

# Do demographic, and clinical characteristics influence meeting NICE quality standards for young people transitioning to adult intellectual disability services?

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## Abstract

**Purpose** – This study aims to evaluate the quality of transition from child and adolescent services to adult intellectual disability services, using the relevant National Institute for Health and Care Excellence (NICE) standard (QS140). In addition, this study also identifies any differences in transition quality between those young people with intellectual disability with and without autism.

**Design/methodology/approach** – Using routinely collected clinical data, this study identifies demographic and clinical characteristics of, and contextual complexities experienced by, young people in transition between 2017 and 2020. Compliance with the quality standard was assessed by applying dedicated search terms to the records.

**Findings** – The study highlighted poor recording of data with only 22% of 306 eligible cases having sufficient data recorded to determine compliance with the NICE quality standard. Available data indicated poor compliance with the standard. Child and adolescent mental health services, generally, did not record mental health co-morbidities. Compliance with three out of the five quality statements was higher for autistic young people, but this only reached statistical significance for one of those statements (i.e. having a named worker,  $p = 0.02$ ).

**Research limitations/implications** – Missing data included basic clinical characteristics such as the level of intellectual disability and the presence of autism. This required adult services to duplicate assessment procedures that potentially delayed clinical outcomes. This study highlights that poor compliance may reflect inaccurate recording that needs addressing through training and introduction of shared protocols.

**Originality/value** – To the best of the authors' knowledge, this is the first study to examine the transition process between children's and adults' intellectual disability health services using NICE quality standard 140.

**Keywords** Learning disability, Mental health, Young people, Adolescent, Autism, NICE quality standards

**Paper type** Research paper

(Information about the authors can be found at the end of this article.)

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## Introduction

Transition to adult services is recognized to be difficult for young people and their families, with some of the problems identified being poor communication between services (Gauthier-Boudreault *et al.*, 2021; Culnane *et al.*, 2020; Brown *et al.*, 2019; Franklin *et al.*, 2019), a relative lack of appropriate adult services (Piccoli *et al.*, 2020; Culnane *et al.*, 2020;

[Shanahan et al., 2020](#)), difficulty in accessing adult services due to restrictive access criteria ([Young-Southward et al., 2017](#); [Belling et al., 2014](#); [Barron et al., 2013](#)) and loss of integrated health care ([Brown et al., 2019](#)). [Sloper et al. \(2010\)](#) in their wide-ranging study of the impact of transition teams on the effectiveness of transition for young people found a high level of unmet need including factors impacting on mental health. They found that having a named transition worker significantly improved the transition experience for young people and their families.

All this can result in poor experience of care, unmet needs and poorer health outcomes for transitioning young people, including poorer mental health ([Brown et al., 2019](#)).

In England, the provision of National Health Service (NHS) mental health services for children and young people with intellectual disability, including for those with autism, is typically delivered by child and adolescent specialist mental health services and is separate and distinct to those provided for adults with intellectual disability. Child and adolescent specialist services are provided by child and adolescent intellectual disability services or child and adolescent mental health services (CAMHS) in conjunction with paediatricians, but on reaching 18 years of age this ends and the child is transferred to adult intellectual disability services and general practice through a transition process.

Good practice, as identified in the Children's and Families Act and the Care Bill ([Learning Disability Professional Senate, 2019](#)), is for the transition process to commence early, minimize disruptions during transition for the young person and support long-term outcomes. This is operationalized within guidance provided by the National Institute for Health and Care Excellence [National Institute for Health and Care Excellence (NICE), 2016a, 2016b]. However, local clinical experience suggests that young people with intellectual disability often experience similar difficulties to the transition processes as identified above.

Adherence to good practice principles according to National Institute for Health and Care Excellence (NICE) quality standards, by mental health services in the transition for young people with intellectual disability has not been empirically studied before using recorded data within a single NHS organization which provides both child and adult services for people with intellectual disabilities. We, therefore, examined the transition process for young people with intellectual disability across a large UK-based NHS provider of community and hospital-based mental health services in the North West area of England. We observed demographic and clinical characteristics of the study population, along with compliance of the services with the national guidelines relevant to the transition from children's services to adult intellectual disability services (i.e. NICE quality standard 140). In addition, we also examined any differences in quality statement compliance between those with or without autism.

## Methods

The study was a cross-sectional study using primary demographic data and secondary data recorded on the electronic patient record for young people with intellectual disability who transitioned from CAMHS to adult intellectual disability services. The study was conducted in a large UK-based NHS provider of community and hospital-based mental health services in the North West of England serving a population of approximately 1.5 million. Routinely collected data were extracted from the electronic patient record used in both children's and adults' intellectual disability services across the NHS provider Trust for the calendar years 2017 – 2020. The NHS Trust Health Records Policy requires all patient contacts and communication to be recorded at the time of contact and thus the routinely recorded data should reflect actual practice, enabling adherence to the quality standards to be measured.

The data variables for the study included demographics characteristics, namely, age at the point of transfer, gender, ethnicity and indices of multiple deprivation (IMD); IMD deciles were sourced from participants' postcodes using <https://imd-by-postcode.opendatacommunities.org/imd/2019>.

The clinical characteristics examined included level of intellectual disability, autism diagnosis, co-existing mental health diagnosis and contextual complexity factors. The diagnoses were made according to International Classification of Disease (ICD) 10th Revision as recorded in the electronic patient record (World Health Organization, 1993). Data describing contextual complexity factors of relevance to the well-being of children was also drawn from the electronic patient records. These factors, which constitute the "Current View" information, fell within the domains of family/carer context (e.g. social service input, young carer status, parental health and financial difficulties), physical health comorbidity, trauma (e.g. refugee/asylum seeker and experience of war/torture) and conduct problems (e.g. contact with youth justice system). The electronic patient record was interrogated using the search function to identify the relevant population and the demographic and clinical characteristics. A further keyword search was used to identify compliance to the quality statements.

We carried out descriptive statistical analysis to summarize the demographic profile of the population, their clinical characteristics and compliance with the quality statements. Where appropriate, we used Chi square tests to compare compliance with the quality standard based on the level of intellectual disability and the presence or absence of autism. We used a  $p$ -value of 0.05 for significance level. We used *Stata Statistical Software: Release 17*. College Station, TX: StataCorp LLC. (StatCorp, 2021) for statistical analysis.

## Results

### *Demographic characteristics of the study population*

Over the four years included in the study, 306 young people with intellectual disability transitioned from children's mental health services to adult intellectual disability services. The majority were male (63%) and for the total cohort ethnicity was not recorded for 13% of the population. Where it was, it was primarily white British (79%) with this increasing to over 90% for those where clinical complexities were identified.

There was no statistically significant difference in the distribution of deciles of IMD across the overall cohort, in the cohort with complete clinical and contextual complexity data, among those with intellectual disability alone, and among those who also had autism (Table 1).

Complete data was available for only 67 (22%) of those transitioning to adult services; this included, clinical characteristics and contextual complexities, recorded in the electronic patient record. Of those with complete data, the majority were autistic (64%), and male (63%); approximately one-third of the young people were referred to adult services before the age of 18 years with this increasing to 41% for young people with intellectual disability alone and 43% for those who also have autism (Table 1).

### *Clinical characteristics of the study population*

In almost half of the cohort (46%) with data on clinical characteristics ( $N = 67$ ), the level of intellectual disability was not recorded. Of the young people with a recorded level of intellectual disability, four out of five had mild or moderate intellectual disability; this was similar for autistic adults with intellectual disability (Table 2). Mental health co-morbidities were present in 28%; this went up to 35% in autistic adults with intellectual disability. Where mental health co-morbidities were identified, these were primarily the ICD-10 diagnoses F40–49 (anxiety disorders) and F90–99 (behavioral and emotional disorders with onset in childhood). Of the contextual complexity factors recorded, 60% were deemed as "child in

**Table 1** Demographics of young people in transition from children’s mental health services to adult intellectual disability services from 2017 to 2020 with intellectual disabilities and with autism (N = 306)

Demographic	All young people		Young people with incomplete data		Young people with ID with complexities		Young people with ID with complexities and Autism	
	N	(%)	N	(%)	N	(%)	N	(%)
<i>Total</i>	306	(100)	239	(100)	67	(100)	43	(100)
<i>Age</i>								
16	18	(6)	12	(5)	5	(8)	4	(9)
17	77	(25)	55	(23)	22	(33)	15	(35)
18	129	(42)	99	(41)	31	(46)	18	(42)
19	81	(26)	9	(4)	9	(13)	6	(14)
Missing	1	(0)	64	(27)				
<i>Gender</i>								
Male	194	(63)	152	(64)	42	(63)	32	(74)
Female	112	(37)	87	(36)	25	(37)	11	(26)
<i>Ethnicity</i>								
White	242	(79)	179	(75)	63	(94)	40	(93)
Asian	9	(3)	8	(3)	1	(2)	1	(2)
Mixed	8	(3)	7	(3)	1	(2)	1	(2)
Unknown	37	(12)	35	(15)	2	(3)	1	(2)
Missing	4	(1)	10	(4)				
<i>Indices of multiple deprivation</i>								
1–2	81	(26)	59	(25)	23	(34)	12	(28)
3–4	54	(18)	43	(18)	11	(16)	8	(19)
5–6	39	(13)	33	(14)	6	(9)	4	(9)
7–8	56	(18)	46	(19)	10	(15)	7	(16)
9–10	72	(24)	57	(24)	15	(22)	10	(23)
Missing	4	(1)	1	(<1)	2	(3)	2	(5)

need,” 30% had serious physical health issues including chronic fatigue, 27% had experience of abuse and 27% had parental health issues. For autistic adults with intellectual disability, 42% were deemed as “child in need,” 20% had serious physical health issues and 13% had an experience of abuse (Table 2).

### *Compliance with the National Institute for Health and Care Excellence guideline*

We found generally low compliance to the NICE guideline for transition (Table 3). There was very low compliance to quality statement one (start of the transition planning at the age of 14 years). Compliance to quality statement two (annual meeting to review transition), three (named worker to coordinate care) and four (introduction to adult services’ worker before transition) was found in around half the young people in transition. Although quality statement five appears to show low compliance, this records a low level of missed first appointments in adult services.

There was no significant difference in compliance between young people with only intellectual disability and autistic young people with intellectual disability for quality statements two and four. However, for the quality statement three, there was a statistically significant difference ( $p = 0.02$ ) with more young people with autism having a named worker to coordinate care through the transition process.

### **Discussion**

This is the first study in the UK to look at the transition data to examine compliance with NICE quality standard 140 for young people in transition from child to adult mental health

**Table 2** Clinical characteristics of young people who have clinical complexities (*n* = 67) in transition from children's mental health to adults' intellectual disability services

Clinical characteristic	Total		ID with Autism	
	<i>n</i>	(%)	<i>n</i>	(%)
<i>Learning disability</i>				
<i>Mild</i>	16	(24)	11	(26)
<i>Moderate</i>	13	(19)	11	(26)
<i>Severe</i>	8	(12)	6	(14)
<i>unrecorded</i>	30	(46)	15	(35)
<i>Co-morbidities (F70–79 and F80–89 are absent as they identify ID and autism)</i>				
<i>Present</i>	19	(28)	15	(35)
<i>Absent</i>	48	(72)	28	(65)
<i>ICD 10 codes for co-morbidities (multiple response)</i>				
<i>F20–29</i>	1	(2)	0	(0)
<i>F30–39</i>	2	(3)	0	(0)
<i>F40–49</i>	8	(12)	1	(2)
<i>F50–59</i>	2	(3)	1	(2)
<i>F60–69</i>	1	(2)	0	(0)
<i>F90–99</i>	9	(13)	2	(3)
<i>Complexity factors on current view</i>				
<i>Child looked after</i>	10	(15)	6	(9)
<i>Young carer status</i>	0	(0)	0	(0)
<i>Serious physical health issues (including chronic fatigue)</i>	20	(30)	13	(20)
<i>Neurological issues (e.g. Tics or Tourette's)</i>	7	(10)	6	(9)
<i>Current protection plan</i>	1	(2)	1	(2)
<i>Deemed "child in need" of social service input</i>	40	(60)	28	(42)
<i>Refugee or asylum seeker</i>	0	(0)	0	(0)
<i>Experience of war, torture or trafficking</i>	0	(0)	0	(0)
<i>Experience of abuse or neglect</i>	18	(27)	9	(13)
<i>Parental health issues</i>	18	(27)	9	(13)
<i>Contact with youth justice system</i>	1	(2)	1	(2)
<i>Living in financial difficulty</i>	0	(0)	0	(0)

**Table 3** Compliance to QS140 standard

NICE quality standard QS140 statements	Total ( <i>n</i> = 67)		ID with Autism ( <i>n</i> = 43)		<i>p</i> -value
	<i>N</i>	(%)	<i>N</i>	(%)	
<i>QS1 – Transition planning starts by age 14</i>	2	(3)	1	(2)	0.67
<i>QS2 – Annual meeting to review transition</i>	36	(54)	26	(60)	0.14
<i>QS3 – Named worker to coordinate care before, during and post transition</i>	35	(53)	27	(63)	0.02
<i>QS4 – Introduction to adult services worker before transition</i>	32	(48)	23	(54)	0.21
<i>QS5 – Adult services follow up missed appointments post transfer</i>	6	(9)	4	(9)	0.89

services. Given the extent of the missing data, caution needs to be exercised when generalizing to clinical populations. Nevertheless, there are five key findings.

First, there was a large amount of missing data for young people with intellectual disability coming through transition. Where there was relatively more information, details like ICD-10 diagnosis were missing for some. There are several possible explanations. It is possible that children's services tend not to record ICD-10 diagnoses routinely, hence, the relatively small number of ICD-10 categories used. Children's mental health services are organized differently with different teams being involved based on the level of intellectual disability of the young person. This might result in differing approaches to recording data or data being

lost during transition. It is also possible that the missing data was due to how and where it was recorded on the electronic patient record system.

Second, there were more males than females coming through transition. This difference was even more marked for autistic young people with intellectual disability (Table 1). Our 2:1 ratio of male to female for young people with intellectual disability without autism was markedly lower than the 4:1 ratio previously described in an intellectual disability population (Manakshi *et al.*, 2013), but closer to the 3:2 ratio found in Hourigan *et al.*'s (2017) study. The 3:1 male to female ratio for young people with intellectual disability and autism is in line with previous studies where there were three times the number of males to females (National Autistic Society, 2015; Loomes *et al.*, 2013).

The higher numbers of males being transferred to adult services is broadly in line with expectations from the literature. In our study, the higher numbers of males may be explained by both children's and adults' services primarily supporting people with emotional and behavior disorders where these issues are seen less frequently in females.

Third, very few mental health comorbidities were recorded as ICD-10 codes for the study cohort or for those young people who also had autism. The two areas with higher prevalence were anxiety disorders, and behavioral and emotional disorders with onset in childhood. However, a very small proportion of autistic young people coming through transition had these diagnoses. This prevalence is lower than expected and far below the level where 80% of people with an intellectual disability had at least one psychiatric comorbidity (Turygin *et al.*, 2014). A systematic review of children and adolescents with autism supported this prevalence with studies showing 0%–82% diagnosed with anxiety and between 0 and 39% diagnosed with depression (Bougeard *et al.*, 2021). The numbers of young people with a diagnosis of Attention Deficit Hyperactivity Disorder (ADHD) (F90–99) was lower than expected at 13% overall and 3% for those with autism and intellectual disability (Table 2) in contrast to the findings of Antshel *et al.* (2016) where the majority of people with autism also had ADHD symptoms.

Lower than expected numbers of recorded mental health comorbidities could be due to high levels of missing data, and although the study cohort of 67 had relatively more complete data (and their demographic data was similar to the overall numbers making the transition from child to adult services), it is likely that the low number of comorbidities reflected this pattern of data not being recorded.

In addition, child and adolescent services recorded data differently. They recorded complexities, including autism, using the "Current View" section of the electronic patient record. "Current View" also included problem descriptors that highlighted co-morbid mental health difficulties; this might have led professionals not to record ICD-10 diagnoses separately, or not to routinely record ICD-10 coding for autism or for other mental health conditions. Community services for adults with intellectual disability did not use "Current View" and used ICD-10 coding. This suggestion is also supported by the high numbers of young people where no level of intellectual disability was recorded.

There might be an additional issue of reluctance on the part of some CAMHS clinicians to use diagnostic labels.

In addition, health needs of children and young people are met through different commissioning arrangements with educational services providing some of the assessments and interventions. This could result in all the information not being available to health services.

We found that only one young person had a comorbidity indicating psychosis (F20–29). This is far below expectations for the general population and especially for intellectual disability population with or without autism, where rates of mental ill health are higher (Dunn *et al.*, 2020). The highest rate of comorbidity found was for behavioral and emotional

disorders with onset in childhood. It is possible that signs and symptoms of psychotic conditions are being recorded as behavioral and emotional disorders with a consequent under diagnosis of psychosis in children and adolescents.

Fourth, most prevalent complexity factors on the “Current View” for those coming through transition with complete records were: being deemed “child in need” for social services input, serious physical health issues, history of experience of abuse and parental health issues. In the absence of high levels of recorded mental health comorbidities, it is possible that those with higher complexity factors were considered as needing transition through to adult community intellectual disability services.

Finally, compliance with the NICE quality standard was poor overall. There was very low compliance with quality statement one (start of transition planning at the age of 14 years). Although compliance with quality statements two (annual meeting to review transition), three (named worker to coordinate care) and four (introduction to adult services’ worker before transition) was better for those with intellectual disability and autism than for those with intellectual disability alone, this difference was only significant for quality statement three, with those with autism more likely to have a named worker. Increase in the compliance to quality statements two to four is reflective of the higher prevalence of complexity factors and with that the requirement for annual review and named workers for those identified as “a child in need.” In line with the recommendations of [Sloper \*et al.\* \(2010\)](#) a higher number of young people were recorded as having a named worker for transition with this being identified as a key factor in the transition experience for young people. Poor overall compliance could be due to lack of awareness of the quality standard, or it could be a result of professionals not reflecting on the complexity and need for robust transition.

There are three clinical implications and recommendations to consider. First, there was high amounts of missing data. This included basic clinical characteristics e.g. level of intellectual disability, presence of autism, etc. Where data was available, there was variation as to how data was recorded. Lack of appropriate recording of data and lack of recording of underlying mental health co-morbidities in a standardized form meant that there was incomplete handover of treatment needs through transitions process. This was likely to have negative impact on the overall health outcomes for the young person coming through transition. It also meant that adult intellectual disability services could not rely on the information coming through transition and would need to reassess needs including mental health needs. This puts unnecessary strain on the adult services resources. It may be that child and adolescent services lack the resource to routinely measure IQ and make an ICD-10 diagnosis of level of learning disability or to assess for and diagnose autism. Services and commissioners should consider how this can be provided whilst in child and adolescent services to make more efficient use of resources and improve the transition process and experience.

Second, child and adolescent services were using “Current View” to understand complexities. This was a useful way to understand the need for wider multiagency input. Such complexity factors are also likely to have an impact on overall health outcomes and health inequalities. This should, along with level of intellectual disability, presence or absence of autism, mental health co-morbidities and underlying physical health conditions form part of all transition processes.

Third, poor compliance with the quality standard would need addressing. Adherence to quality statements would help address other findings of poor practice in the study, including poor recording of the data. It might be that the poor compliance reflects poor recording of the data with workers not realizing the significance of robust transition. This need addressing through education and training. There is also a need for clear protocols and standard operating procedures to ensure consistent recording of data, appropriate use and recording of diagnosis, and for adherence to the quality standard across both child and adult services.

Despite the missing data, the study had some strengths. Finding of large amount of missing data is a significant finding as it highlighted an immediate area for improvement. This will have real benefits for service users. The study collected data systematically and all young people in transition were included. It looked at the complexity factors and compliance with the NICE quality standard and was the first UK study looking at all these factors in a systematic way. The study also followed STROBE guidelines (von Elm *et al*, 2007). However, there were a few weaknesses: missing data made it difficult to make certain interpretations. There was not enough data to see if the level of intellectual disability, and the presence or absence of co-morbid mental health conditions, had an impact on compliance with the NICE quality standard 140 and whether the differences seen were statistically significant.

## Conclusions

In this study, we determined that there was poor compliance to the NICE quality standard 140 for transition from child and adolescent to adult intellectual disability services and that for many young people in transition much of the expected routinely recorded data was missing. This has enabled us to identify areas for improvement in clinical practice and routine data recording in both child and adolescent and adult intellectual disability services. Whilst we have determined that compliance with the quality standard is poor, further research seeking to understand the reasons behind this is indicated. This should include examining clinician's experiences and understanding of the transition process and their responsibilities in this from both children's and adults' services.

Transition is a much wider issue. This study looked at the transition between CAMHS services and adult Community intellectual disability services. Not every child or young person accesses CAMHS services for their health needs. Also, not all the referrals for transition aged young people with intellectual disability come through CAMHS services. To address the barriers to good transition, we do need to understand the needs of the population. For this, we will need further research using data from education and social care services, and from paediatric services. Further work is also needed to understand the awareness among health and social care staff of the NICE quality standards on transition and to understand the challenges they face when working with multiple agencies for seamless transition. It would also be extremely useful to know the experiences of families and carers of transition and involve them in any future service improvement initiatives.

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The study was approved through the NHS Trust's research ethics approval process. Data was extracted and anonymized from the standard electronic patient record system used in routine clinical care. According to the Health Research Authority algorithm (see [www.hra-decisiontools.org.uk/research/](http://www.hra-decisiontools.org.uk/research/)) this study was not defined as research and therefore did not require submission to the Integrated Research Application System (a single system for applying for the permissions and approvals for health and social care/community care research in the UK).

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