Job] Interviews are an obstacle so I practised how to answer questions properly. I took a job interview skill course after my undergraduate degree. I kept getting rejected and when I finally got an interview -BAM- it worked " is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.706	Retain the null hypothesis.
34	The distribution of VIEWS ON TRANSITION PLANNING - 34. Planning for the transition to adulthood should start when young people begin secondary school. is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.700	Retain the null hypothesis.

35	The distribution of VIEWS ON TRANSITION PLANNING - 35. Planning for the transition to adulthood should start when young people turn 14. is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.134	Retain the null hypothesis.
36	The distribution of VIEWS ON TRANSITION PLANNING - 36. Planning for the transition to adulthood should start when young people are preparing to finish compulsory education. is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.702	Retain the null hypothesis.
37	The distribution of VIEWS ON TRANSITION PLANNING - 37. Planning for the transition to adulthood should start when young people have reached an appropriate level of maturity to manage adult tasks, meaning the decision should not be based on age. " Young people may not be following the transition to adulthood pathway at the same chronological age as their peers and this needs to be factored into supporting them so that they do not feel that they are failing if they are not progressing at the exact same age as others " is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.690	Retain the null hypothesis.
38	The distribution of VIEWS ON TRANSITION PLANNING - 38. When planning for transition, making sure the process happens gradually and not suddenly is crucial. is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.383	Retain the null hypothesis.
39	The distribution of VIEWS ON TRANSITION PLANNING - 39. When planning for transition, ensuring young people have enough time to process information and change is crucial. is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.140	Retain the null hypothesis.
40	The distribution of VIEWS ON TRANSITION PLANNING - 40. When planning for transition, having clear goals and breaking down the steps to achieve them is crucial. " Improving clarity on my goals and the steps to achieve them [has helped] " is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.808	Retain the null hypothesis.
41	The distribution of HELPFUL TOOLS AND PROCESSES - 41. It is critical for autism to be formally diagnosed early in childhood for young people to better understand themselves and receive early intervention. " You need a formal diagnosis, without it you won't get anything " is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.947	Retain the null hypothesis.
42	The distribution of HELPFUL TOOLS AND PROCESSES - 42. It is critical for families to be signposted to appropriate services and be provided with information leaflets. is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.864	Retain the null hypothesis.
43	The distribution of HELPFUL TOOLS AND PROCESSES - 43. It is critical for families to have a transition checklist as a tool to help young people during the transition to adulthood. is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.851	Retain the null hypothesis.

44	The distribution of HELPFUL TOOLS AND PROCESSES - 44. It is critical for families to receive support for a broad range of needs in one centralized service. is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.401	Retain the null hypothesis.
45	The distribution of HELPFUL TOOLS AND PROCESSES - 45. It is critical for families to have a single point of contact to coordinate support from different services. " A professional to coordinate all aspects of transition [would help] " is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.205	Retain the null hypothesis.
46	The distribution of HELPFUL TOOLS AND PROCESSES - 46. It is critical for all different adults caring for a young person (e.g. family, teachers, social workers, doctors) to be involved in planning discussions. is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.144	Retain the null hypothesis.
47	The distribution of HELPFUL TOOLS AND PROCESSES - 47. Regular liaison between education and healthcare professionals is a key factor in supporting young people. is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.469	Retain the null hypothesis.
48	The distribution of HELPFUL TOOLS AND PROCESSES - 48. Financial support from the government is a key factor in supporting young people in transition. is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.860	Retain the null hypothesis.
49	The distribution of HELPFUL TOOLS AND PROCESSES - 49. Having a dedicated transition worker or access to a specialist transition team is a critical factor for young people. is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.074	Retain the null hypothesis.
50	The distribution of HELPFUL TOOLS AND PROCESSES - 50. A directory of local support services available to young people and their families should exist for each county/London borough. " Better understanding of transition support available in different areas - building a directory [would help] " is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.682	Retain the null hypothesis.
51	The distribution of HELPFUL TOOLS AND PROCESSES - 51. It would be helpful to implement more mentor schemes for young people to access for support. is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.775	Retain the null hypothesis.
52	The distribution of HELPFUL TOOLS AND PROCESSES - 52. Services should offer workshops for young people and their families on topics voted for by service users e.g. Daily living skills, Relationships, Jobs. is the same across categories of Group.	Independent-Samples Kruskal-Wallis Test	.235	Retain the null hypothesis.

a. The significance level is .010.

b. Asymptotic significance is displayed.

Appendix Q: Round three statistical analysis results

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.[a,b]	Decision
1	The distribution of It is a helpful exercise for young people to imagine themselves in the future as adults.	Independent-Samples Kruskal-Wallis Test	.154	Retain the null hypothesis.
2	The distribution of Being able to maintain friendships and positive peer relationships is a critical factor for young people.	Independent-Samples Kruskal-Wallis Test	.705	Retain the null hypothesis.
3	The distribution of Family members are the best people to provide emotional support and support with daily living skills to young people.	Independent-Samples Kruskal-Wallis Test	.385	Retain the null hypothesis.
4	The distribution of The well-being of other family members is important to consider when young people transition to adulthood.	Independent-Samples Kruskal-Wallis Test	.643	Retain the null hypothesis.
5	The distribution of Learning organisational skills and how to balance multiple demands is a critical factor for young people.	Independent-Samples Kruskal-Wallis Test	.338	Retain the null hypothesis.
6	The distribution of Attending and succeeding in higher education is a critical factor for young people.	Independent-Samples Kruskal-Wallis Test	.582	Retain the null hypothesis.
7	The distribution of Obtaining and maintaining employment is a critical factor for young people.	Independent-Samples Kruskal-Wallis Test	.556	Retain the null hypothesis.
8	The distribution of Moving out of the family home and living independently is a critical factor for young people.	Independent-Samples Kruskal-Wallis Test	.373	Retain the null hypothesis.
9	The distribution of Social inequalities and stigma are the biggest barriers preventing young people from successfully transitioning to adulthood.	Independent-Samples Kruskal-Wallis Test	.748	Retain the null hypothesis.
10	The distribution of Helping parents to step back and young people to take more responsibility is a critical area of support needed.	Independent-Samples Kruskal-Wallis Test	.103	Retain the null hypothesis.

11	The distribution of Planning for the transition to adulthood should start when young people begin secondary school.	Independent-Samples Kruskal-Wallis Test	.157	Retain the null hypothesis.
12	The distribution of Planning for the transition to adulthood should start when young people turn 14.	Independent-Samples Kruskal-Wallis Test	.466	Retain the null hypothesis.
13	The distribution of Planning for the transition to adulthood should start when young people are preparing to finish compulsory education.	Independent-Samples Kruskal-Wallis Test	.360	Retain the null hypothesis.
14	The distribution of Planning for the transition to adulthood should start when young people have reached an appropriate level of maturity to manage adult tasks, meaning the decision should not be based on age.	Independent-Samples Kruskal-Wallis Test	.117	Retain the null hypothesis.
15	The distribution of It is critical for autism to be formally diagnosed early in childhood for young people to better understand themselves and receive early intervention.	Independent-Samples Kruskal-Wallis Test	.556	Retain the null hypothesis.
16	The distribution of It is critical for families to have a transition checklist as a tool to help young people during the transition to adulthood.	Independent-Samples Kruskal-Wallis Test	.630	Retain the null hypothesis.
17	The distribution of It is critical for families to receive support for a broad range of needs in one centralized service.	Independent-Samples Kruskal-Wallis Test	.372	Retain the null hypothesis.
18	The distribution of It is critical for families to have a single point of contact to coordinate support from different services.	Independent-Samples Kruskal-Wallis Test	.175	Retain the null hypothesis.
19	The distribution of It is critical for all different adults caring for a young person (e.g. family, teachers, social workers, doctors) to be involved in planning discussions.	Independent-Samples Kruskal-Wallis Test	.271	Retain the null hypothesis.
20	The distribution of Regular liaison between education and healthcare professionals is a key factor in supporting young people.	Independent-Samples Kruskal-Wallis Test	.502	Retain the null hypothesis.

21	The distribution of Financial support from the government is a key factor in supporting young people in transition.	Independent-Samples Kruskal-Wallis Test	.183	Retain the null hypothesis.
22	The distribution of Having a dedicated transition worker or access to a specialist transition team is a critical factor for young people.	Independent-Samples Kruskal-Wallis Test	.012	Retain the null hypothesis.
23	The distribution of It would be helpful to implement more mentor schemes for young people to access for support.	Independent-Samples Kruskal-Wallis Test	.519	Retain the null hypothesis.

a. The significance level is .010.

b. Asymptotic significance is displayed.

Appendix R: Statement ratings of importance for rounds two and three

32/42 participants completed the question asking which three statement(s) they thought to be most important in round two. The three statements that were most frequently rated as 'most important' overall are in **bold**.

Statement	**Overall (n= 32)**	**Autistic young adults (n=13)**	**Parents (n=6)**	**Clinicians (n=13)**
1. Young people need to build up their self-esteem to be successful in adulthood.	0	0	0	0
2. Being able to manage difficult emotions is a critical factor for young people.	1	1	0	0
3. Understanding themselves and their needs is a critical factor for young people.	15	5	2	8
4. It is a helpful exercise for young people to imagine themselves in the future as adults.	0	0	0	0
5. Being able to maintain friendships and positive peer relationships is a critical factor for young people.	0	0	0	0
6. Family members are the best people to provide emotional support and support with daily living skills to young people.	1	0	0	1
7. The well-being of other family members is important to consider when young people transition to adulthood.	0	0	0	0
8. Talking to trusted adults, such as professionals or mentors, is critical support for youth transitioning to adulthood.	0	0	0	0
9. Learning organisational skills and how to balance multiple demands is a critical factor for young people.	0	0	0	0
10. Practicing daily living skills (e.g. hygiene, shopping, cooking, managing finances) is a critical factor for young people.	1	0	0	1
11. Daily living skills should be taught as part of the curriculum in secondary school.	0	0	0	0
12. Keeping physically healthy and safe is a critical factor for young people.	2	0	1	1

13. Engaging in meaningful activities and hobbies is a critical factor for young people.	7	0	2	5
14. Attending and succeeding in higher education is a critical factor for young people.	0	0	0	0
15. Obtaining and maintaining employment is a critical factor for young people.	0	0	0	0
16. Moving out of the family home and living independently is a critical factor for young people.	0	0	0	0
17. Enabling and encouraging young people to make decisions and advocate for themselves is a critical factor for successful transition.	1	0	1	0
18. Social inequalities and stigma are the biggest barriers preventing young people from successfully transitioning to adulthood.	2	0	0	2
19. More needs to be done to ensure autistic people receive equal opportunities to non-autistic people.	2	0	1	1
20. Training and education regarding autism should be delivered routinely within organizations.	1	0	0	1
21. There should be more initiatives to improve awareness and understanding of autism in society.	1	1	0	0
22. Services need to ensure families are aware of existing adult mental health services.	1	1	0	0
23. Helping parents to step back and young people to take more responsibility is a critical area of support needed.	0	0	0	0
24. More specialist adult autism services need to be created.	2	0	1	1
25. Transfer to adult services should happen routinely for all young people instead of needing to seek a referral for support from mental health services.	2	2	0	0
26. Providing individualized support for all demographics of autistic people (e.g. autistic females, black and minority ethnic autistic people, autistic people without learning disability, autistic adults) is a critical area of support needed.	1	1	0	0
27. Helping young people to know when and how to actively seek support for themselves is a critical area of support needed.	13	6	1	6

28. There needs to be more investment into NHS services to improve access to services and availability of resources.	2	1	0	1
29. Having universally accessible forms of support (e.g. online information and advice) is a critical support for young people.	1	1	0	0
30. Having easy access to non-statutory organisations (e.g. community groups, charities, youth groups) is a critical support for young people.	0	0	0	0
31. Having easy access to educational support (e.g. special educational needs coordinator, tutors, autism champion positions) is a critical support for young people.	2	1	0	1
32. Having easy access to support at university (e.g. career support, mental well-being, mentors, educational accommodations) is a critical support for young people.	0	0	0	0
33. Having easy access to employment support (e.g. job interview preparation, liaison with managers, general employment skills) is a critical support for young people.	7	2	1	4
34. Planning for the transition to adulthood should start when young people begin secondary school.	1	1	0	0
35. Planning for the transition to adulthood should start when young people turn 14.	0	0	0	0
36. Planning for the transition to adulthood should start when young people are preparing to finish compulsory education.	0	0	0	0
37. Planning for the transition to adulthood should start when young people have reached an appropriate level of maturity to manage adult tasks, meaning the decision should not be based on age.	0	0	0	0
38. When planning for transition, making sure the process happens gradually and not suddenly is crucial.	0	0	0	0

39. When planning for transition, ensuring young people have enough time to process information and change is crucial.	0	0	0	0
40. When planning for transition, having clear goals and breaking down the steps to achieve them is crucial.	0	0	0	0
41. It is critical for autism to be formally diagnosed early in childhood for young people to better understand themselves and receive early intervention.	2	1	0	1
42. It is critical for families to be signposted to appropriate services and be provided with information leaflets.	1	0	1	0
43. It is critical for families to have a transition checklist as a tool to help young people during the transition to adulthood.	1	1	0	0
44. It is critical for families to receive support for a broad range of needs in one centralized service.	2	1	1	0
45. It is critical for families to have a single point of contact to coordinate support from different services.	1	0	1	0
46. It is critical for all different adults caring for a young person (e.g. family, teachers, social workers, doctors) to be involved in planning discussions.	0	0	0	0
47. Regular liaison between education and healthcare professionals is a key factor in supporting young people.	1	1	0	0
48. Financial support from the government is a key factor in supporting young people in transition.	0	0	0	0
49. Having a dedicated transition worker or access to a specialist transition team is a critical factor for young people.	1	0	1	0
50. A directory of local support services available to young people and their families should exist for each county/London borough.	13	6	3	4

51. It would be helpful to implement more mentor schemes for young people to access for support.	7	5	1	1
52. Services should offer workshops for young people and their families on topics voted for by service users e.g. Daily living skills, Relationships, Jobs.	1	1	0	0

20/34 participants completed the question asking which three statement(s) they thought to be most important in round three. The three statements that were most frequently rated as 'most important' overall are in **bold**.

Please note that one clinician provided two votes only.

Statement	**Overall (n= 20)**	**Autistic young adults (n=7)**	**Parents (n=4)**	**Clinicians (n=9)**
1. Young people need to build up their self-esteem to be successful in adulthood.	0	0	0	0
2. Being able to manage difficult emotions is a critical factor for young people.	2	1	0	1
3. Understanding themselves and their needs is a critical factor for young people.	10	3	3	4
4. It is a helpful exercise for young people to imagine themselves in the future as adults.	0	0	0	0
5. Being able to maintain friendships and positive peer relationships is a critical factor for young people.	0	0	0	0
6. Family members are the best people to provide emotional support and support with daily living skills to young people.	1	0	0	1
7. The well-being of other family members is important to consider when young people transition to adulthood.	0	0	0	0
8. Talking to trusted adults, such as professionals or mentors, is critical support for youth transitioning to adulthood.	0	0	0	0

9. Learning organisational skills and how to balance multiple demands is a critical factor for young people.	0	0	0	0
10. Practicing daily living skills (e.g. hygiene, shopping, cooking, managing finances) is a critical factor for young people.	2	0	0	2
11. Daily living skills should be taught as part of the curriculum in secondary school.	0	0	0	0
12. Keeping physically healthy and safe is a critical factor for young people.	0	0	0	0
13. Engaging in meaningful activities and hobbies is a critical factor for young people.	4	0	1	3
14. Attending and succeeding in higher education is a critical factor for young people.	0	0	0	0
15. Obtaining and maintaining employment is a critical factor for young people.	0	0	0	0
16. Moving out of the family home and living independently is a critical factor for young people.	0	0	0	0
17. Enabling and encouraging young people to make decisions and advocate for themselves is a critical factor for successful transition.	2	0	1	1
18. Social inequalities and stigma are the biggest barriers preventing young people from successfully transitioning to adulthood.	2	1	0	1
19. More needs to be done to ensure autistic people receive equal opportunities to non-autistic people.	1	0	0	1
20. Training and education regarding autism should be delivered routinely within organizations.	1	0	0	1
21. There should be more initiatives to improve awareness and understanding of autism in society.	1	1	0	0
22. Services need to ensure families are aware of existing adult mental health services.	0	0	0	0
23. Helping parents to step back and young people to take more responsibility is a critical area of support needed.	0	0	0	0
24. More specialist adult autism services need to be created.	2	1	0	1

25. Transfer to adult services should happen routinely for all young people instead of needing to seek a referral for support from mental health services.	2	2	0	0
26. Providing individualized support for all demographics of autistic people (e.g. autistic females, black and minority ethnic autistic people, autistic people without learning disability, autistic adults) is a critical area of support needed.	1	1	0	0
27. Helping young people to know when and how to actively seek support for themselves is a critical area of support needed.	6	3	1	2
28. There needs to be more investment into NHS services to improve access to services and availability of resources.	2	1	0	1
29. Having universally accessible forms of support (e.g. online information and advice) is a critical support for young people.	0	0	0	0
30. Having easy access to non-statutory organisations (e.g. community groups, charities, youth groups) is a critical support for young people.	0	0	0	0
31. Having easy access to educational support (e.g. special educational needs coordinator, tutors, autism champion positions) is a critical support for young people.	2	0	1	1
32. Having easy access to support at university (e.g. career support, mental well-being, mentors, educational accommodations) is a critical support for young people.	0	0	0	0
33. Having easy access to employment support (e.g. job interview preparation, liaison with managers, general employment skills) is a critical support for young people.	1	1	0	0
34. Planning for the transition to adulthood should start when young people begin secondary school.	1	0	0	0
35. Planning for the transition to adulthood should start when young people turn 14.	0	0	0	0

36. Planning for the transition to adulthood should start when young people are preparing to finish compulsory education.	0	0	0	0
37. Planning for the transition to adulthood should start when young people have reached an appropriate level of maturity to manage adult tasks, meaning the decision should not be based on age.	0	0	0	0
38. When planning for transition, making sure the process happens gradually and not suddenly is crucial.	0	0	0	0
39. When planning for transition, ensuring young people have enough time to process information and change is crucial.	0	0	0	0
40. When planning for transition, having clear goals and breaking down the steps to achieve them is crucial.	0	0	0	0
41. It is critical for autism to be formally diagnosed early in childhood for young people to better understand themselves and receive early intervention.	1	1	0	0
42. It is critical for families to be signposted to appropriate services and be provided with information leaflets.	0	0	0	0
43. It is critical for families to have a transition checklist as a tool to help young people during the transition to adulthood.	0	0	0	0
44. It is critical for families to receive support for a broad range of needs in one centralized service.	0	0	0	0
45. It is critical for families to have a single point of contact to coordinate support from different services.	2	0	1	1
46. It is critical for all different adults caring for a young person (e.g. family, teachers, social workers, doctors) to be involved in planning discussions.	0	0	0	0

47. Regular liaison between education and healthcare professionals is a key factor in supporting young people.	4	1	1	2
48. Financial support from the government is a key factor in supporting young people in transition.	0	0	0	0
49. Having a dedicated transition worker or access to a specialist transition team is a critical factor for young people.	0	0	0	0
50. A directory of local support services available to young people and their families should exist for each county/London borough.	5	2	1	2
51. It would be helpful to implement more mentor schemes for young people to access for support.	4	1	2	1
52. Services should offer workshops for young people and their families on topics voted for by service users e.g. Daily living skills, Relationships, Jobs.	1	1	0	0

Appendix S: End of study notification letter sent to REC, HRA and R&D

Dear colleagues,

I am writing to provide a summary of the research project conducted sponsored by Canterbury Christ Church University.

Title

Transition to adulthood: Developing a consensus on support for autistic young people without learning disability in the UK

Background

The transition to adulthood can be difficult for autistic young people without a learning difficulty, who often lose support from services at 18. Research findings reporting poor outcomes in adulthood for this population are common. Whilst barriers to transition are known, knowledge of facilitators is limited. This study aimed to explore the experiences of key stakeholders to understand which factors are agreed to represent a successful transition, what support is needed and what resources are most important.

Method

In total 46 stakeholders were recruited to this study. Stakeholders were defined as autistic young adults without a learning disability (n=19), caregivers of autistic young people without a learning disability (n=11) and healthcare clinicians working with autistic young people without a learning disability (n=16). Participants completed either two or three online questionnaires. A three round Delphi method was used. The initial qualitative questionnaire was analysed using thematic analysis to develop a second quantitative questionnaire. A third questionnaire finalised consensus across stakeholders. Data collection took 10 months in total.

Results

Overall consensus was high: 40/52 statements achieved a strong consensus across experts, 4/52 reached moderate consensus, 1/52 reached weak consensus and 7/52 reached no consensus. Every statement achieving consensus reflected agreement across stakeholders. The full list of statements that reached agreement across stakeholders is shown below.

Amongst several statements that reached strong consensus, three were voted as most important. It was agreed that ‘understanding themselves and their needs’ is key to a successful transition, and ‘helping young people to know when/how to seek support for themselves’ is core support. It was agreed a directory of local support services is a needed resource.

It is believed that the findings of this study will help services to improve the support offered to autistic young people and their families during the transition to adulthood in the future. Further research is required to operationalise and evaluate key facilitators of a successful transition to adulthood for AYP.

Ideas that reached strong consensus across expert groups

Critical factors related to Personal Qualities and Relationships:

- Young people need to build up their self-esteem to be successful in adulthood.
- Being able to manage difficult emotions.
- Understanding themselves and their needs.
- Being able to maintain friendships and positive peer relationships.

- The well-being of other family members is important to consider when young people transition to adulthood.
- Talking to trusted adults, such as professionals or mentors.

Critical factors related to Goals for Daily Living:

- Practicing daily living skills (e.g. hygiene, shopping, cooking, managing finances).
- Daily living skills should be taught as part of the curriculum in secondary school.
- Keeping physically healthy and safe.
- Engaging in meaningful activities and hobbies.
- Enabling and encouraging young people to make decisions and advocate for themselves.

Critical factors related to Inclusivity:

- Social inequalities and stigma are the biggest barriers preventing young people from successfully transitioning to adulthood.
- More needs to be done to ensure autistic people receive equal opportunities to non-autistic people.
- Training and education regarding autism should be delivered routinely within organizations.
- There should be more initiatives to improve awareness and understanding of autism in society.

Critical factors relating to Areas of Development for Mental Health Services:

- Services need to ensure families are aware of existing adult mental health services.
- Helping parents to step back and young people to take more responsibility.
- More specialist adult autism services need to be created.
- Transfer from child to adult services should happen routinely for all young people instead of needing to seek a referral for support from mental health services.
- Providing individualized support for all demographics of autistic people (e.g. autistic females, black and minority ethnic autistic people, autistic people without a learning disability, autistic adults).
- Helping young people to know when and how to actively seek support for themselves.
- There needs to be more investment into NHS services to improve access to services and availability resources.

Critical factors relating to Other Sources of Support:

- Having universally accessible resources (e.g. online information and advice).
- Having easy access to non-statutory organisations (e.g. community groups, charities, youth groups).
- Having easy access to educational support (e.g. special educational needs coordinator, tutors, autism champion positions).
- Having easy access to support at university (e.g. career support, mental well-being, mentors, educational accommodations).
- Having easy access to employment support (e.g. job interview preparation, liaison with managers, general employment skills).

Critical factors relating to Views on Transition Planning:

- Planning for the transition to adulthood should start when young people have reached an appropriate level of maturity to manage adult tasks, meaning the decision should not be based on age.
- When planning for transition, making sure the process happens gradually and not suddenly.
- When planning for transition, ensuring young people have enough time to process information and change.
- When planning for transition, having clear goals and breaking down the steps to achieve them.

Critical factors relating to Helpful Tools and Processes:

- For autism to be formally diagnosed early in childhood for young people to better understand themselves and receive early intervention.
- For families to be signposted to appropriate services and be provided with information leaflets.
- For families to receive support for a broad range of needs in one centralized service.
- For families to have a single point of contact to coordinate support from different services.
- Regular liaison between education and healthcare professionals.
- Having a dedicated transition worker or access to a specialist transition team.
- A directory of local support services available to young people and their families should exist for each county/London borough.
- It would be helpful to implement more mentor schemes for young people to access for support.
- Services should offer workshops for young people and their families on topics voted for by service users e.g. Daily living skills, Relationships, Jobs.

A summary of the study has been shared with all participants. Participants are aware that this research will be submitted to a relevant journal.

Yours sincerely,

Hannah Bowman

Trainee Clinical Psychologist
Salomons Institute for Applied Psychology

Appendix T: Submission guidelines for Autism (SAGE journals)

1. What do we publish?

1.1 Aims & Scope

Before submitting your manuscript to Autism, please ensure you have read the Aims & Scope.

There is no need to submit a pre-submission enquiry to the journal, and in fact we discourage this as our scope is clearly stated at the link above.

It is journal policy for all submitted manuscripts to be screened by an Editor who will decide whether to send the manuscript for review. In this screening process, Editors will focus on:

- fit with the journal aims and scope, and listed Article Types (see below)
- relevance to autistic people's quality of life
- justification of the research question
- relevance and quality of the methods and analysis methods for the topic under study
- validity of the conclusions in relation to the methods and findings
- quality of the writing
- potential for practical impact

1.2 Article Types

The Journal considers the following kinds of article for publication:

Research Reports. Full papers describing new empirical findings. These papers may present quantitative and/or qualitative data. In each case, the methods should be carefully selected to address the research question being posed, with due justification being given for: needfulness of the research; relevance to autistic people's quality of life; appropriateness of the sample size and diversity; quality of the methods; robustness of the analysis methods; validity of the conclusions.

Fundamental or basic scientific discoveries can be considered for publication but need to make a convincing case for relevance to autistic people's lives, especially if future implementation of the discovery is still far off.

Research Reports are generally restricted to a maximum of 6,000 words, including all elements (title page, abstract [200 words maximum], notes, tables, text), but excluding references. Editors may ask authors to make certain cuts before sending the article out for review

Before submitting a Research Report, please make sure to review the author guidelines, and especially section 2.8 for our reporting expectations.

Review Articles. General reviews that provide a synthesis of an area of autism research. These will normally be systematic but narrative and/or focused reviews can be considered if the authors make a convincing case for their ability to address a gap in knowledge.

Review Articles are generally restricted to a maximum of 6,000 words, including all elements (title page, abstract [200 words maximum], notes, tables, text), but excluding references. Editors may ask authors to make certain cuts before sending the article out for review.

Before submitting a Review, please make sure to review the author guidelines and especially section 2.8 for our reporting expectations.

Short Reports. Brief papers restricted to a maximum of 2,000 words with no more than two tables. The title should begin with 'Short Report'. Short reports also report empirical findings from quantitative and / or qualitative data, but these may be preliminary, low-impact, or otherwise less substantial than a Research Report. Another reason to submit a Short Report is if your rationale, methods and findings are simple and neat. If your paper can be reported within the 2000 word limit we would encourage you to do so.

Letters to the Editors. Readers' letters should address issues raised by articles published in our journal, or issues in the field of autism research more generally. The issues should be contextualised within the literature to permit readers to draw general conclusions. Letters might cover: discussions of existing debates in the literature, articulations of new or controversial ideas, comments on work published in our journal, theoretical perspectives, methodological or conceptual critiques, The decision to publish is made by the Editors, in order to ensure a timely appearance in print. Letters should be no more than 1000 words, with no tables and a maximum of 5 references.

Registered Reports, Pre-Data or Post-Data:

There are two types of Registered Reports:

- Registered Reports – Pre-Data, i.e., before any data have been gathered
- Registered Reports – Post-Data, i.e., before already existing data have been examined and analysed.

These submissions are reviewed in two stages. In Stage 1, a study proposal is considered for publication prior to data collection and/or analysis. Stage 1 submissions should include a complete Introduction, Methods, and Proposed Analyses. High-quality proposals will be accepted in principle before data collection and/or data analysis commences. Once the study is completed, the author will finish the article including Results and Discussion sections (Stage 2). Publication of the Stage 2 submission is guaranteed as long as the approved Stage 1 protocol is followed and the conclusions are appropriate. Full details can be found here. The Journal's manuscript requirements should be adhered to for the stage 2 submission.

1.3 Writing your paper

The Sage Author Gateway has some general advice and on how to get published, plus links to further resources. Sage Author Services also offers authors a variety of ways to improve and enhance their article including English language editing, plagiarism detection, and video abstract and infographic preparation.

1.3.1 Make your article discoverable

When writing up your paper, think about how you can make it discoverable. The title, keywords and abstract are key to ensuring readers find your article through search engines such as Google. For information and guidance on how best to title your article, write your abstract and select your keywords, have a look at this page on the Gateway: How to Help Readers Find Your Article Online.

2. Editorial policies

2.1 Peer review policy

Autism operates a strictly anonymous peer review process in which the reviewer's name is withheld from the author and, the author's name from the reviewer. The reviewer may at their own discretion opt to reveal their name to the author in their review but our standard practice is for both identities to remain concealed. Each new submission is carefully read by one of the Editors to decide whether it has a reasonable chance of getting published, consulting with other Editors if and when they feel it is necessary. Our Editors strive to make this initial review within two weeks after submission, so that authors do not have to wait long for a rejection. In some cases, feedback may also be provided on how to improve the manuscript, or what other journal would be more suitable. The criteria used by the Editors when determining what to reject or send for review as described here [https://journals.sagepub.com/author-instructions/aut#Aims-Scope]. Each manuscript which passes this initial screening, is sent out for peer review by at least two referees. All manuscripts are reviewed as rapidly as possible, and an editorial decision is generally reached within (e.g.) 6-8 weeks of submission.

2.2 Authorship

All parties who have made a substantive contribution to the article should be listed as authors. Principal authorship, authorship order, and other publication credits should be based on the relative scientific or professional contributions of the individuals involved, regardless of their status. A student is usually listed as principal author on any multiple-authored publication that substantially derives from the student's dissertation or thesis.

Please note that AI chatbots, for example ChatGPT, should not be listed as authors. For more information see the policy on Use of ChatGPT and generative AI tools.

2.3 Acknowledgements

All contributors who do not meet the criteria for authorship should be listed in an Acknowledgements section. Examples of those who might be acknowledged include a person who provided purely technical help, or a department chair who provided only general support.

Please supply any personal acknowledgements separately to the main text to facilitate anonymous peer review.

2.3.1 Third party submissions

Where an individual who is not listed as an author submits a manuscript on behalf of the author(s), a statement must be included in the Acknowledgements section of the manuscript and in the accompanying cover letter. The statements must:

- Disclose this type of editorial assistance – including the individual's name, company and level of input
- Identify any entities that paid for this assistance
- Confirm that the listed authors have authorized the submission of their manuscript via third party and approved any statements or declarations, e.g. conflicting interests, funding, etc.

Where appropriate, Sage reserves the right to deny consideration to manuscripts submitted by a third party rather than by the authors themselves.

2.4 Funding

Autism requires all authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit the Funding Acknowledgements page on the Sage Journal Author Gateway to confirm the format of the acknowledgment text in the event of funding, or state that: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

Important note: If you have any concerns that the provision of this information may compromise your anonymity, you should withhold this information until you submit your final accepted manuscript.

2.4.1 National Institutes of Health (NIH) funded articles

If you have received NIH funding for your research, please state this in your submission and if your paper is accepted by *Autism* an electronic version of the paper will automatically be sent to be indexed with the National Library of Medicine's PubMed Central as stipulated in the NIH policy.

2.5 Declaration of conflicting interests

Autism encourages authors to include a declaration of any conflicting interests and recommends you review the good practice guidelines on the Sage Journal Author Gateway. In particular, for working reporting on the development or evaluation of interventions the ICJME Conflict of Interest form provides an excellent template for considering a range of potential sources of conflict, and this can be uploaded and submitted with your manuscript if relevant.

Where an Editor of Autism is a lead or contributing author to a paper submitted to publication, the paper is always handled through the peer review process by another member of the Editor team and three reviews are obtained in each case. A statement is also published on each article where this occurs.

2.6 Research ethics and patient consent

Medical research involving human subjects must be conducted according to the World Medical Association Declaration of Helsinki

Submitted manuscripts should conform to the ICMJE Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals, and all papers reporting animal and/or human studies must state in the methods section that the relevant Ethics Committee or Institutional Review Board provided (or waived) approval. Please ensure that you have provided the full name and institution of the review committee, in addition to the approval number.

For research articles, authors are also required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal.

Information on informed consent to report individual cases or case series should be included in the manuscript text. A statement is required regarding whether written informed consent for patient information and images to be published was provided by the patient(s) or a legally authorized representative.

Please also refer to the ICMJE Recommendations for the Protection of Research Participants

2.7 Clinical trials

Autism conforms to the ICMJE requirement that clinical trials are registered in a WHO-approved public trials registry at or before the time of first patient enrolment as a condition of consideration for publication. The trial registry name and URL, and registration number must be included at the end of the abstract.

2.8 Reporting guidelines

2.8.1 Transparent reporting of trials

The relevant EQUATOR Network reporting guidelines should be followed depending on the type of study. For example, all randomized controlled trials submitted for publication should include a completed CONSORT flow chart as a cited figure and the completed CONSORT checklist should be uploaded with your submission as a supplementary file. Systematic reviews and meta-analyses should include the completed PRISMA flow chart as a cited figure and the completed PRISMA checklist should be uploaded with your submission as a supplementary file. The EQUATOR wizard can help you identify the appropriate guideline.

The What Works Clearinghouse (WWC) guidelines should be followed when submitting in single-case design (SCD) and meet the standards outlined for internal validity of the SCD.

Other resources can be found at NLM's Research Reporting Guidelines and Initiatives

2.8.2 Sample selection and demographic characteristics

Autism now requires authors to report the following information for all Research Reports (including systematic reviews):

i. procedures for sample selection and recruitment; and
ii. major demographic characteristics, including age, gender, race/ethnicity and socioeconomic status.

Including this information will provide greater clarity regarding sample characteristics and generalisability of the findings, even when such characteristics are not used in the analysis (although we encourage investigation of subgroup differences, where possible). It should also encourage researchers to consider the way in which context and culture contribute to their findings.

If authors are unable to report some or all of this information, its absence must be acknowledged with a clear statement of explanation (e.g., "specific data on socioeconomic status and educational attainment levels were not recorded"). Manuscripts that contain neither the required information nor an appropriate statement will be returned prior to consideration by the editors.

2.8.3 Community involvement

Autism encourages research that is actively carried out 'with' or 'by' members of the Autistic and autism communities (rather than 'to', 'about', or 'for' them), often referred to as 'co-production', 'participatory research', 'patient and public involvement' or 'integrated knowledge translation'.

We therefore now require authors to include a community involvement statement at the end of the Methods section for Research Reports, outlining whether autistic people or family members, community providers, policy makers, agency leaders or other community stakeholders were involved in developing the research question, study design, measures, implementation, or interpretation and dissemination of the findings. Community members should be duly acknowledged – as authors or in the acknowledgements section – depending on the extent and nature of their contribution. We recommend that authors follow the BMJ's editorial guidelines for documenting how community stakeholders were involved in their research.

If community members were not involved in the study, authors should state this.

For more details about the reasoning behind this journal requirement, and editorial expectations of authors, please download this FAQs document.

2.9 Data Policy Statement

Autism supports open research practices and FAIR principles. As such encourages authors to share their data wherever possible and submit their data (or a link to it) and where applicable, their syntax/command files for the analyses presented in the contribution. Authors can make data available through a third party data repository or on the journal website as a supplementary data file.

If cited data is restricted (e.g. classified, require confidentiality protections, were obtained under a non-disclosure agreement, or have inherent logistical constraints), authors should notify the editor at the time of submission. The editor shall have full discretion to follow their journal's policy on restricted data, including declining to review the manuscript or granting an exemption with or without conditions. The editor shall inform the author of this decision prior to review.

Where data is sensitive and cannot be shared in an open forum, authors are encouraged to share metadata and provide a contact for requesting access if the raw data itself cannot be made available.

Data can be submitted with your article and hosted on the Sage *Autism* website where we work with Figshare to host data content. Authors can use a recognised third party data repository service to host their data such as Open Science framework. Authors may use their institution's data sharing repository.

Autism also encourages authors to delineate clearly the analytic procedures upon which their published claims rely, and where possible provide access to all relevant analytic materials. If such materials are not published with the article, we encourage authors to share to the greatest extent possible through a digital repository (above).

Autism encourages authors to use data citation practices that identify a dataset's author(s), title, date, version, and a persistent identifier. In sum, data should be referenced and cited, where possible, as an intellectual product of value.

3. Publishing Policies

3.1 Publication ethics

Sage is committed to upholding the integrity of the academic record. We encourage authors to refer to the Committee on Publication Ethics' International Standards for Authors and view the Publication Ethics page on the Sage Author Gateway.

3.1.1 Plagiarism

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