

Draft paper Young people with autism spectrum disorder

Title: Predictors and experience of transfer of young people with ASD from child and adolescent mental health services.

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Abstract

Transition to adulthood can be difficult for young people with ASD, as they juggle the challenges of adolescence and navigate leaving child and adolescent mental health services (CAMHS). This analysis describes the experiences and outcomes of a sample of UK young people aged 14-21 years, with ASD and additional mental health problems, as they were discharged from CAMHS. The young people were followed over 3 years. Measures of mental health and qualitative contextual (clinical, family, social, educational) information was used to capture their experiences. Having an ADHD diagnosis and taking medication were predictors of transfer to adult mental health services. The qualitative themes allowed us to understand the young people's transition experiences and identify variables associated with positive outcomes and ongoing problems.

Introduction

Transition into adulthood involves a number of different developmental tasks, including entering further education or employment, having meaningful social participation, and developing independent living skills or leaving home.¹⁶⁴ Transition for young people with autism spectrum disorder (ASD) to adulthood has been a topic of increased interest as it becomes evident that it can be a particularly difficult period for individuals and their families.¹⁶⁵ Some of these difficulties include low rates of post-secondary education and employment,¹⁶⁶ low social participation,¹⁶⁷ higher rates of bullying,¹⁶⁸ and struggles gaining autonomy and independence in young adulthood.^{169, 170} These difficulties have been identified for young people with high functioning ASD when compared with equally able young people in the general population.¹⁷¹

One aspect that may make transition particularly difficult for this group is the presence of additional commonly occurring comorbidities, including mental health problems such as attention deficit hyperactivity disorder (ADHD), anxiety, and emotional disorders.¹⁷²⁻¹⁷⁴ As well as managing several major life transitions, these young people with ASD and additional mental health problems also have to navigate the transition from children and adolescent mental health services (CAMHS).¹⁷⁵ Healthcare providers, parents and young people have reported concerns about healthcare transitions, in particular those with high functioning ASD.^{175, 176} Studies of the experiences of young people with ASD (without intellectual disabilities), and their parents, as they negotiate transition into young adulthood, report that the uncertainties about the challenges of accessing appropriate support and services was a worry, particularly in terms of the potential negative impact on the young person's wellbeing and mental health.¹⁷⁷ The presence of co-morbidities together with an ASD diagnosis may also be acting as an additional barrier to finding meaningful day time activities and potentially result in lower levels of social participation.¹⁷⁸

Most young people in England and Wales attending CAMHS are discharged to primary care services (family practitioner) rather than being referred onto adult mental health services (AMHS).¹⁷⁹ This can be due to a variety of reasons including no longer needing clinical mental health involvement, presenting problems not meeting criteria for AMHS, or disengagement from services.¹⁸⁰ For some young people discharge to primary care is an appropriate course of action. However, in a UK study of young people with ongoing mental health disorders, certain groups of young people such as those with emotional, neurodevelopmental (including ADHD and ASD), or emerging personality difficulties were found to be at an increased risk of not accessing adult services and were described as 'falling through the CAMHS-AMHS gap'.^{179, 181} There is then a concern that for some of these young people with neurodevelopmental disorders, their unmet mental needs may increase their risks of poorer outcomes with low levels of participation and wellbeing compared to other young people, crisis presentations at accident and emergency departments, or contact with criminal justice system. These young people may then at a later date be at an increased risk of presenting to adult services following a crisis, or with more serious and enduring mental health problem.

For young people with ongoing mental health needs that are referred from CAMHS to AMHS, poorly planned transitions can make the shift from the child-centred developmental approach of CAMHS to the adult-centred care of AMHS difficult for both the young people and their families.⁵ There are also reports of unmet need and dissatisfaction with care.¹⁸² This applies especially to young people with ASD who report a lack of support for both the ASD and the mental health problem, particularly when services are designed for neurotypical individuals.¹⁸³

In one UK study investigating predictors of service use outcomes for young people discharged from CAMHS,¹⁷⁹ found that being on medication at the time of transition and having a severe or enduring mental health condition, such as schizophrenia, bipolar affective disorder and psychotic disorders, were predictors of transfer to AMHS. This might raise an expectation that young people with ASD and ADHD and in particular those in receipt of regular medication, would be referred on to AMHS. However according to the UK NICE clinical guideline for individuals (children and adults) with ADHD (albeit not necessarily with additional ASD), shared care agreements with primary care (family practitioner) should exist.¹⁸⁴

Not all young adults with ASD experience an exacerbation of their difficulties when they are transitioning to adulthood. For some, outcomes (e.g. education, employment, independent living and social participation) in adulthood are more positive, for example with meaningful employment and independent living being achieved in adulthood. Farley¹⁸⁵ in a US study of 41 adults with average or near average cognitive abilities (mean age 32.5 years) highlighted the importance of community support and integration in increasing social participation. Kirby¹⁸⁶ in a systematic review of predictors of successful social outcomes in young adults with ASD, identified five conceptual categories: 'personal characteristics' (e.g. age, gender and race), 'individual functioning' (e.g. IQ, diagnosis/severity), 'family context' (e.g. household income, educational level of parents), 'services' (e.g. career counselling), and 'other' (e.g. general health). The review also identified varying levels of evidence for these predictors of successful outcome and highlighted a need for more high-quality research on outcomes for adults with ASD to inform practice, especially in relation to factors related to the family and services received. However, outcomes need to be defined and assessed in a more nuanced manner taking into account the preferences of individuals with ASD and their families, for instance in terms of what is achievable and preferable for each individual rather than simply comparing across population norms.¹⁸⁷

This paper uses data from a recently completed UK longitudinal study of young people with long term conditions (diabetes, cerebral palsy and ASD with additional mental health problems). We were able to review, over a 3-year period, the outcomes of the group of young people with ASD and additional MH problems as they were discharged from CAMHS. The aim of this secondary analysis was to identify those young people with ASD who transferred from CAMHS to AMHS, and to compare their levels of achievement and need with those who were discharged to primary care and those who remained in CAMHS beyond age 18 years. This analysis is intended to inform future practice, especially in respect to identifying how best to facilitate appropriate transition arrangements for this group of young people as they are discharged from CAMHS.

Methods

Young people aged 14-18 years, with a diagnosis of ASD who were accessing CAMHS for an additional mental health problem, were recruited to the Transition Longitudinal project (<http://research.ncl.ac.uk/transition/>) between October 2012 and October 2013. All were referred as in the average ability range, and able to complete questionnaires (with or without support). Young people were recruited from mental health clinical services in three different parts of England. The young people were visited once a year for 3 years (four visits in total) and asked to complete several questionnaires. Full details of the study protocol have previously been published⁶¹ and baseline characteristics of the sample.⁶²

The study received a favourable ethical opinion from Newcastle and North Tyneside 1 Research Ethics Committee. Numbers 12/NE/0059 and 12/NE/0284. All young people provided signed consent to join the study. For young people under sixteen years of age, the young people signed an assent form and a parent provided signed consent for their child to join the study.

Measures

The following measures were completed at each visit:

Sociodemographic Questionnaire: Using a bespoke questionnaire we collected data on gender, education and employment status, and socioeconomic status (postcodes used to calculate the 'index of multiple deprivation' (IMD), higher scores indicate more socioeconomic deprivation.⁶⁹

*Hospital Anxiety and Depression Scale (HADS)*⁸⁰: a 14-item questionnaire completed by the young people measures the severity of mental health problems with two subscales of *anxiety* and *depression*. Total scores can be categorised into 'normal' (0-7), 'borderline abnormal' (8-11) and 'abnormal' or clinical caseness (12-21). An initial validation study of this questionnaire has shown excellent psychometric properties in samples of older adolescents and young adults with ASD.⁸¹

*Warwick and Edinburgh Mental Wellbeing Scale (WEMWBS)*⁷⁷: a 14-item, questionnaire (also completed by the young people), developed in the UK and valid in the age range 13 to 21 years that captures young people's mental wellbeing. The scale had good internal consistency supporting the suitability of this measure for this group.

The Strengths and Difficulties Questionnaire (SDQ)^{188, 189} SDQ: was completed by both the young person and the parent.

*Social Responsiveness Scale*¹⁹⁰: This measure was completed by the parents and was used to confirm autism characteristics.

Information collated by the research assistants:

Information derived from clinical case notes: Before each of the follow-up visits the trained research assistants (RA) with the young people's consent, accessed the clinical mental health case notes to record details of appointments including whether the appointment was attended, medication prescriptions given, and diagnoses. This information was used to determine a date of final appointment in children's services (described as date of transfer).

Qualitative Data: At each visit the RAs made notes of contextual information about each young person, their family, and service provision (e.g. family issues, changes in school or service provider, comments about access to and lack of support or problems at school). Information was also recorded from clinical mental health case notes that was relevant to the process of transition, referrals made, and issues discussed during clinical appointments. The RAs recorded descriptions of difficulties and complexities for the young person, their family and relevant professionals together with positive successes and achievements for the young people.

Data Analysis

Quantitative Data Analysis: SPSS version 23 was used for data analysis. Descriptive statistics of education and employment status, age, gender, transfer location, age at transfer, medication use, additional mental health problem(s) and measures of mental health are presented. Logistic regression was used to identify predictors of transfer from CAMHS to either AMHS or discharge to primary care (family practitioner).

Qualitative Data Analysis: Framework analysis¹⁹¹ was used to consider all the available recorded contextual data for young people and their families. Authors 1 and 2 familiarised themselves with the data, noting initial emerging themes. Themes were informed by the authors' knowledge of the literature. A thematic framework was then developed and applied to the data. The data were presented as a table with each row representing a participant and each column representing a theme. This allowed each theme to be summarised and for exploration of patterns and associations in the data. A 10% sample was double sorted to ensure consistency and reliability. These themes were then refined into categories which are presented below. Any differences were discussed and resolved through consensus. The themes and categories were reviewed and finalised with the fifth author.

Mental Health Trajectories:

To help us understand further the interaction of the young people's self-reported mental health and their transition to adulthood over the 3-year study period, we reviewed the trajectory of the young people's HADS scores for those who completed HADS data on at least three of the four visits (n=87). The HADS is a measure of each young person's mental health status for the week prior to each research visit. Using the sequence of each young person's self-reported HADS scores, young people were grouped into three types of trajectories: those *doing well* with 'normal' HADS scores across all visits or showing improvement from abnormal or borderline abnormal scores to normal scores at the final visit; those with *continued moderate difficulty*, who continued to have borderline abnormal mental health problems over the visits or fluctuated between borderline and abnormal scores; and those who were *not doing well* where the young person reported continued abnormal HADS scores or had a decrease in scores over the study period ending with a score in the abnormal range. The trajectory of each young person was individually assessed by the first two authors and a consensus agreed.

Results

Baseline Demographics

In total, 118 young people with ASD and additional mental health problems were recruited and completed baseline measures (mean age: 16.1yrs, range: 14yrs-18.9yrs). Eighty-two (69.5%) of the sample were male, 36 (30.5%) female, and nearly all were white British (98.3%). At baseline the majority of young people were in full time education (either school or college; 93.2%). A small number of the young people had a part time job (6%) or did some volunteer work (2.6%).

All the young people had a diagnosis of ASD at recruitment and were accessing CAMHS for support with additional mental health problems. The mean total young person -reported SDQ score at baseline was 17.6 (SD = 6.1), parent reported SDQ was 22.8 (SD = 5.9), and the mean SRS score was 117.2 (SD = 29.7). SDQ scores of our sample were found to be significantly higher (indicating greater severity) than scores of a subset of young people aged 16 years with ASD from the UK Special Needs and Autism Project (SNAP) community sample.¹⁷⁴ The young people's median wellbeing score (WEMWBS) at baseline was 47 (IQR: 41–52), significantly below population norms¹⁹² and remained significantly below population norms at all visits.

Out of the 118 young people recruited, 88 completed a final visit. As previously reported, there were no significant differences between those who remained in the study and those who withdrew from the study in terms of condition severity or socio-demographic factors.

Transfer Location

Of the 30 young people who withdrew from the study, information was available for five subjects on their transfer location and so were included in the analyses. For the 93 young people for whom transfer data was available, 20 young people were still accessing CAMHS, 48 had transferred to primary care, and 25 had transferred to AMHS. Table 16 compares the characteristics of the young people by transfer location.

Table 16: Characteristics of sample by transfer location

Transfer location	CAMHS	General practitioner	AMHS
	(final visit data)	(pre-transfer visit data)	
	<i>N</i> (%)	<i>N</i> (%)	<i>N</i> (%)
	20	48	25
Gender			
Male	16 (80)	31 (65)	16 (64)
Female	4 (20)	17 (35)	9 (36)
Age at visit before transfer			
Mean	17.7	17.4	18.2
Range	16.13 - 20.30	14.7 – 19.75	16.5 – 19.9
SD	0.89	0.89	0.69
WEMWBS ¹			
Mean (SD)	49.4 (7.47)	45.6 (8.00)	46.52 (10.17)
Range	28-58	29-60	27-70
IMD at baseline			
Mean (SD)	18.98 (11.36)	23.94 (18.133)	24.45 (18.74)
Range	2.46-38.82	2.17-80.51	3.72-71.83
Prescribed medication	16 (80)	27 (56)	20 (80)
Education and employment			
Full/Part Time Education	15 (75)	41 (85.4)	21 (84)
Employed	4 (20)	1 (2)	2 (8)
Not In Education Or Employment	1 (5)	6 (12.5)	2 (8)
Number of mental health problems			
1	8 (40)	27 (56)	15 (60)
≥2	12 (60)	16 (33)	10 (40)
Mental health problem			
ADHD/ADD	12 (60)	8 (16.7)	15 (60)
Mood ^a	2 (10)	18 (38)	7 (28)
Anxiety ^b	9 (45)	22 (46)	6 (24)
Odd/Challenging Behaviour ^c	2 (10)	5 (10)	1 (4)
Sleep disorders ^d	6 (30)	7 (15)	4 (16)
Other ^e	4 (20)	1 (2)	3 (12)
Self-harm	(5)1	2 (4)	5 (20)
HADS (Anxiety)			
<8	7 (35)	20 (42)	10 (40)
≥8	13 (65)	28 (58)	15 (60)
HADS (Depression)			
<8	18 (90)	39 (81)	17 (68)
≥8	2 (10)	9 (19)	8 (32)
Developmental disorder^f	3 (15)	5 (10)	5 (20)
Physical health problem^g	11 (55)	12 (25)	10 (40)

¹Significantly below population norms across all groups

^a Depression, low mood; ^b Anxiety, Obsessive Compulsive Disorder, phobia, social anxiety;

^c Oppositional Defiant Disorder, Conduct Disorder, challenging behaviour, behavioural problems, aggression, anger management problems; ^d Insomnia, requiring melatonin

Conversion disorder, psychosis (1 young person), chronic fatigue syndrome

^f Dyslexia, dyspraxia, dyscalculia, Developmental Coordination Disorder

^g asthma, epilepsy (1 young person), allergies, migraines, thyroid dysfunction

The logistic regression findings are presented in Table 17. Overall the model was significant in predicting transfer outcome, $\chi^2(7)=18.58$, $p=0.010$. Nagelkerke R^2 indicates that the model explains 32% of the variation in outcome. The odds of being transferred to adult services were significantly greater for those young people who had a diagnosis of ADHD (OR= 8.22 (95% CI=2.33-29.02) $p=0.001$) and young people who were prescribed medication for their mental health problem (OR=3.99 (95% CI=1.00-15.95), $p=0.05$).

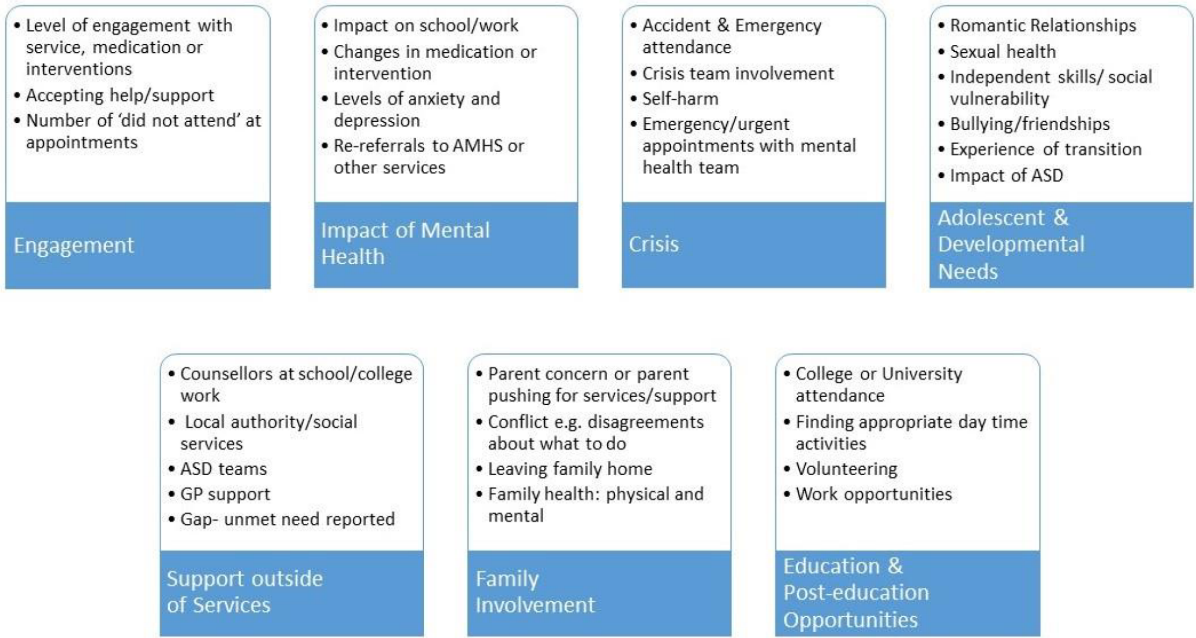
Table 17: Logistic Regression for predictors of transfer location

Variable	N (%)	OR (95% CI)	Significance
	71		
Prescribed medication			
Yes	47 (66)	3.99 (1.00-15.95)	0.05
No	24 (34)		
Additional mental health problem			
ADHD	23 (32)	8.22 (2.33-29.02)	0.001
Not ADHD	48 (68)		
Number of mental health problems			
1	45 (63)	1.04 (0.31-3.43)	0.95
≥ 2	26 (37)		
HADS anxiety		1.06 (0.89-1.25)	0.53
HADS depression		1.03 (0.85-1.26)	0.75
WEMWBS		1.04 (0.94-1.15)	0.51
IMD score (baseline)		0.99 (0.96-1.03)	0.71

Qualitative Analysis

Framework analysis was used to explore the qualitative data using all available visits of the 118 young people who joined the study. Twenty-four themes were identified and then summarised into seven categories that described the young people's and their parents' experience of transition during their time in the study (see Figure 14).

Figure 14: Categories from framework analysis



The framework identified a number of themes related to the young people's mental health including their level of engagement with mental health services, engagement with medication and/or interventions, and times of crisis where their mental health problems resulted in emergency department attendance, self-harm or crisis team involvement. Other themes related to developmental and adolescent factors such as school transitions, seeking employment and managing social relationships, describing both successes in these areas as well as the difficulties experienced by some of the young people. How the young people experienced their ASD symptomology and how this impacted on developmental transitions and their transition from CAMHS was a theme of considerable significance for both young person and families. Some broader themes around family support and family health were raised, as well as the parents' concerns about the young person's social/emotional maturity and vulnerability as they dealt with the discharge from CAMHS and the wider agenda of transition of their child into adulthood.

Mental Health Trajectory

Using the sequence of each young person's self-reported HADS scores, young people were grouped into three types of trajectories: those *doing well* (N=23), those with *continued moderate difficulty* (N=29), and those who were *not doing well* (N=30). There were no significant differences in transfer outcome, age, baseline SRS scores, or additional mental health diagnoses between the three groups. However there were some differences between the groups in terms of WEMWBS, SDQ scores and gender (Table 18): the WEMWBS scores was significantly lower in the '*not doing well*' group compared to the other groups across all time points; those in the '*doing well*' group reported significantly lower baseline SDQ scores than the other two groups (add test and level of significance), and there were significantly more females in the '*not doing well*' group. Using the combination of the different data sources enabled appreciation of the experiences of the young people, their families and clinicians (see Table 18) across the three HADS groupings.

Table 18: Differences between HADS trajectory groups

	Doing well	Moderate difficulty	Not doing well	
	N (%)	N (%)	N (%)	
CAMHS	6 (26.1)	5 (17.2)	7 (23.3)	
Transfer location				
Primary care	10 (43.5)	15 (51.7)	16 (53.3)	$\chi^2(2)=0.53, p=0.77$
AMHS	7 (30.4)	9 (31)	7 (23.4)	
Gender				
Female	3 (13)	9 (31)	18 (60)	$\chi^2(2)=13.0, p=.002$
Male	20 (87)	20 (69)	12 (40)	
	Mean (SD)	Mean (SD)	Mean (SD)	
Young person SDQ total¹	14.17 (3.6)	19.49 (4.5)	20.38 (6.7)	$F(2,77)=10.3, p<0.001$
Parent SDQ total¹	22.09 (5.3)	22.45 (5.3)	22.23 (6.9)	$F(2,74)=0.02, p=0.98$
SRS scores¹	114.41 (19.7)	123.41 (27.9)	109.38 (31.8)	$F(2,77)=1.85, p=0.16$
WEMWBS²				
Visit 1	49.96 (7.8)	44.0 (8.2)	42.57 (9.0)	$F(2,79)=5.3, p=0.007$
Visit 2	52.27 (6.9)	45.25 (8.4)	41.89 (9.1)	$F(2,75)= 8.8, p<0.001$
Final visit	53.96 (8.1)	46.61 (7.6)	41.32 (10.3)	$F(2,76)=13.1, p<0.001$

¹ Higher scores reflect more difficulties on the SDQ and greater social impairment on the SRS

² Higher scores reflect better mental wellbeing

SDQ Strength and difficulties questionnaire

SRS Social responsiveness scale

WEMWBS Warwick Edinburgh Mental Wellbeing Scale

HADS 'doing well' group

Most young people were described in the clinical mental health case notes as well engaged with mental health services. They were said to be 'doing well' and/or coping well with their current treatment regime (with or without medication). There were very few reports about needing to access urgent care or incidents of self-harm or overdoses.

'Young person now uses Cognitive Behavioural Therapy (CBT) techniques on his own to manage his condition/anxiety/OCD symptoms when needed'

Notes suggested that individuals in this group were accessing a range of support services in addition to mental health services. These included school counsellors, social services and community ASD teams. Some young people described how they had decided not to attend an assessment in AMHS as their clinician discussed that they may not meet AMHS criteria.

The clinical records also indicated that the clinicians were considering some of the broader needs of young people. For example, there were comments about trying to encourage the young person to increase their independence in appointments and become more aware of their ASD, and how their diagnosis may be affecting them.

'Discussed...current romantic relationship: 'emotional distress tends to be focussed around his girlfriend, who was also a close family friend' - talked about how his Asperger's might affect his relationship'

Notes contained evidence that some young people were engaged in developmentally appropriate tasks. Some were beginning to be involved with romantic relationships, several were attending mainstream college following leaving school, but few had made the transition to university by the end of the study. Overall, in addition to positive references to levels of engagement with services, there appeared to be evidence of more stability in terms of education achievements and family life in this group compared to the other two groups. In summary, the data suggest that individuals in this group were learning to manage their mental health concerns, developing an awareness of the impact of their ASD and learning to negotiate, with support, some developmentally appropriate aspects of transition to adulthood.

HADS moderate difficulty group

For some young people, the clinical mental health case notes referred to problems with attendance and poor engagement with CAMHS over the three years of the study. In some cases these problems led to discharge from services. The pattern of the mental health needs appeared to fluctuate, with requests for urgent appointments, changes in types and doses of medication, and sudden events including self-harm attempts.

'Young person not doing so well at the moment'

There were also notes about changes in family circumstances, such as parents being ill (physically or mentally) or parents separating. These changing circumstances may well have contributed to some of the fluctuations young people experienced in their mental health.

As with the 'doing well' group, there were comments about young people not transferring to AMHS due to not meeting criteria or opting to not go for assessment. However, in this group there were also comments about families feeling unsupported as a consequence of either infrequent appointments or of being discharged from CAMHS.

'They only see someone once every 6 months or so now which parents have indicated that they don't feel is enough and dad especially would like more help with transitioning to adulthood and support with work etc. Currently see a different doctor every time they go so feel it is very impersonal.'

The young people were recorded as accessing a range of other community services, both in childhood and post 18 years in adult services- counsellors at school or through primary care, psychological wellbeing services and Improving Access to Psychological Therapies (IAPT) services (an adult community Cognitive Behaviour Therapy provision).

In terms of the other activities, there were comments from the parents of young people in this group with concerns about their child's independence skills (e.g. ability to leave home). Some of the young people had been in vulnerable situations (e.g. one young person had been led into messaging inappropriate images). Many of the young people had made the transition from school to college and some had hopes of applying for university. However, unlike the young people in the previous group, several of these young people had attended special needs schools and so through education services they had received additional support from, for example, occupational therapists and/or speech and language therapists during school hours. Some young people went on to experience considerable challenges as they transitioned to, and also in, their post-school education placements - for example those who had taken up a university placement often took some time to settle in and were accessing available support services.

'Young person is now at university. Had a few panic attacks to begin with but is doing ok. He has a counsellor at university.'

Others had experienced disruptions in their education provision, for example, being out of education for some time as a consequence of bullying or being expelled from a previous school. One young person also expressed feeling unsupported with job applications and requested help with interview skills.

HADS 'not doing well' group

The young people in this group experienced higher rates of crisis situations (such as episodes of self-harm or overdoses and suicide attempts) than young people in the other groups. Some had experienced episodes of inpatient hospital care while for others, police had been involved due to concerns about their risk-taking behaviour.

Concerns were also raised about poor attendance and compliance at health service appointments. Some young people refused treatment options or support and for some their level of disengagement led to premature discharge from CAMHS. Many young people and their families frequently reported a strong sense of feeling unsupported by services and described negative experiences with clinicians.

'He is now regularly seeing a Psychiatrist for talking therapy to help him deal with his anxiety. Mum feels this could have been avoided if he had received more help following child services rather than having a gap.'

Within this group it also appeared that their ASD was having a greater impact on their progress than the other two groups. There were several comments from the clinical records of the young people being given details of ASD teams to access for support around this. For example, some of the young people were accessing services/support for training in friendships, socialising and independence skills.

'Given literature from NAS [UK National Autistic Society] and list of books specific to ASD. Referral to Social Eyes service designed to help people with ASD to develop their social understanding and social skills.'

This group were also accessing more specialist services such as drug and alcohol support services or anger management teams. Discussions that had been had in appointments were recorded in the clinical notes about how illicit drug use would be interacting with their medication and mental health.

Although many young people were at school and college, there were comments about struggles to find appropriate placements for college or reports about time out from education. Others had been expelled or had dropped out of education due to difficulties. Encouragingly a couple of the young people had been able to obtain full-time work with the help of family members following dropping out of education.

'Young person was expelled from college so waiting to see if he can go back in the near future or September. He is now working full time with his dad.'

Discussion

The aim of this study was to identify predictors of transfer location and to understand the experience of transition in a sample of young people with ASD and additional mental health problems. In the three-year Transition Longitudinal study just over a third (35.3%) of the young people over 17 years transferred to AMHS and 64.7% transferred to primary care. The logistic regression analysis showed that only a diagnosis of ADHD and taking prescribed medication was a predictor of transfer location, explaining 32% of the variance. The qualitative analysis provided additional insights into potentially important individual, family and wider developmental and contextual themes that related to transfer location and provided valuable insights into young people's experience of transition.

The finding that an ADHD diagnosis, as well as whether the young person was receiving prescribed medication, predicted whether young people transfer into AMHS may reflect UK ADHD NICE guidelines (NG 87, NICE 2018). NG87 recommends that both diagnosis of ADHD and the initiation of drug treatment should only be initiated by an appropriately qualified healthcare professional with expertise in ADHD, and that continued prescribing and monitoring of drug therapy may be performed by primary care physicians, under shared care arrangement with the specialist services¹⁸⁴. In an audit undertaken in the North West of the UK, only 15% of young people with a diagnosis of ADHD (from an eligible sample of 104 adolescents) were successfully referred and transferred to a specialist adult ADHD clinic, though it is unclear whether this sample included young people with coexisting ASD. Singh¹⁷⁹ also highlighted the problems for young people with neurodevelopmental disorders (both ADHD and /or ASD) achieving successful transfer to AMHS. Our findings seem to buck this trend. We are aware that within the mental health NHS organisations involved in the Transition Longitudinal Study, local arrangements for the management of young people and adults with ADHD were under review. For example, in one organisation a decision was made, during the course of the study, for CAMHS to take on the adult ADHD follow up clinics. It still remains unclear whether UK AMHS are adequately resourced to provide diagnostic and follow up clinics for adults with ADHD and additional co-occurring conditions including ASD and other behavioural and mental health problems. Certainly, within our sample, parents and young people commented that six 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 problems and other social and educational needs.

Interestingly, none of the other factors that we had identified as potential markers of severity or vulnerability (number of co-morbid problems, SES, HADS, wellbeing) predicted transfer to AMHS. Much has been written about the limited access to AMHS for young people with a range of mental health problems (ASD and additional mental health problems, other neurodevelopmental disorders (such as ADHD), emotional disorders and emerging personality disorders).^{179, 181} In UK the eligibility criteria for accepting a referral to an AMHS can vary but tends to be restricted to those suffering severe and enduring mental illness such as psychosis and severe depression. This may mean that some young people who reach the age of 18 years may find that, although their mental health problems do not suddenly change, they cannot access an ongoing mental health service.¹⁴ Of course, not all young people with mental health problems will either want or need to be transferred to AMHS. For some, discharge to primary care may be the appropriate pathway, especially if the young person is coping well with their ongoing mental health problems, adhering to treatment/medication and doing well at school/college. As was seen in the qualitative analysis, some of the young people and their families opted not to be referred to AMHS due to the likelihood of not meeting criteria, or due to no further clinical need. However, the qualitative analysis also identified a sub-set of young people where the pathway of discharge to primary care was not successful. These young people accessed crisis teams several times or received time-limited support in AMHS before being discharged again.

Further, for some young people and their families in this sample, engagement with services was a more longstanding problem. For these young people, if they had not engaged with CAMHS, this usually resulted in discharge to primary care - a finding consistent with the UK TRACK study.¹⁸⁰

Overall, the young people in our sample appeared to be doing reasonably well, with 67.5% in full time education (either school or college) at the end of the study. Under a third of our sample were in neither education nor employment. The analysis of the HADS trajectories also confirmed that some young people appeared to be doing well, managing their mental health, and able to engage successfully with services. These young people and their families also had not apparently experienced additional crises or life events. However, across all HADS groups, the majority of young people were experiencing episodes or continued levels of high anxiety. Thus, despite what appears as positive outcomes for young people (e.g. attending higher education), the HADS trajectories and qualitative data showed that the young people were struggling, particularly when faced with more challenging academic and social educational environments (such as university). Our data also highlight that females seem to be at increased risk of falling into the '*not doing well group*'. This finding needs further consideration in larger samples of able young people with ASD. However, it is in keeping with recent studies and the increased awareness of the social and emotional needs of females with ASD, and especially those of normal ability, who may struggle to understand their own mental health needs.^{193, 194}

How should we identify those young people (both male and female) that might be particularly at risk through transition? Our data suggest that engaging with young people, and using a regular self-report check such as the HADS (which the young people in this study were able to complete at each annual follow up visit), may help young people and the professionals supporting them to identify their own trajectory, the impact of individual and family life experiences, and any mental health needs that may be helping or hindering their personal goals and achievements.

The key themes emerging in the qualitative data included engagement, broader ASD social and emotional developmental needs, impact of family, and personal events which seem to adversely affect functioning. Consistent with previous research, positive influences on the young people's experience of transition seem to be the ability to participate socially, engage consistently and constructively with services, positive support including employment opportunities from family, and other community resources including education.¹⁸⁶

The qualitative data also revealed a common concern of ‘unmet need’ and/or ‘lack of support’ irrespective of whether the young person had been discharged to primary care or AMHS. These unmet needs were usually around broader aspects of functioning relevant to the young person’s diagnosis of ASD, rather than just their mental health difficulties. These identified unmet needs reflect findings from other research where young people of normal intellectual ability with ASD can fall short of criteria for access to community learning disability or more specialist ASD services as well as mental health service.¹⁶⁹ Access to local community support around interpersonal support, advice and information especially if the services have expertise in working with young adults with ASD and their families, could help reduce this unmet need.¹⁹⁵

Strengths and Limitations

This study is a secondary analysis of data collected during the Transition Longitudinal study. The sample of young people with ASD and additional mental health problems is relatively small (93 in total), all were of normal ability and recruited from four mental health NHS clinical services across the UK. This means that the findings have limited generalizability when considering young people with ASD across the ability range. Further, although the qualitative data were consistently collected by the trained RAs from clinical mental health notes and during the interactions with young people and their families, the data were not primarily obtained for the purpose of this analysis. Therefore, some aspects of the young people’s experience of transition over the three years of the study may not have been recorded. Finally, although the young people have been successfully followed up, the sample remains relatively young (aged 14-17 years at recruitment). Thus, although all young people were approaching or had experience of planning for or achieving discharge from CAMHS, 20 young people had not left CAMHS by the end of the study and we do not have follow up information for any individuals over the age of 21 years.

Conclusion

Despite the observations that the young people in this sample (all of whom had one or more mental health problems) consistently reported lower mental wellbeing than other young people of similar age and ability, two-thirds of the sample were in education or higher education by the end of the three year follow up period. For some young people, discharge from CAMHS was seen as a new beginning as they moved onto higher education opportunities, gained a growing understanding about how to manage their mental health difficulties and gradually acquired the adaptive life skills to address their developmental needs. For others, and perhaps especially for the females in the sample, ongoing mental health difficulties, social, emotional and relationship needs (particularly associated with ASD), and a feeling of lack of understanding and a perceived absence of professional understanding about their and their families’ level of unmet need with regard to both mental health and local authority services, resulted in a negative experience of transition. In our sample, encouragingly, it was a relatively small number of individuals who had multiple negative experiences of services, struggled with engagement, felt unsupported, and presented with multiple crises over the study period. We propose that the use of a tool such as the HADS may be a useful adjunct for individuals and their supporting clinicians to identify patterns of functioning over time; the monitoring may help identify those young people especially at risk of negative outcomes and crisis presentations. Successful transfer to AMHS is one aspect of mental health support but these services currently vary according to local service design. Further, both AMHS and primary care may or may not include expertise in ASD. This study confirms the need to increase community practitioner clinical skills relevant to young people with ASD and additional mental health problems. Our findings also suggest the potential benefit of a more nuanced approach to identifying and prioritising the needs of those young people at greatest risk of poor outcomes. Clinicians and other professionals with specialist expertise could then support these young people and their families identify and prioritise their goals for timely community support before they are discharged from CAMHS. The longer-term impact of this prioritisation of resource use would need to be evaluated.