ESSS Outline

Mental health of young people with learning disabilities in transition

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Introduction

This evidence summary seeks to address the following question relating to transition for young adults with learning disabilities:

What is the relationship between learning disabilities and mental health for young people, particularly in transitional period? What strategies have been identified in relation to this?

About the evidence presented below

We searched for academic research and grey literature using a wide range of search terms including: comorbidity, developmentally disabled, emerging adults, intellectual disability, learning disabled young people, life stages, life transitions, mental health, psychopathology, school to community transition, school to university transition, school to work transition, transition and young people.

It is acknowledged in the literature that there are a lack of high-quality studies investigating the impact of transition to adulthood on the health of people with learning disabilities (Crane et al. 2018; Cvejic and Trollor 2018; Young-Southward et al. 2017a). Recent studies, such as those conducted by Young-Southward et al. (2017b), aim to address this gap, and research in this area is continuing to develop.

Accessing resources

We have provided links to the materials referenced in the summary. Some materials are paywalled, which means they are published in academic journals and are only available with a subscription. Some of these are available through the The Knowledge Network with an NHS Scotland

OpenAthens username. The Knowledge Network offers accounts to everyone who helps provide health and social care in Scotland in conjunction with the NHS and Scottish Local Authorities, including many in the third and independent sectors. You can register here. Where resources are identified as 'available through document delivery', these have been provided to the original enquirer and may be requested through NHS Scotland's fetch item service (subject to eligibility).

Where possible we identify where evidence is published open access, which means the author has chosen to publish their work in a way that makes it freely available to the public. Some are identified as author repository copies, manuscripts, or other copies, which means the author has made a version of the otherwise paywalled publication available to the public. Other referenced sources are pdfs and websites that are available publicly.

Background

Transition can be broadly defined as the process of moving from childhood to adulthood (Cvejic and Trollor 2018). Young people may experience multiple transitions throughout this developmental period within domains such as school, work, healthcare, housing, and relationships (Stewart et al. 2014). The complexity of this process means that the transition to adulthood can be a challenging period for almost any young person (Biggs and Carter 2016; Forte et al. 2011). While studies indicate that a high prevalence of distress exists among young adults both with and without learning disabilities during this time (Austin et al. 2018), there is evidence that transition-age youth with autism or learning disabilities experience lower quality of life ratings than similar-age youth (Biggs and Carter 2016). Under-diagnosis, reduced treatment accessibility and reduced awareness of comorbid mental health disorders and learning disabilities among young adults can also have a negative impact on this group (Austin et al. 2018).

The studies show that leaving behind the structure and routine of school might trigger mental health issues, such as anxiety and depression, especially if a young person has no daytime activity to replace the school routine, as is more likely to be the case for those with learning disabilities (Young-Southward et al. 2017a). In their qualitative study looking at the worries of transition-aged adolescents, Young et al. (2016) found that those with learning disabilities were significantly more anxious than their non-disabled peers. For young people on the autism spectrum, estimates of co-morbid mental health problems vary greatly from 4–81%, and the most prevalent psychiatric disturbances reported were those related to anxiety and depression (Levy and Perry 2011). Transition can be a notoriously challenging time, with high rates of bullying and victimisation, as well as low rates of post-secondary education, employment and social participation (Crane et al. 2018). The research shows that individuals who lack social connectedness are more likely to experience anxiety, have self-esteem difficulties, and have difficulty trusting others (Stein et al. 2016).

The evidence also describes poorer transition outcomes for young people with learning disabilities compared with those without, with studies demonstrating that individuals in this group are less likely to be employed, to live independently or to experience community participation than their non-disabled counterparts (Young-Southward et al. 2017b). The evidence indicates that individuals with learning disabilities may have limited options for meaningful daytime activity once they leave school, with Scotland's Census indicating that only 4% of individuals with intellectual disabilities in Scotland aged 16-24 were in paid employment full time, 5.6% were in paid employment part time, and 39.9% were students (Scottish Learning Disabilities Observatory 2016). In addition to this, a number of child, family and contextual factors have been identified as increasing the risk of developing mental health problems in adulthood within this population during transition (Levy and Perry 2011).

Moving between services

Youth with disabilities often require multiple supports and services, which are part of multiple systems, which adds to the complexity of transitions (Stewart et al. 2014). This group may confront not only the everyday challenges of growing up and moving from school to further education and employment, but also the challenges of moving from child to adult social care and health services (Mitchell 2015). While the transition to adult adult mental health services is considered an especially critical period, studies suggest that young people may experience a lack of support from services in navigating this (Cvejic and Trollor 2018). In their study looking at the mental health experiences of young autistic adults in England, Crane et al. (2018) found that the poor transition from child to adult services was seen as an area of particular concern, with many young people reporting a sudden decrease in the amount of help and support available. Young people with learning disabilities highlighted these changes in their support networks during transition as an important issue (Young-Southward et al. 2017a).

Impact of family

In their longitudinal study, Wallander et al. (2006) found that parental distress and family dysfunction were risk factors for psychopathology for young people with disabilities. According to Levy and Perry (2011) the following family factors are associated with increased risk of developing mental health problems:

- Family composition
- Harsh child management practices
- Family functioning
- Parental mental health
- Higher number of stressful life events

Individuals from lower socio-economic status families are also at increased risk (Levy and Perry 2011). Other research identifies family involvement as a significant factor in promoting successful transition (Stein et al. 2016).

However, expectations to fulfil adult roles, or in the case of young people with learning disabilities, a lack of expectations, might cause problems within families that could contribute to poor mental health outcomes (Young-Southward et al. 2017a). Transition also often occurs when other family situations are changing, such as siblings moving out of home, or grandparents ageing and requiring increased support, which can create additional strain (Leonard et al. 2016). For parents, the transition period is generally associated with worry and stress. A study conducted by Leonard et al. (2016) found that more than half of participating parents felt that the transition process had impacted on their own daily life and wellbeing and, to a slightly lesser extent, on their families' wellbeing. These issues seemed to be compounded by complex systems, which are meant to assist these families, causing additional stress and worry (Leonard et al. 2016).

Potential strategies

Nguyen et al. (2018) suggest taking a lifecourse approach in the planning and delivery of transition services, stating "youths' needs for services and supports do not cease once they turn 18". Other research highlights issues around the lack of involvement of young people in the transition planning process, with Mitchell (2015) writing that it is often assumed that because of communication difficulties and impaired intellectual capacity, the views of people with a learning disability are either irrelevant or inadequate. Some of the evidence in this summary calls for a broader agenda to overcome social exclusion and limited life opportunities for young people with disabilities (Biggs and Carter 2016; Council for Disabled Children 2011; Forte et al. 2011). The findings from Nguyen et al. (2018) show that it is not enough to build the capacity of the young person making a transition, in fact that can make them frustrated. They state:

> [W]e also must build the capacities of the people in their environments, both the one they are leaving and the one they are transitioning into, to understand, support, and promote the inclusion of youth with disabilities.

Other proposed interventions listed in the evidence below include:

- Treatment programmes that target insight and maladaptive coping and promote resilience to reduce worry (Austin et al. 2018; Forte et al. 2011)
- Improving mental health literacy so young people can identify signs and symptoms of mental illness (Crane et al. 2018)
- Transition planning developed in collaboration with young people (Council for Disabled Children 2011; Francis et al. 2018; Kaehne and Beyer 2014; Mitchell 2015)
- Provision of specialised information and guidance, as well as real-life experiences (Council for Disabled Children 2011; Health and Social Care Alliance 2017; Leonard et al. 2016; Nguyen et al. 2018)
- Interagency collaboration and communication between systems, including clear guidelines to distribute roles and responsibilities (Council for Disabled Children 2011; Harwick et al. 2017; Nguyen et al. 2018; Pallisera 2014)
- Improving access to employment services (Barron et al. 2013; Kaehne and Beyer 2014)

Evidence

We gathered a wide range of evidence for this Outline, including a mix of empirical research and grey literature, which is presented below in two categories. The first section is concerned broadly with the prevalence of mental health problems for young people with learning disabilities and autism, with some studies identifying possible risk factors and outcomes associated with these issues. The second part of this section includes evidence around potential interventions to support young people with disabilities during transition.

It is generally acknowledged in the literature that there are a lack of high-quality studies investigating the impact of transition to adulthood on the health of people with learning disabilities (Crane et al. 2018; Cvejic and Trollor 2018; Young-Southward et al. 2017a). Recent studies, such as those conducted by Young-Southward et al. (2017b), aim to address this gap, and research in this area is continuing to develop.

Learning disabilities and mental health

According to Austin et al. (2018), mental health symptoms in young people with disabilities are often misattributed as inherent to the disability. As a result, mental illness in this group is commonly under-diagnosed, despite some studies showing prevalence of mental health needs of up to 67% (Hassiotis and Turk 2012). This section looks at mental illness in young people with disabilities in more detail. We also included a selection of studies exploring how transition can impact on the wellbeing of young people with disabilities because, as stated by The Mental Health Foundation (2015), experiencing poor mental wellbeing over time can contribute to the development of mental health problems, such as depression or anxiety.

Austin KL et al. (2018) Depression and anxiety symptoms during the transition to early adulthood for people with intellectual disabilities, *Journal of Intellectual Disability Research*, 62(5), pp.407-421 (paywalled)

137 young adult participants aged between 18 and 30 years completed a transition to adulthood questionnaire using a number of different measures, including depressive and anxiety symptoms, coping style, and achieved adulthood. Of these participants, 55 had a learning disability, and they completed additional measures covering cognitive abilities, life events and support needs. The findings indicate that insight and maladaptive coping are the strongest predictors of anxiety and depressive symptoms in young adults with learning disabilities. Young adults with learning disabilities were also less likely to achieve traditional adulthood milestones such as moving out of

the family home, being employed or being partnered and married. Treatment programmes that target insight and maladaptive coping may reduce the high prevalence of anxiety and depressive symptoms in these populations, and may also reduce caregiver burden and improve the transition to adulthood for young people.

Barron DA et al. (2013) Urban adolescents with intellectual disability and challenging behaviour: costs and characteristics during transition to adult services, *Health and Social Care in the Community*, 21(3), pp.283–292 (paywalled)

27 individuals in transition to adult services with challenging behaviour and their family carers agreed to take part in this study. 23 of these participants had mental health diagnoses and 18 had physical diagnoses. Severity of challenging behaviour did not correlate with cost of care. Informal care accounted for the highest proportion of the total cost of care (66%) with education being the second largest contributor at 22%. Evidence on transition outcomes for young people with complex needs and intellectual disabilities and associated costs is lacking. This article illustrates some of the relevant issues in this area.

Biggs EE and Carter EW (2016) Quality of life for transition-age youth with autism or intellectual disability, *Journal of Autism and Developmental Disorders*, 46(1), pp.190–204 (paywalled)

Parents of 389 transition-age youth with autism or learning disability were surveyed in this study using standardised and research-created measures, including those looking at psychological wellbeing and social support. The results show that quality of life ratings were lower for this group than similar-age youth, with the lowest ratings in this sample being social support for young people with autism. Greater involvement in out-of-school activities was associated with higher ratings in the social support domain, such as the participation in community activities. Religious faith and character strengths may also contribute to several areas of quality of life.

Crane L et al. (2018) ‘Something needs to change’: mental health experiences of young autistic adults in England, *Autism*, p.1362361318757048 (author manuscript)

130 young autistic adults took part in the research, with 109 completing an online survey and 21 taking part in detailed interviews. Of the 109 survey respondents, 88 said they had experienced mental health problems, and 49 of these respondents felt their mental health symptoms were different to their ‘normal’. The interviews found that many young autistic people were unsure whether the difficulties they were experiencing were due to their autism or due to mental health problems, and felt that any support offered needed to bridge both autism and mental health, as they were so interlinked. Respondents also felt there was a general lack of available services, both in relation to autism and mental health. The transition from child to adult services was an area of particular concern, with some respondents feeling they were suddenly expected to manage their own mental health independently. High levels of stigma associated with both autism and mental health problems rendered participants less likely to seek personal or professional help for the difficulties they were experiencing. The authors state that improving mental health literacy among this group may help them to identify the signs a symptoms of mental health problems, although there is limited evidence on how best to do this.

Cvejic RC and Trollor JN (2018) Transition to adult mental health services for young people with an intellectual disability, *Journal of Paediatrics and Child Health*, 54(10), pp.1127–1130

Young people with learning disabilities in Australia experience high rates of mental ill health, particularly during the period of transition to adulthood. During this time, young people and their carers have high support needs, but in the transfer from child- to adult-oriented care, these needs are frequently left unmet. Key challenges include:

- Lack of training and capacity of the mainstream mental health workforce
- Differences in service models between child and adolescent and adult mental health services in terms of eligibility, service responsibilities and intensity of support
- Lack of involvement of mental health services in transition planning
- Difficulties with the increased autonomy and responsibility for young people's own health care that comes with adulthood

Forte M et al. (2011) An anxious time? Exploring the nature of worries experienced by young people with a mild to moderate intellectual disability as they make the transition to adulthood, *British Journal of Clinical Psychology*, 50(4), 398-411 (paywalled)

52 participants, including 26 with mild learning disabilities and 26 typically developing adults aged between 17 and 20 years took part in a 'worry' interview. The results show that the group with learning disabilities experienced worries such as being bullied, losing someone they are dependent upon and failing in life, were largely different from their non-disabled peers, which included finding a job and concerns around money. Participants with learning disabilities also reported ruminating significantly more about their worries and being more distressed by them; the authors therefore suggest interventions that target young people's resilience.

Harwick RM et al. (2017) In their own words: overcoming barriers during the transition to adulthood for youth with disabilities who experienced foster care, *Children and Youth Services Review*, 73, pp.338–346 (paywalled)

Semi-structured interviews were conducted with seven young adults who had exited care over a six-month time period. Overall, these findings show that young adults with disabilities transitioning out of foster care hoped to achieve stability and personal fulfillment as independent adults. Participants also identified common barriers encountered including unmet mental health needs and lack of disability awareness or the implications of mental health diagnosis. Personal strengths that helped overcome those barriers included resilience, advocacy, and self-determination.

Hassiotis A and Turk J (2012) Mental health needs in adolescents with intellectual disabilities: cross-sectional survey of a service sample, *Journal of Applied Research in Intellectual Disabilities*, 25(3), pp.252–261 (author manuscript)

In this study, individual assessments of 75 adolescents with learning disabilities aged 12–19 were conducted in West Essex. The main outcome was the presence of mental health needs, as measured by the Developmental Behaviour Checklist. The prevalence of mental health needs in this sample ranged from 51% as reported by parents to 67% as judged by clinical interviews.

Hulbert-Williams L and Hastings RP (2008) Life events as a risk factor for psychological problems in individuals with intellectual disabilities: a critical review, *Journal of Intellectual Disability Research*, 52(11), pp.883–895 (open access)

This narrative review looks at research on life events as they occur to people with learning disabilities. There is reasonable evidence that life events are associated with psychological problems, and there is some tentative evidence that life events play a causal role, although to date, no relationship with psychosis in people with intellectual disabilities has been demonstrated. Services should therefore acknowledge that life events are likely have a detrimental impact on the psychological well-being of their clients.

Leonard H et al. (2016) Transition to adulthood for young people with intellectual disability: the experiences of their families, *European Child and Adolescent Psychiatry*, 25(12), pp.1369–1381 (paywalled)

This mixed-methods study utilised information from two cohorts: young people with Down syndrome in Western Australia (n = 190) and young people with intellectual disability (of any cause) in Queensland, Australia (n = 150). The parent-report questionnaires administered in both states comprised two parts: part 1 collected information about the individual with intellectual disability including information on health, functioning and service needs, and about specific transition related issues; and part 2 collected information about the health and well-being of their family. Many parents raised concerns related to their child’s capacity to cope outside the school system, which for many years had provided structured support and opportunities to learn.

Levy A and Perry A (2011) Outcomes in adolescents and adults with autism: a review of the literature, *Research in Autism Spectrum Disorders*, 5(4), pp.1271–1282 (paywalled)

This paper is a critical review of the studies that have addressed the progress of individuals with autism as they move from childhood and adolescence into adulthood. It looks at the prognosis in this population in terms of diagnostic severity, cognitive functioning, language, academic performance and social outcomes. Overall, studies have shown that outcomes in adolescence and adulthood are highly variable with some individuals improving markedly, others experiencing deterioration in functioning and many continuing a stable maturational course. The literature further suggests that outcomes for this population are dependent on factors such as autism severity, cognitive functioning, language development, additional psychopathology and access to intervention programs and services.

Social Care Institute for Excellence (2017) Transition from child and adolescent to adult mental services: a young person's perspective (video)

Three young people describe how transition from CAMHS felt for them. They discuss the onset of their mental health problems and their experience of transition to adult services, which they describe as scary, confusing, and ‘like falling down a cliff with rocky bits’. Admission to adult wards was particularly frightening. Young people and their families want information, joined up services, and to be listened to.

Stewart D et al. (2014) Complexities during transitions to adulthood for youth with disabilities: person-environment interactions, *Disability and Rehabilitation*, 36(23), pp.1998–2004 (paywalled)

In this study, over 50 people, including youth with different disabilities, parents/caregivers and service providers from different organizations and systems across Canada participated in individual and/or focus group interviews. This exploration revealed important interactions between person and environment that were complex in nature. Daily life experiences, starting in childhood, influence the developmental journey of youth with disabilities: inclusive experiences promote a positive trajectory, but negative experiences and attitudes in the environment around youth can have a negative impact.

Wallander JL et al. (2006) Risk factors for psychopathology in children with intellectual disability: a prospective longitudinal population-based study, *Journal of Intellectual Disability Research*, 50(4), pp.259–268 (paywalled)

This study examined risk factors for the development of psychopathology in children with learning disabilities in the developmental, biological, family and social-ecological domains. 968 children, aged 6-18 , enrolled in special schools in the Netherlands were initially assessed, and 58 % (474 participants) were selected at random and re-contacted about 1 year later. The results show that psychopathy was highly consistent over the year, with risk factors identified as physical symptoms, together with parental distress and family dysfunction.

Young R et al. (2016) Leaving school: a comparison of the worries held by adolescents with and without intellectual disabilities, *Journal of Intellectual Disability Research*, 60(1), pp.9–21 (paywalled)

25 adolescents with mild to moderate learning disabilities and 27 adolescents without IDs, aged 15 to 18 years, took part in structured interviews for this study. Analysis of the interviews identified differences between the worries of the two groups of participants, with the adolescents with learning disabilities expressing more general worries about failure and personal threat. Level of distress about worries was positively correlated with anxiety in both groups. The adolescents with learning disabilities were significantly more anxious than their non-disabled peers.

Young-Southward G et al. (2017a) What effect does transition have on health and well-being in young people with intellectual disabilities? A systematic review, *Journal of Applied Research in Intellectual Disabilities*, 30(5), pp.805–823 (author manuscript)

This systematic review looked at 17 articles about the transition to adulthood for people with learning disabilities. While the results were mixed, these studies suggested the presence of some health and wellbeing issues in this group, with with obesity, sexual health and social conflict being three areas of concern. However, the authors state that the most striking finding of the review overall is the limited quantity of research on this important topic. Given the large variability in study designs and outcome variables, the findings from this review are somewhat inconclusive.

Young-Southward G et al. (2017b) Physical and mental health of young people with and without intellectual disabilities: cross-sectional analysis of a whole country population, *Journal of Intellectual Disability Research*, 61(10), pp.984–993 (paywalled)

Using data drawn from Scotland’s Census, 2011, this study compared health during transition for individuals with and without learning disabilities. A total of 5556 out of 815,889 young people aged 13–24 years had learning disabilities. Those with intellectual disabilities were 9.6–125.0 times more likely to have poor health on seven outcomes (general health, mental health, physical disabilities, hearing impairment, visual impairment, long-term illness and day-to-day activity limitations). Within the population with intellectual disabilities, the 19-to 24-year-olds with intellectual disabilities were more likely to have mental health problems than the 13-to 18-year-olds, but did not have poorer health on the other outcomes. The difference between age groups for mental health problems was greater for young people who did not have intellectual disabilities, but their overall level of mental health problems was substantially lower than for the young people with intellectual disabilities. Given this mental health finding, and the substantial burden of health problems in the youth with intellectual disabilities, it is clear that transition planning at this time of change from child to adult services must be carefully planned in order to ensure that existing health conditions are managed and emerging problems minimised.

Supporting transition

This section includes evidence around potential interventions to support young people with disabilities during transition. According to Leonard et al. (2016) considerable progress has been made in identifying strategies which could aid in the transition period, such as employment preparation programs, social skills training, daily living skills training, self-determination, family involvement and community collaboration. However, it is important to remember that, as stated by Nguyen et al. (2018) “[w]e should not assume we know what is a support or a barrier—we need to ask the person—and not oversimplify these transitions”.

Beyer S and Kaehne A (2008) The transition of young people with learning disabilities to employment: what works?, *Journal on Developmental Disabilities*, 14(1), pp.85–94

This paper examines the transition from school of 87 young people with learning disabilities, with interviews occurring both in their last year of school and six months post graduation. The study also reports on the vocational advice given to students with LD by schools/colleges and external transition support organisations in their last year of school. Differences in the type of activity offered were found for schools/colleges and the external transition support providers. Logistic regression analyses revealed that work experience provided by the external support organizations, as well as work awareness training provided by schools/ colleges were significantly related to subsequent employment.

Council for Disabled Children (2011) Information and learning from the Aiming High for Disabled Children Transition Support Programme (pdf)

This publication identifies five focus areas as a basis for local activity in addressing the challenges of providing transition support. These are:

- Multi-agency partnerships involving adult and child services may contribute to better experiences of transition for young people
- Participation by young people in shaping services can result in more appropriate provision
- Person-centred approaches encourage control and ownership over transition plans
- Improved sharing of assessment processes between agencies can support forward planning, quality assurance and effective commissioning

- Developing employment opportunities for disabled young people and providing specialist information, advice and guidance can improve the transition process

Francis GL et al. (2018) Transition strategies and recommendations: perspectives of parents of young adults with disabilities, *British Journal of Special Education*, 45(3), pp.277–301 (paywalled)

26 parents of graduates from postsecondary education programmes (PSEs) were interviewed for this study. PSEs are college programmes designed to allow young adults with disabilities to gain academic, social, employment, self-determination and independent living skills. Participants described seven primary strategies that parents and professionals can use to support positive transition experiences, which are:

- Start earlier and be more proactive with transition planning
- Maintain high expectations, which can contribute to motivation
- Permit choice and risk through supporting young adults in decision making
- Recognise family interdependence and involvement, ensuring self-determination is promoted
- Prioritise parent skill development through facilitating parent-to-parent connections
- Maximise technology to communicate
- Promote inclusion in mainstream activities and community-based learning experiences

Health and Social Care Alliance Scotland and Scottish Government Directorate for Children and Families (2017) Experiences of transitions to adult years and adult services (pdf)

This qualitative study about transitions to adult years and services was commissioned by Scottish Government and completed by the Health and Social Care Alliance between July 2016 and March 2017. The study is primarily based upon the experience of some 30 individuals and families for whom the transition paths to adult years and services has been impacted by a broad spectrum of complex and interacting disabilities. Effective transitional support has depended upon:

- An understanding of family and of the interaction of relationships that are part of each young person's growth and development through transitional stages
- Sufficient continuity of a coordinating key professional during transitional phases
- Approachability and pro-activity of key professionals
- Practicality and expertise of key professionals offering guidance during loss, separation and service change
- Early, guided accessibility to information about processes, resources and timelines
- Adequacy/inadequacy of budget allocation in relation to all wellbeing needs
- Creative bridging of gaps for individuals through partnerships between family, third sector and statutory services
- Respect, honesty, encouragement and support for parents and carers who may find

Kaehne A and Beyer S (2014) Person-centred reviews as a mechanism for planning the post-school transition of young people with intellectual disability, *Journal of Intellectual Disability Research*, 58(7), pp.603–613 (paywalled)

This study consisted of a documentary analysis of 44 person-centred plans for young people with learning disabilities in a local authority in the UK, as well as telephone interviews with all families participating in the programme. This study showed that organising transition review meetings in a person-centred manner by itself does not produce improved post-school options, but may improve the chances of young people and parents to articulate their needs and preferences. It may also increase the involvement of all relevant stakeholder in the process as long as they are willing to engage.

Mental Health Foundation (2015) How to commission better mental health and wellbeing services for young people (pdf)

This guide is aimed at those with a responsibility for commissioning mental health and wellbeing services for young people aged 16–25. Some of the risk factors for mental wellbeing identified in this document, such as discrimination, peer rejection and isolation, and stressful life events, disproportionately impact young people with learning disabilities. Tips for commissioning young people’s services include:

- Identify and gather information about the mental health needs of young people on their terms
- Planning for support that bridges the gap between child and adolescent services and adult services
- Fostering multi-sector partnerships
- Encouraging young people to define their own goals and outcomes from the services they use as a form of monitoring and evaluation

Mills J et al. (2013) Ensuring the successful transition of adolescents to adult services, *Learning Disability Practice*, 16(6), pp.26–29 (paywalled)

The authors of this study conducted a retrospective clinical audit of referrals between August 2011 and March 2012 that involved individuals aged under 25 who were about to begin adult care. 20 individuals, 14 male and six female, were found to be eligible for study. The findings indicate that, when young people are referred to adult services, mental health organisations already involved with their care are more likely to follow the approved protocol, complete referral letters and encounter fewer problems during transitions.

Mitchell F (2015) Facilitators and barriers to informed choice in self-directed support for young people with disability in transition, Health and Social Care in the Community, 23(2), pp.190–199 (paywalled)

This study used multiple qualitative methods, such as secondary analysis of archived qualitative longitudinal interview data, and primary interviews with nine individuals in Scotland. Factors facilitating informed choice included supportive family and professional networks, advocacy, accessible information and experiential knowledge. Barriers to informed choice were seen to be low expectations, poor collaboration between child and adult services and bureaucratic organisational cultures.

Nguyen T et al. (2018) Looking back to move forward: reflections and lessons learned about transitions to adulthood for youth with disabilities, *Child: Care, Health and Development*, 44(1), pp.83–88

This paper reports the results of a narrative review of five studies, with thematic analysis of the key findings of the included studies revealing five important themes:

- The importance of promoting a noncategorical and lifecourse approach to care
- Active collaboration among stakeholders involved in transition
- Capacity building through peer mentorship
- Significance of opportunities and experiences
- Significance of information, education, and research

This study also highlights a number of areas for future research, including studies that focus on the significance of everyday experiences; community capacity-building, particularly in relation to building awareness and understanding of the strengths of youth and young adults with disabilities among everyday community members such as employers, coaches, and other social groups; and more investment in knowledge translation.

NHS England (2018) Commissioning for transition to adult services for young people with special educational needs and disability (pdf)

This guide is intended to help local areas develop their transition processes for young people with Special Educational Needs and Disability (SEND) from childhood to adulthood. Key guidance includes:

- Young people and their families should be involved in the design, delivery and evaluation of the transition pathway
- The multidisciplinary nature of transition requires leadership and ownership across the transition pathway, to ensure there are no gaps in the support provided for young people
- Protocols and arrangements for the sharing of information between services, such as safeguarding data
- Delivering specific services for young people in transition

Pallisera M et al. (2014) Transition to adulthood for young people with intellectual disability: exploring transition partnerships from the point of view of professionals in school and postschool services, *Journal of Intellectual & Developmental Disability*, 39(4), pp.333–341 (author manuscript)

Semi-structured interviews were conducted with 45 key professionals from different post-school and school projects, obtaining information regarding the main problems found in coordinating transition services and suggestions for improvement. A lack of continuity was highlighted in the support for young people with learning disabilities during the transition process. Insufficient information and collaboration between services and professionals, and a lack of leadership, were the main problems perceived by professionals.

Scottish Transitions and Association for Real Change (2017) Facing the future together: a national survey of young people with additional support needs and their parents and carers about their experiences of leaving school (pdf)

This report describes the findings from two national surveys in Scotland that set out to hear the voices of young people (14 to 25 years) with additional support needs and those of their parents and carers about their experiences of leaving school and moving into adulthood. A total of 740 responses were received across the two surveys, 270 from young people and 470 from parents and carers. Key findings from the young people's responses include:

- Young people with additional support needs were broadly optimistic about the future, however there is a significant minority who were concerned about leaving school
- They are mainly happy with the future choices available to them and excited by the prospect of taking control of their own lives, however some worry about a potential lack of support from adults
- There seems to be a significant disparity between young people's stated ambitions for adult life while still at school and the actual outcome they experience in the first few years after leaving school
- Their transitions would be improved by more effective adult support, more time invested in planning for the transition and a more flexible approach to exploring the options available to them in the next stage of their lives

Stein KF et al. (2016) Youth, caregiver, and staff perspectives on an initiative to promote success of emerging adults with emotional and behavioral disabilities, *Journal of Behavioral Health Services and Research*, 43(4), pp.582–596

In this study, focus groups were conducted with 25 transition age youth participating in the Healthy Transitions Initiative (HTI), as well as their caregivers and staff. Findings from these interviews reveal several behavioral health practice implications for promoting successful transition for young adults, such as support, empowerment, and individualised care, as well as systemic implications regarding the process for transition age youth and importance of interagency collaboration.

References

Austin KL et al. (2018) Depression and anxiety symptoms during the transition to early adulthood for people with intellectual disabilities, *Journal of Intellectual Disability Research*, 62(5), pp.407–421 (paywalled)

Barron DA et al. (2013) Urban adolescents with intellectual disability and challenging behaviour: costs and characteristics during transition to adult services, *Health and Social Care in the Community*, 21(3), pp.283–292 (paywalled)

Beyer S and Kaehne A (2008) The transition of young people with learning disabilities to employment: what works?, *Journal on Developmental Disabilities*, 14(1), pp.85–94 (author manuscript)

Biggs EE and Carter EW (2016) Quality of life for transition-age youth with autism or intellectual disability, *Journal of Autism and Developmental Disorders*, 46(1), pp.190–204 (paywalled)

Council for Disabled Children (2011) Information and learning from the aiming high for disabled children Transition Support Programme (pdf)

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