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Transition for young people with learning disabilities

learning from research

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Transition for young people with learning disabilities

Transition remains a difficult time for many young people with learning disabilities and their families. This document outlines some of the main messages that emerged from research on transition for young people with learning disabilities. It may help practitioners to discuss existing strengths and weaknesses in their own service.

This document is not the result of a systematic review. Transition has been the subject of research for a substantial number of years. Inevitably there are many specific findings that may be important for social care services. However, this summary will present only some of the main messages in three distinct but interrelated domains: transition experiences, needs of services users and partnership work. Sections are organised into a list of research findings followed by relevant references. At the end of the document, all references are individually listed and include brief summaries for each research paper included.

Domains

[Experiences of young people and parents](#)

[Needs](#)

[Partnership work](#)

1 Experiences of families and young people

Much research has focused on the experiences of young people and their families with transition from children or adolescent to adult services. Transition has often been described as a 'wicked problem' due to the involvement of many different agencies and their professional boundaries. Policy has recognised the need to understand the perspective of parents and young people when navigating service transition. Many researchers therefore think it important to describe the experiences of parents and young people during times of transition to identify service problems or service gaps.

Families and young people often experience:

- a lack of timely, accurate and accessible information on what happens during and after transition
- an absence of proper multi-agency planning for post-transition options
- a multitude of assessments during times of transition
- repeated home visits by staff from different organisations asking them to 're-tell their story'
- confusion or lack of information regarding eligibility for adult services
- uncertainty about post-transition placements such as FE colleges or day centre provision
- a lack of options or severely restricted choices between post-school placements
- a lack of employment options or available employment support
- a sharp decline in some services such as physiotherapy, mental health or psychological support

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2 Needs

There are some needs that are specific to some user groups. While people with learning disabilities present with a whole range of needs and abilities, their support needs also differ substantially. Consequently, researchers have attempted to identify particular need profiles of specific sub-groups in the learning disability population. Sub-groups may be formed around demographic characteristics, pathogenesis or behavioural phenotypes.

Despite the differences, all people with learning disabilities however are lifelong recipients of health and social care services and require support for some elements of their routine activities.

There are differences with respect to:

- the intensity or type of support needed in their home or future home
- the complexity of the support needed due to the confluence of factors such as communication and mobility
- the availability of social networks and family support
- the linguistic and cultural background which may impact on the ability to access specialist or mainstream services
- generally, higher unmet needs in BME groups
- young people looked after by LAs who may not have any transition planning

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3 Partnership work

Policy and research are agreed that the main vehicle to address the problems encountered by young people and their families during times of transition is multi-agency cooperation. There is also a broad consensus in the literature on what constitutes good multi-agency work and how to bring it about. This is often called partnership work but some social care and health agencies are now working actively to achieve even closer integration between their members of staff. The basic principles of transition support have been described as comprehensiveness, communication, coordination, continuity and choice (Heslop 2002).

Organisations involved in planning transition for young people with learning disabilities need to

- proactively share information about young people and families across organisational boundaries, most helpfully facilitated by the implementation of information sharing protocols
- hold multi-agency meetings that allow services to discuss and review transition planning for individual cases to ensure needs are identified and met
- agree procedures for assigning a lead professional or key worker to each family
- harmonise eligibility criteria and increase awareness amongst staff and service users about differing service eligibility criteria where harmonisation is not possible
- integrate or reconcile referral systems across services (ideally creating a single referral point and path)

- identify service gaps resulting from different eligibility criteria, different service approaches or routines to mitigate negative impact of transition from intensive children/adolescent services to mainstream adult services in social care and health
- increase the involvement of mental health professionals, psychiatric and psychology support staff and voluntary agencies in transition planning meetings
- explore useful tools to mitigate disruption of transition to families and young people such as shared clinics or shared family visits or handover meetings with families and young people
- reduce tokenistic activities such as Careers Services advice which is inaccessible to young people with learning disabilities
- produce, review and implement a shared, comprehensive, accessible transition plan from the year 9 onwards (age 14)
- ensure that all cases are frequently reviewed and progression is monitored to ensure necessary changes in service provision and planning
- create IT systems that are capable of facilitating information sharing between services where necessary and practical

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References regarding Experiences of young people and parents

Kaehne, A., & Beyer, S. (2008). Carer Perspectives on the Transition of Young People With Learning Disabilities to Employment. *Journal on Developmental Disabilities*, 14(1), 91-100.

- study of 87 carers and their young people in UK on transition advice they received and preferences for post-school destinations
- advice to carers often does not include employment options
- carers' preferences differ significantly from actual post-school destinations
- employment agencies need to be involved earlier in transition planning

Kaehne, A., & Beyer, S. (2011). 'Stroppy' or 'confident'? Do carers and professionals view the impact of transition support on young people differently? *British Journal of Learning Disabilities*, 39, 154-160.

- carers and professionals understand transitions differently
- carers often stress how things change within the family during the time of transition while teachers and support staff emphasise changes in independence and social skills of the young people in our study
- this has implications for how professionals can bridge expectations of carers about transition support

Cooney, B. F. (2002). Exploring Perspectives on Transition of Youth With Disabilities: Voices of Young Adults, Parents, and Professionals. *Mental Retardation* 40(6), 425-435.

- study on expectations of transition outcomes for young people, carers and professionals
- young people mainly noted lack of post-school opportunities
- professionals viewed transition as process to match needs with available programmes
- significantly different perspectives on transition process between carers, young people and professionals may contribute to stalled progress

Neece, C. L., Kraemer, B. R., & Blacher, J. (2009). Transition Satisfaction and Family Well Being Among Parents with Young Adults with Severe Intellectual Disability. *Intellectual and Developmental Disabilities*, 47(1), 31-43.

- study on parental satisfaction and family well being of parents with young people with learning disabilities
- work arrangements of parents have a significant impact on family satisfaction with transition
- family involvement in transition is also important factor to improve family satisfaction with young people's transition

Rapanaro, C., Bartu, A., & Lee, A. H. (2008). Perceived Benefits and Negative Impact of Challenges Encountered in Caring for Young Adults with Intellectual Disabilities in the Transition to Adulthood. *Journal of Applied Research in Intellectual Disabilities*, 21, 34-47.

- study on perceived benefits negative impact of transition for 119 families
- carers reported positive and negative impact of some stressful events during transition
- positive aspects may be personal growth and enhanced personal resources
- carers use language of stress but also language of fulfilment, growth and gain when referring to transition period

Milner, C. (2008). Experiences of health transition for young people with learning difficulties and complex health needs in Northumberland (report). Northumberland: NHS Care Trust Northumberland.

- study of health transition experiences for young people with complex needs in Northumberland
- personal relationship between professionals with young person is of paramount importance
- out of county placement present a particular challenge to health transitions
- still lack of information about transition and proper handover to adult care
- improvements may come through overlap of care by children's and adult services, regular health checks and improved information for carers

Abbott, D., & Carpenter, J. (2009). Transition to Adulthood for Young Men with Duchenne Muscular Dystrophy and their Families. Bristol: School of Policy Studies.

- study of 40 young people with Duchenne Muscular Dystrophy
- no consistent use of transition plans
- social isolation of participants contributes to poor transition outcomes
- lack of support for carers contributes to poor transition planning
- great variety of support and care across participant group

Abbott, D., & Heslop, P. (2008). Where next? Transition pathways for young people with learning difficulties in UK Residential Schools and Colleges. *Journal of Developmental Disabilities*, 14(1), 52-58.

- study of 15 young people with learning disabilities who go to residential schools or colleges
- young people in out-of-area placements do not receive consistent transition planning
- there is general lack of support for this group of young people not living at home

Johnson, D. R., Stodden, R. A., Emanuel, E. J., Luecking, R., & Mack, M. (2002). Current Challenges Facing Secondary Education and Transition Services: What Research Tells Us. *Exceptional Children*, 68(4), 519-531.

- examination of existing implementation data of transition guidance in US
- educational reforms, transition services and policy do not pull into the same direction

Allen, D., Cohen, D., Robling, M., Hood, K., Atwell, C., Lane, C., et al. (2010). *The transition from paediatric to adult diabetes services: what works, for whom and in what circumstances?* London: NIHR Service Delivery and Organisation Programme.

- study on models of transition support for young people with diabetes
- 4 models of transition support found across health systems in England
- validation of 4 models show that some support interventions improve transition experiences significantly
- study does not include young people with learning disabilities

Murphy, E., Clegg, J., & Almack, K. (2011). Constructing Adulthood in Discussion about the Futures of Young People with Moderate-Profound Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities*, 24, 61-73.

- study of discourses amongst 28 young people and their families through transition
- two discourses identified: self-determination and 'realism' of continuing aspects of dependencies and impairment
- good decision making during transition planning needs to address both dimensions, increased self-determination as well as the ongoing need for support in areas of dependencies

Unwin, G., LeMesurier, N., Bathia, N., & Deb, S. (2008). Transition for adolescents and young adults with learning disabilities and mental health problems/challenging behaviours: the parent carers' views. *Advances in Mental Health and Learning Disabilities*, 2(1), 22-28.

- scoping study of mental health problems of young people with learning disabilities during transition
- emerging themes relate to access to information about rights and services, and potential conflicts between carers and professionals

Blacher, J. (2001). Transition to Adulthood: Mental Retardation, Families, and Culture. *American Journal on Mental Retardation*, 106(2), 173-188.

- conceptual study of transition arguing that the period from 18-26 years of age is critical
- authors suggest that transitional experiences influence family well being but transition outcomes vary depending on individual characteristics, environment, culture, and family involvement

Blacher, J., Kraemer, B. R., & Howell, E. J. (2010). Family expectations and transition experiences for young adults with severe disabilities: does syndrome matter? *Advances in Mental Health and Learning Disabilities*, 4(1), 3-16

- study of 246 young people aged between 18-26, syndromes include autism, Downs', and cerebral palsy as well as non-specific learning disabilities
- findings indicate more community expectations for Downs' Syndrome group and more restrictive expectations for the autism group of young people
- worries about transition most pronounced amongst parents of children with autism

Hogansen, J. M., Powers, K., Geenen, S., Gil-Kashiwabara, E., & Powers, L. (2008). Transition Goals and Experiences of Females With Disabilities: Youth, Parents, and Professionals. *Exceptional Children*, 74(2), 215-234.

- qualitative study on transition experiences 67 young women with learning disabilities
- gender has significant influence on transition goals and experiences
- lack of specific goals of transition planning widespread amongst group
- disputes between professionals and parents about lack of planning impacts on outcomes of transition

Glidden, L. M., & Jobe, B. M. (2007). Measuring Parental daily Rewards and Worries in the Transition to Adulthood. *American Journal on Mental Retardation*, 112(4), 275-288.

- meta-study of 847 parental worries and experiences during transition of their young people
- study reports the validity of measures used

Heslop, P., & Abbott, D. (2007). School's Out: pathways for young people with intellectual disabilities from out-of-area residential schools or colleges. *Journal of Intellectual Disability Research*, 51(7), 489-496.

- study of 15 parents of young people with learning disabilities in out-of-area placements on satisfaction with post-school pathways
- four main process issues were identified: parental peer support, proactive approach, lack of information, and long term planning

Bhaumik, S., Watson, J., Barrett, M., Raju, B., Burton, t., & Forte, J. (2011). Transition for Teenagers with intellectual disability: Carer's perspectives. *Journal of Policy and Practice in Intellectual Disabilities*, 8(1), 53-61.

- mapping exercise of needs of young people with learning disabilities (aged 16-19) in one UK area as reported by carers
- use of services of identified group of young people yet carers reported some unmet need
- about half of carers had difficulty accessing some services
- carers also reported lack of information on planning and study confirmed need for standardised tools for transition planning

References regarding Needs

Katsiyannis, A., Zhang, D., Woodruff, N., & Dixon, A. (2005). Transition Supports to Students with Mental Retardation: An Examination of Data from the National Longitudinal Transition Study 2. *Education and Training in Developmental Disabilities, 40*(2), 109-116.

- large scale study of available transition support data from US
- results: 60% of young people with LD have transition planning start at age 14
- low levels of involvement of young people in planning
- variety of post-school goals reflecting diversity of transition options in US system

Kaehne, A. (2009). Choices for young people with learning disabilities in post-education transition. *Mental Health Review Journal, 14*(2), 37-43.

- review of research and literature of choice for young people with learning disabilities in transition
- lack of data on how choice can be operationalised for this group during transition
- repeated experiences of different environments and social contexts may widen choice

Hudson, B. (2006). Making and missing connections: learning disability services and the transition from adolescence to adulthood. *Disability and Society, 21*(1), 47-60.

- investigation of barriers to effective transition support in UK
- inter-agency work significant barrier, in contrast, person-centred approach may facilitate improved transition planning and outcomes

Hughes, C. (2001). Transition to Adulthood: Supporting Young Adults to Access Social Employment, and Civic Pursuits. *Mental Retardation and Developmental Disabilities Research Reviews, 7*, 84-90.

- review of existing studies of models of transition support
- more than 500 support activities reviewed
- two main categories of support: environmental support and increase of young person's competences

Abbott, D., & Carpenter, J. (2009). Transition to Adulthood for Young Men with Duchenne Muscular Dystrophy and their Families. Bristol: School of Policy Studies.

- study of 40 young people with Duchenne Muscular Dystrophy
- no consistent use of transition plans
- social isolation of participants contributes to poor transition outcomes
- lack of support for carers contributes to poor transition planning
- great variety of support and care across participant group

Wittenburg, D. C., Golden, T., & Fishman, M. (2002). Transition options for youth with disabilities: An overview of the programs and policies that affect the transition from school. *Journal of Vocational Rehabilitation, 17*, 195-206.

- review of existing support programmes for transition into employment in US
- poor co-ordination between school and non-school agencies
- improvement needed in planning and co-ordinating school based and post-school programmes

MacIntyre, G. (2009). Transitions for young people with learning disabilities. In A. Petch (Ed.), *Managing Transitions. Support for individuals at key points of change* (pp. 41-57). Bristol: Policy Press.

- review of transition policy and practice in the UK
- review includes England, Wales and Scotland
- paper outlines serious failings in transition planning and post-college transition

O'Brien, G. (2006). Young adults with learning disabilities: a study of psychosocial functioning at transition to adult services. *Developmental Medicine and Child Neurology, 48*, 195-199.

- study of psychosocial functioning and transition destination of a birth-period cohort (149 young people)
- lack of early detection of LD and intervention contributes to poor post-transition outcomes for this group

Cowlard, J. (2003). Cystic fibrosis: transition from paediatric to adult care. *Nursing Standard, 18*(4), 39-41.

- review of care transition in general hospital from children to adult services for group of young people with cystic fibrosis
- report indicates some improvements in care transition yet further changes are needed

White, J., & Weiner, J. S. (2004). Influence of least restrictive environment and community based training on integrated employment outcomes for transitioning students with severe disabilities. *Journal of Vocational Rehabilitation, 21*, 149-156.

- examination of transition outcomes for 104 young people with severe disabilities in supported employment programmes
- community based training was positively correlated with integrated employment outcomes for this group

Clegg, J., Sheard, C., & Cahill, J. (2001). Severe intellectual disability and transition to adulthood. *British Journal of Medical Psychology*, 74, 151-166.

- small scale qualitative study on institutional and psychological aspect of transition for young people with severe disabilities
- challenging behaviour and correlation between parents and staff perceptions are explored

Shaw, K. L., Southwood, T. R., & McDonagh, J. E. (2006). Development and preliminary validation of the 'Mind the Gap' scale to assess satisfaction with transitional health care among adolescents with juvenile idiopathic arthritis. *Child: Care, Health and Development*, 33(4), 380-388.

- evaluation of tool to investigate transition support for young people and their carers
- current evaluation does not include people with LD but authors conclude that it may be suitable for other groups as well

Florian, L., Dee, L., Byers, R., & Maudslay, L. (2000). What happens after the age of 14? Mapping transitions for pupils with profound and complex learning difficulties. *British Journal of Special Education*, 27(3), 124-128.

- large survey of current transition provision in England and Wales
- assessment criteria include Quality of Life aspects
- aim of study is to construct a framework for learning to improve transition support for this group

Grigal, M., Hart, D., & Migliore, A. (2011). Comparing the Transition Planning, Postsecondary Education, and Employment Outcomes of Students with Intellectual and other Disabilities. *Career Development for Exceptional Individuals*, 34(1), 4-17.

- secondary analysis of US data set on transition support programmes
- people with LD are less likely to have secondary education and competitive employment identified as transition goals

Raghavan, R., & Pawson, N. (2008). Transition and social networks of young people with learning disabilities. *Advances in Mental Health and Learning Disabilities*, 2(3), 25-28.

- case study of young people and their social networks during transition
- authors highlight the importance of social networks for effective transition planning

Baer, R. M., III, A. W. D., Flexer, R. W., Queen, R. M., & Meindl, R. S. (2011). Students with Intellectual Disabilities: Predictors of Transition Outcomes. *Career Development for Exceptional Individuals*, 34(3), 132-141.

- large scale US study of what predicts full-time employment and college attendance after school for young people with intellectual disabilities
- gender and minority significantly predicted post-school outcomes for this group

Blum, R. M. (2003). Transition to adult health care for adolescents and young adults with chronic conditions. *Journal of Adolescent Health*, 33, 309-311.

- conceptual paper on transition from children to adult health care for young people with chronic conditions
- paper reviews some aspects specific to young people with LD such as key working and parental involvement

Blum, R. W. (1993). Transition from Child-centered to Adult Health-Care Systems for Adolescents with Chronic Conditions. *Journal of Adolescent Health*, 14, 570-576.

- paper sets out the need for transition support transition in health care for young people with chronic conditions
- paper defines key elements of transition support and need for further research

Flexer, R. W., III, A. W. D., Baer, R. M., Queen, R. M., & Meindl, R. S. (2011). An Epidemiological Model of Transition and Postschool Outcomes. *Career Development for Exceptional Individuals*, 34(2), 83-94.

- large scale study based on US data on transition outcomes
- two outcomes were examined: secondary education and employment
- gender and minority status predicted outcomes, yet training and career education programmes did not [these findings have not been corroborated so far in UK studies, AK]

Viner, R. (1999). Transition from paediatric to adult care. Bridging the gaps or passing the buck? *Archives Disability Child*, 81, 271-275.

- conceptual paper that lists elements of health care transition and relevant support activities
- author advocates delay of transition to adult health care in some instances

Viner, R. (2008). Transition of care from paediatric to adult services: one part of improved health services for adolescents. *Archive Disability Child*, 93, 160-163.

- paper that argues for better transition to adult health care for young people with chronic conditions
- prerequisites of improved transition are identified as: transition must be seen to be central to NHS care; young people need to be involved in care transition; care systems must be more responsive to needs of group

Beyer, S., & Kaehne, A. (2008). The Transition of Young People With Learning Disabilities to Employment: What Works? *Journal on Developmental Disabilities*, 14(1), 81-90.

- large scale study of transition support programmes to employment in UK
- authors identify careers advice delivered by external agencies, community based support and some work based training as necessary to obtain employment

References regarding Partnership work

While, A., Forbes, A., Ullman, R., Lewis, S., Mathes, L., & Griffiths, P. (2004). Good practices that address continuity during transition from child to adult care: synthesis of evidence. *Child: Care, Health and Development*, 30(5), 439-452.

- Review of evidence of transition support activities in health care transition
- authors argue that various models of support can be identified and should be tested in further research

Cowen, A., Murray, P., & Duffy, S. (2011). Personalised Transition: A Collaborative Approach to Funding Individual Budgets for Young Disabled People with Complex Needs Leaving School. *Journal of Integrated Care*, 19(2), 30-36.

- study investigates the use of individual budgets to improve person-centred transition planning and support
- authors argue that individual budgets usefully shifts the emphasis from the service user to the individual young person when planning support

Kaehne, A. (2010). Multi-agency protocols in intellectual disabilities transition partnerships: a survey of Welsh local authorities. *Journal of Policy and Practice in Intellectual Disabilities*, 7(3), 182-188.

- scoping study of current collaborative approaches in transition partnerships in all Welsh local authorities
- study identified significant variation in multi-agency partnerships
- lack of involvement of external non-statutory agency in transition partnerships may account for poor transition outcomes for some young people

Kaehne, A. (2010). Transition from children and adolescent to adult mental health services for young people with intellectual disabilities: a scoping study of service organisation problems. *Advances in Mental Health and Learning Disabilities*, 5(1), 9-16.

- study of mental health services and their role in transition partnerships in Wales
- mental health professionals are rarely involved in planning transition
- study also indicates that there are significant service gaps for some young people with LD

Kaehne, A., & Beyer, S. (2009). Views of professionals on aims and outcomes of transition for young people with learning disabilities. *British Journal of Learning Disabilities*, 37, 138-144.

study of professionals involved in planning transition for young people with LD and their views on goals and outcomes for this group
findings indicate that professionals often fail to link general goals with clear identifiable outcomes of post-school transition for this group
this may contribute to lack of viable options of post-school placements for this group

Hudson, B. (2003). From Adolescence to Young Adulthood: The partnership challenge for learning disability services in England. *Disability and Society*, 18(3), 259-276.

conceptual paper that argues that transition support for young people with LD requires additional support compared to generic transition support
partnership work is viewed as essential component of policy and practice to improve transition outcomes for young people with LD

Hart, D., Zimbrich, K., & Ghiloni, G. (2001). Interagency partnerships and funding: Individual supports for youth with significant disabilities as they move into postsecondary education and employment options. *Journal of Vocational Rehabilitation*, 16, 145-154.

study that investigates a particular new funding model to support transition for young people with LD in the US
new model includes cross sectoral funding arrangements which research identifies as critical to ensure improved transition outcomes

Barron, D. A., & Hassiotis, A. (2008). Good practice in transition services for young people with learning disabilities: a review. *Advances in Mental Health and Learning Disabilities*, 2(3), 18-22.

useful review of current transition practices, research on transition and policy
authors argue that principles of transition support from young people with LD and with other neurodevelopmental disorders and mental disorders should essentially be similar although their experiences are different

Barnes, P. (2008). Multi-agency working: what are the perspectives of SENCOs and parents regarding its development and implementation? *British Journal of Special Education*, 35(4), 230-240.

small scale study that investigates perception and components of multi-agency working amongst parents and professionals
author argues that no particular model of partnership working is the most suitable
partnership work however should be reviewed regularly by schools and the community

Mittler, P. (2007). Education - the missing link at transition. Learning Disability Review, 12(2), 14-21.

discussion paper on why multi-agency work has not led to improved transition outcomes for young people with LD
paper reviews the implications of Valuing People and identifies integrated services between LEAs, schools and the FE sector as critical for further progress

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