# Facilitating successful post-school transition for young people with learning disabilities

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### **Abstract**

**Aims** This article aimed to examine the experiences of post-school transition in children and young people with learning disabilities in order to identify barriers faced and how the process can be improved.

**Methods** A literature search was completed using the search terms "'transition' AND 'learning disability OR intellectual disability'". Papers were only included if they focused on experiences of the transition process in the UK and could be accessed in full with no charge. No exclusions were made on the basis of publication date.

**Results** Six studies matched the search criteria and were selected for inclusion. These studies broadly explored transition planning and its effectiveness, wellbeing during transition, and family and carers' perspectives on transition.

**Conclusion** Experiences of post-school transition vary substantially. Transition planning needs to take place as early as possible with the full involvement of people who know the young person best. A desire for increased adult social care involvement in transition was also demonstrated. There needs to be more informational support for people whose first language is not English so that these individuals have equal access to transition care and opportunities.

# Introduction

A learning disability may be described as a difficulty with day-to-day activities due to a reduced intellectual ability. Post-school transition for young people with learning disabilities (PWLD) describes the process of leaving school and beginning further education, training or employment.<sup>1</sup> It is recommended that preparation for transition should begin as early as possible, and no later than age 14.2 Early preparation allows for more planning and continued support when the young person finishes compulsory schooling at age 16. The transition process is not always without complications; one study showed that only ~25% of carers were content with the process.3 Measuring patient experience allows for the development of targeted interventions that support improvements to the transition process.4 This article will, therefore, explore experiences with transition planning, placements, wellbeing during transition and barriers to achieving an effective transition. Positives and negatives of current transition approaches will then be identified and recommendations for improvement made.

# **Methods**

Background information was found on the Mencap and Together for Short Lives websites. The search was completed in April 2019 and the search terms used to find papers were "transition' AND 'learning disability OR intellectual disability". The literature was obtained from a variety of sources, such as the PubMed database, the Wiley Online

Library and the Elsevier ScienceDirect database. Papers were only included if they focused on experiences of the transition process in the UK and could be accessed in full with no charge. No exclusions were made on the basis of publication date.

#### Results

Six studies matched the search criteria and are summarised in **Table 1**.

Table 1. Studies included in the literature review.

Selected studies	Research method(s)	Sample size (n)	Content/theme
Bhaumik et al, 2011 <sup>3</sup>	Postal questionnaires and interviews for carers	79	Carers' perspectives of the transition to adult services and unmet needs
Kaehne et al, 2013 <sup>5</sup>	Documentary analysis of all person-centred plans Telephone interviews with families	44	Application of person-centred planning to transition
Small et al, 2013 <sup>6</sup>	Two semi- structured interviews with each young person: one at recruitment and one a year later	43	How social networks changed for young people during transition from school to college
Young- Southward et al, 2017 <sup>7</sup>	Semi-structured interviews with young PWLD and parents of young PWLD	Young people: 17 Parents: 23	Identifying the impacts of transition on health and wellbeing
Raghavan et al, 2012 <sup>8</sup>	Two semi- structured interviews with each young person: one at recruitment and one a year later	43	Family carers' perspectives of transition for young PWLD with special reference to ethnicity
Ward et al, 2003 <sup>9</sup>	Questionnaires for parents of young people at various transition stages and interviews with 27 young people and 27 carers	272	The effectiveness of transition planning for young people and their families

Transition planning was one of the most recurrent themes discussed in these studies. Despite recommendations advising early planning, transition meetings were sometimes held near the end of the final year of school. This left little time for young people and their families to discuss their transition plan, which meant that they felt rushed

in making a decision and their needs were less likely to be met. Only 52% of transition meetings were attended by social workers, according to available data in one study.<sup>5</sup> In addition, a combined 67% of young people reported having little to no involvement in transition meetings. Some young people stated that one-to-one meetings with a transition professional were more effective and less daunting than a group meeting.<sup>9</sup>

For young people with severe and profound learning disabilities, the only post-school options were daycare centres.<sup>3</sup> Carers often perceived these placements to be unsuitable due to lack of staff to meet the young person's needs, but felt that there was little choice and had to accept these placements.<sup>6</sup> Young people with mild and moderate learning disabilities mainly expressed desires to go to college or pursue further educational opportunities.<sup>6</sup> There was some emphasis on work placements and employment goals in transition meetings, and these placements were generally enjoyed by young people.<sup>5</sup>

One study extensively investigated the impact of post-school transition on wellbeing, and showed that management of mental health conditions concerned parents more than physical health conditions.<sup>7</sup> In this study, 38.4% of young people scored in the abnormal range in a Strengths and Difficulties Questionnaire (SDQ) and a further 11.5% were in the borderline range. These scores indicated the presence and possible presence of mental health problems, respectively.<sup>7</sup> Parents' accounts mirrored these results as they reported concerns about their child's mental health during the transition period, particularly regarding increased anxiety.<sup>7</sup> This shows that there is scope for transition-specific mental health support or a service to bridge the gap between child and adult mental health services.

Ethnicity seemed to be a predictor of transition experience,<sup>3</sup> as problems, such as role confusion and lack of awareness, were worse for carers whose first language was not English.<sup>8</sup> Bangladeshi and Pakistani carers were more inclined to hand down caring responsibilities to siblings and were reluctant to allow young people to move into supported homes or residential care in the future.<sup>8</sup> Pakistani Muslim carers were worried about the young person disregarding religious beliefs and customs in certain care settings.<sup>8</sup>

## **Discussion**

Here we discuss six studies that analysed transition planning, placements, wellbeing during transition and/or barriers to achieving an effective transition. It was found that transition planning was a recurrent theme that was a major point of discussion in these studies. Interestingly, social workers only attended half of the transition meetings in one study.<sup>5</sup> This reinforces the demand for more social care involvement.<sup>5</sup> However, as this finding was only derived from available data, it could be possible that these figures are not accurate. It was also noted that accessibility to transition meetings for young people could be improved, as 67% of young people said they had little to no involvement.

Post-school placement options seemed to be influenced by the degree of learning disability, since young people with severe learning disabilities were only offered daycare centres.<sup>3</sup> Carers thought these placements were unsuitable for these individuals due to limited staff but felt there was little choice but to accept the placements.<sup>6</sup> This highlights the need for increased care provision, such as respite care, for young people with more complex needs. It must be noted that there was a higher number of young people with a severe and profound learning disability in this study in comparison with the local average,<sup>6</sup> which could make the problems reported seem disproportionately more severe.

One study that investigated the impact of post-school transition on wellbeing showed that mental health problems were present in PWLD during the transition period, and that parents were concerned about these issues.<sup>7</sup> These findings demonstrate that there is scope for transition-specific mental health support or a service to bridge the gap between child and adult mental health services.

Ethnicity was also shown to be important for the transition experience<sup>3</sup> as language and religion<sup>8</sup> were found to influence type of care. In particular, there were concerns that religious beliefs would be disregarded in certain care settings.<sup>8</sup> This demonstrates the need for culturally-sensitive provision, so familial values and beliefs are upheld in post-school placements.<sup>3</sup>

#### **Summary points**

- Post-school transition for PWLD can be a stressful process but this difficulty can be mitigated with appropriate support
- There were several shortcomings in transition planning, including late planning and lack of involvement of key stakeholders
- More support is needed to ensure mental wellbeing during the transition process
- A multidisciplinary approach is required in order to synthesise and deliver key information and support individuals through the process

**Conclusion** Drawing upon the evidence considered in this review, it is clear that experiences of post-school transition vary substantially. Transition planning needs to take place as early as possible with the full involvement of people who know the young person best, so they can collude with professionals to plan an effective transition. <sup>10</sup> A largely multidisciplinary approach to transition is viewed as most effective, and a desire for increased adult social care involvement in transition has been demonstrated. <sup>11</sup> This ensures that young PWLD have adequate social support and suitable post-school placement options. There also needs to be more informational support for people whose first language is not English so that these individuals have equal access to transition care and opportunities.

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#### References

- Mencap (2018) Transition into adult services. Available from: www. mencap.org.uk/advice-and-support/children-and-young-people/ education-support/transition-adult-services. Accessed: 6 May 2019.
- Together for Short Lives (2020). Transition to adult services factsheet.
   Available from: www.togetherforshortlives.org.uk/get-support/supporting-you/family-resources/transition/. Accessed: 6 May 2019.
- 3. Bhaumik S, Watson J, Barrett M, et al. Transition for teenagers with intellectual disability: carers' perspectives. *Journal of Policy and Practice in Intellectual Disabilities*, 2011; 8:53–61.
- NHS Improvement (2018). Patient experience improvement framework. Available from: https://improvement.nhs.uk/resources/patient-experience-improvement-framework/. Accessed: 6 May 2019.
- Kaehne A, Beyer S. Person-centred reviews as a mechanism for planning the post-school transition of young people with intellectual disability. *Journal of Intellectual Disability Research*, 2013; 58:603–613.
- Small N, Raghavan R, Pawson N. An ecological approach to seeking and utilising the views of young people with intellectual disabilities in transition planning. *Journal of Intellectual Disabilities*, 2013; 17:283–300.
- Young-Southward G, Cooper SA, Philo C. Health and wellbeing during transition to adulthood for young people with intellectual disabilities: a qualitative study. Research in Developmental Disabilities, 2017; 70:94–103.
- Raghavan R, Pawson N, Small N. Family carers' perspectives on postschool transition of young people with intellectual disabilities with special reference to ethnicity. *Journal of Intellectual Disability Research*, 2012; 57:036-046
- Ward L, Mallett R, Heslop P, et al. Transition planning: how well does it work for young people with learning disabilities and their families? *British Journal* of Special Education, 2003; 30:132–137.
- NHS (2018). Moving from children's social care to adult's social care.
   Available from: www.nhs.uk/conditions/social-care-and-support-guide/caring-for-children-and-young-people/moving-from-childrens-social-care-to-adults-social-care/. Accessed: 6 May 2019.
- National Institute for Health and Care Excellence. Transition from children's to adults' services for young people using health or social care services. Available from: www.nice.org.uk/guidance/ng43/chapter/ Recommendations. Accessed: 6 May 2019.