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West Sussex County Council

Policy and literature review for comprehensive needs assessment of the life pathway for people with disabilities

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1 Introduction

The Institute of Public Care (IPC) has prepared this review for West Sussex County Council (WSCC). It covers recent policy and legislation in relation to children and young adults with disabilities, along with a review of the evidence on good practice and models of care. The paper is comprised of the following parts:

- A brief overview of the policy and legislative context, together with potential opportunities.
- A review of the specific learning from transitions research for children and young people with disabilities.
- A review of pathways approaches
- Examples of good practice models of care in the pathway to adulthood.

2 Policy and legislation

The Care Act 2014, the Children and Families Act 2014, and the Special Educational Needs and Disability Code of Practice: 0 to 25 years, 2015 create a new comprehensive legislative framework for transition focussed on personalised, outcome-based approaches with a new focus on carers that recognises the role of families in the process of transition to adulthood. Some young people will be entitled to support through both pieces of legislation.

- **The Care Act 2014** places a duty on local authorities to conduct transition assessments for children, children's carers and young carers where there is a likely need for care and support after the child in question turns 18 and a transition assessment would be of '*significant benefit*'.

  The assessment process itself must:
  - be person-centred throughout,
  - ensure that the wellbeing of each young person or carer is taken into account, and
  - include any other person who the young person or carer wants to involve.

  The process must establish the outcomes the young person or carer wishes to achieve. The Act aims to ensure continuity in provision until adult services have a plan in place, and to promote the extension of best practice in transition arrangements, highlighting the value of keyworkers in raising the quality of care co-ordination. The Act gives local authorities a legal responsibility to cooperate both internally and externally '*to ensure a smooth transition*', and places a reciprocal duty of cooperation by relevant partners of the local authority.

The Care Act Guidance states that in order to meet these duties fully, local authorities should consider how they can identify young people and carers who are not receiving children's services, but are nevertheless likely to have care and support needs as adults. They should consider how to establish mechanisms to identify young people as early as possible in order to plan for or prevent the development of care and support needs, and thereby fulfil their duty relating to '*significant benefit*' and the timing of assessments.

Examples of groups that are more difficult to identify are set out in the Care Act statutory guidance as follows:

- those with degenerative conditions.
- those whose needs have been largely met by their educational institution, but who, once they leave, will require their needs to be met in some other way (e.g. those with autism).
- those detained in the youth justice system who will move to adult custodial services.
- young carers whose parents have needs below the local authority's eligibility threshold but who may nevertheless require advice or support to fulfil their potential (e.g. a child with deaf parents who is undertaking communication support).
- young people and young carers receiving child and adolescent mental health services (CAMHS) who may also require care and support as adults even if they did not receive children's services from their local authority.

The **Children and Families Act 2014** and the **Special Educational Needs and Disability Code of Practice: 0 to 25 years, 2015** introduced a system of support extending from birth to 25 years of age. This includes:

- Children, young people and their families must be involved in discussions and decisions about their individual support and local provision.
- The right to make requests and decisions under the Act will apply directly to disabled young people and those with SEN over compulsory school age rather than to their parents.
- New Education, Health and Care Plans (EHC) for 0-25 years, replace the current system of Statements and Learning Difficulty Assessments, which reflect the child or young person's aspirations for the future, as well as their current needs.
- Integration of education, health and care to promote well-being and joint commissioning arrangements to secure provision set out in EHC plans.
- Young people have the right to request an (education) personal budget as part of the EHC planning process.
- The EHC planning process requires preparation for adulthood to begin at 14 years (school year 9) with a clear focus on life outcomes.

- A Local Offer of support including information and advice available to children and young people with SEN or disabilities to help them to prepare for adulthood.
- New rights and protections to 16-25 year olds in further education and training.
- New rights to assessment and support for young carers and parent carers.

WSCC were a pilot authority for EHC Plans. EHC Plans have been extended to young people aged 25 to support them into adulthood.

These two Acts and the Guidance provide the key elements to the context in which transition practice occurs. NICE has also produced guidance on transition which includes a series of recommendations linked to the existing legislation and guidance (NICE, 2016). These cover overarching principles for good transition, planning transition, support before and after transfer, and the supporting infrastructure for transition and emphasise that: *Health and social care service managers in children's and adults' services should work together in an integrated way to ensure a smooth and gradual transition for young people*. A wide range of other policy and legislative documents have also been identified as relevant to the transition to adulthood by SCIE (2014).

3 Transition to adulthood: what works for children and young people with disabilities?

The transition process takes place at a pivotal time in the life of a young person and is part of wider cultural and developmental changes that lead them into adulthood. Transition can be a time of celebration, change and challenge for all young people, and they can experience a number of transitions simultaneously. It is a time when young people are considering and making decisions about their continuing education, work and careers, their social life, and about where and how they will live.

The vital importance of a successful transition to adulthood for young people with disabilities has long been recognised in UK government policy publications and guidance. There is now a considerable body of evidence to suggest that too many young people entering adult services are at greater risk of marginalisation and poorer outcomes as a result of the transition process and its conclusion. There is evidence of gaps and discontinuities in services for some young people going through transition. Local authorities need to have in place arrangements to ensure that young people with complex needs have every opportunity to lead as independent a life as possible, and are not disadvantaged by the move from children's to adult services.

Challenges combine organisational and attitudinal issues. For example, the process can be managed very badly and transition to adult services has been described as like '*falling off a cliff*'. There is no reason in law why this should be the case; the fundamental duties for young disabled people as adults, remain to assess their needs and provide services to meet these needs. Some of the obstacles that young people in transition and adults face are also rooted in their own lack of expectation and aspiration about their adult lives, often as a result of negative messages from those around them or simply a lack of understanding. Primarily they involve a combination of individual and organisational factors, although for many the starting point is attitudinal.

Alongside the availability of appropriate provision, a successful transition to adulthood depends on early and effective planning, putting the young person at the centre of the process to help them prepare for transfer to adult services. The process of transition should start while the young person is still in contact with children's services and may, subject to the needs of the young person, continue for a number of years before and after the transfer to adult services. There needs to be an overall focus on outcomes and activities rather than services.

3.1 What is transition?

The transition to adulthood happens at different ages for all young people, including those with complex needs or disabilities. It has been described variously as:

- The purposeful and planned process of supporting young people to move from children's to adults' services (Transition: getting it right for young people, DfES & DH, 2006).
- The point at which young people move from children's to adult services (Don't let me down - Ensuring a good transition for young people with palliative care needs, Marie Curie Cancer Care, 2012).
- The transfer to an adult environment where they [young people] may need to consult several different health teams, therapy teams, and adult social care services (From the pond into the sea: children's transition to adult health services, CQC, 2014).
- For many working with disabled young people and their families transition is understood as the time disabled young people move from children's to adult services, rather than a natural stage of life that includes leaving school, starting work, going to college or university, leaving home, trying out new experiences and making new friends (Cowen, A, 2010, Personalised Transition: Innovations in Health, Education and Support, The Centre for Welfare Reform)

These examples differ in their emphasis on transition as a planned process, point in time or 'natural' stage. What is common to all of them is the expectation of change.

3.2 Why does the transition to adulthood matter?

There is now considerable evidence to point to the importance of the transition experience in terms of immediate and longer-term life outcomes. Poor transitions are likely to be a key contributor to poor outcomes. Young people who are already vulnerable in terms of complexity of needs and/or circumstances are at greater risk of marginalisation during the transition process. The importance of the process of transition to adulthood has been repeatedly emphasised within the literature:

- Research shows that we can set young people up for the rest of their lives and make a huge difference to their life chance outcomes if we share with them a range of choices, good information and support around housing, employment, health, and making friends and social relationships, while they are still at school (Department of Health, 2011).
- The lack of information, support and services available to meet the complex needs of young people and their families can be confusing, creating additional hurdles at what can be an already difficult time (NICE, 2015).

- Young people with any form of disability, chronic disease or with significant mental health problems face even greater challenges, having also to deal with important changes in the care they need and the way it is provided adds to these challenges (Cochrane Collaboration, 2012).
- The interface between children's and adult health services is becoming an increasingly important issue, as the number of young people with chronic illnesses and disabilities entering adulthood, who are in need of support services to achieve their physical, social and psychological potential, is on the increase (Cochrane Collaboration, 2012).

3.3 What do young people and their families have to say about the process of transition?

There is considerable evidence that for most disabled young people the process of transition from child to adult services is problematic, both in terms of services and in terms of giving young people the level of autonomy and control they desire (Sloper et al, 2011). Research indicates that the experience of transition to adulthood for many individual young people remains unacceptable, and parents also identify transition to be one of the most stressful periods, with difficulties experienced around coordination, availability, sufficiency and appropriateness of services (Sloper et al, 2011). Many young people and their families experience difficulty in gaining the social support and health-care required. This can have a negative impact on their longer-term health and social well-being.

The process of transition to adulthood has been described as '*entering into a black hole*', like '*falling off a cliff*', or '*a time when young people have few options, become more isolated and families experience a drop in levels of support*' (Report of the Parliamentary Hearings on Services for Disabled Children, 2006) and a '*nightmare*' (CSCI, 2007). Transition may leave unmet needs in many areas of young people's lives, for example, leisure and social life, housing, career and employment opportunities, and planning future goals and aspirations (Sloper et al, 2011).

3.4 Continuing Challenges on the Pathway to Adulthood

Added complexity is produced by different services having different age points for transition to adult services. In From the Pond into the Sea, the Chief Inspector of Primary Medical Services and Integrated Care said: '*We have put the interests of a system that is no longer fit for purpose above the interests of the people it is supposed to serve*' (CQC, 2014).

Research, guidance and policy point to a number of problems in achieving a coordinated approach to transition to adulthood. These include:

- Poor multi-agency working.
- Absence of a holistic approach to understanding individual and family needs.
- Lack of information and advice for young people and parents.
- Lack of user involvement in the planning process.
- Insufficient attention to the concerns/priorities of the young person.
- Lack of appropriate services/provision to which young people can transfer (Sloper et al, 2011).

A study of ways to support physically disabled young adults found a wide variation in the extent to which transition planning and preparation had included work around preparing to use Direct Payments or Personal Budgets. Many young adults expressed a desire for preparation from social care staff on dealing with issues associated with managing and employing carers/PAs (Mitchell et al, 2015).

Particularly vulnerable groups are identified as young people leaving residential care (Beresford and Cavet, 2009) and young people with life-limiting conditions (Children and Young People's Health Outcomes Forum, 2012).

3.5 The Transition to Adulthood for Young People with Disabilities - What Works?

While there is considerable diversity within transition services in terms of their structure, organisation, and funding arrangements, there are some common features associated with better outcomes in the transition process (see e.g. Sloper et al 2011 and others) including:

- A written transition plan.
- Continuity ‘beyond transition’ of designated lead professionals or key workers who are able to coordinate support to the young person, parent or carer.
- Transition service managers having strategic level involvement (e.g. as ‘champions’).
- Transition workers setting up the adult care package for young people, negotiating funding for it and supporting them until they are settled in adult services.
- Use of person-centred planning.
- User involvement in oversight of services.

So far as the structure of services is concerned, the following features seem especially important:

- Transition workers and transition teams who identify and facilitate coordination of support packages and cooperation between providers.
- Services that ‘narrow the gap’ by providing a bridge between child and adult provision with a focus on preparing the child and family for adulthood.
- Formal intra and inter-agency liaison and agreements, strategic transition protocols and pathways to foster improved communication, co-operation or collaboration.
- Arrangements that promote accessibility of services, including accessibility of universal services.

The available research evidence has focused on what works rather than what does not work in relation to transition.

3.6 Principles and Processes of Effective Transition to Adulthood

This list of twelve principles and processes for an effective transition to adulthood has been derived from a review of the transitions literature (see for example Merriman S, 2009, *Trans Map* for a concise discussion of key principles):

- A focus on outcomes.
- Early planning.
- Holistic assessment, planning and review.
- Active involvement of young people and their families.
- Raising aspirations and focusing on key life chances.
- Provision of information, advice and advocacy.
- Opportunities to engage with providers.
- Flexibility in transfer arrangements i.e. arrangements may need to continue over a period of years.
- Comprehensive multi-agency engagement.
- Integrated streamlined assessment and planning processes across all agencies.
- A range of opportunities for young people to access, including opportunities in education, employment, youth and leisure services.
- Regular audit of services and case management approaches.

Improving the pathway to adulthood is likely to have a number of implications for organisations and the individuals who work in them. A number of the more strategic issues and implications for commissioning activity are usefully rehearsed by the Local Government Association (2013):

- There are organisational and cultural differences between services that need to be overcome. Local authorities need to build a picture of the services that people will need over the course of their lives.
- Ensure you have appropriate and clear transition arrangements. These include transition between services or systems not directly under the council's control.
- Make sure that the views of children, young people and families are listened to.
- Develop relationships with key partners to ensure there is a range of learning, work, and leisure opportunities and to meet local need.
- Ensure that your organisation has ways of measuring outcomes for young people at the transition stage and that these are used in commissioning for choice and improvement of services.
- Encourage an integrated approach to direct payments and personal budgets to support transitions from children's to adults' services.

For practitioners, developing the pathway to adulthood will require:

- Understanding and embracing a new impetus at improving the process of transition.
- Developing a good awareness of the issues involved before, during, and after the experience of transition.
- A commitment to more personalised ways of working.
- Finding out what others do and why.
- Challenging systems and processes that don't work well.
- The reconfiguration of some services.

3.7 Key summary messages

- Transition to adulthood happens at different ages for all young people, including those with complex needs or disabilities. This means that locally there should be flexibility in transfer arrangements i.e. arrangements may need to continue over a period of years. There is now considerable evidence to point to the importance of the experience of the transition process in terms of immediate and longer-term life outcomes. Poor transitions are likely to be a key contributor to poor outcomes.

- The barriers to effective transitions are well understood and include: poor multi-agency working; absence of a holistic approach to understanding individual and family needs; lack of information for young people and parents; insufficient attention to the concerns/priorities of the young person, and; lack of appropriate services/provision into which young people can transfer. The challenges combine organisational and attitudinal issues which may also include a lack of expectation and aspiration by the young person themselves about their adult lives. Statutory planning by itself will not lead to the life outcomes that many young people want.

- Just as the obstacles to effective transition are well understood, so too are the factors that make for better transition. Alongside the availability of appropriate provision, a successful transition to adulthood depends on early and effective planning, and putting the young person at the centre of the process to help them prepare for transfer to adult services. The process of transition should start early and while the young person is still in contact with children's services. Organisations need to ensure that they have ways of measuring outcomes for young people at the transition stage and that these are used in commissioning for choice and improvement of services.

4 The Life Pathway Model and care pathways

The Department of Health's best practice guidance, Pathways to Getting a Life: transition planning for full lives, (2011) identified key pathways into adult life for young people with learning disabilities. The guidance states that it is relevant to *all* young people with additional needs (for example, children and young people with other disabilities).

The pathways approach focuses on outcomes rather than services, on the basis that this generates more creative approaches. The approach focuses on the outcomes of: employment, housing, health, and community participation and developing friends and relationships from school year 9. The guidance brings together the learning from Valuing People and Valuing People Now, and from the Getting a Life programme. It sets out the things that need to happen to support young people to move into adulthood, in order to fulfil their aspirations and enjoy equal opportunities.

Apart from Pathways to Getting a Life, there is a lack of literature on the life pathways approach in relation to children and young people with disabilities. However, there are a number of studies and reports of *care* pathway models which identify several common characteristics:

- A systemic and 'whole systems' approach which seeks to identify and encompass the totality of service contribution within the 'user journey'.
- Unlike guidelines, they define and describe parts of the care process, which involve a number of specified activities, tasks, procedures or choices over time.
- These are service improvement tools that look to embed best practice and evidence within a logical and optimised sequence of care and support over time.
- There is an explicit link between points of intervention and user outcomes within a formalised process of care and support.

Movement is implicit in care pathways, although it may be chronological (events over time), journey through a service cycle (assessment, planning, delivery, review) or a continuum of need (e.g. deploying a graduated or staged approach, such as from general population-based interventions to individualised and specialist interventions).

The use of care pathways as a tool to facilitate integrated working is becoming increasingly commonplace within the health and social care service sectors, where integrated working *involves collaboration between members of different organisations or professions to deliver a service focused on the needs of those who use the service rather the needs of organisations providing it* (Price, 2009). Indeed, they have been described as the '*lynchpin*' of integrated services (WAG, 2005).

4.1 Types of care pathway

Furley (2006) proposes four overall types of care (or support) pathway, each of which depends upon and is developed in line with a specific strategic objective (and may potentially co-exist):

- High-level care pathways

Referred to also as service pathways or models, these are used to agree medium to longer-term strategic visions for services. These models identify service re-design requirements within a whole-systems framework that accommodate the entirety of a service user's journey, regardless of organisational boundaries. They draw on the available evidence base, the benefits that can be realised, the targets to be met and the provider and commissioning changes needed. These models can be used to engage and support multi-professional and agency groups in developing shared objectives and a commitment to longer-term strategic development.

- Integrated care pathways (ICPs)

Integrated care pathways (ICPs) are systematically developed multi-professional tools that set out locally agreed standards of care or support based on the available evidence, and are designed to ensure the recording and monitoring of that care and the measurement of outcomes (McDonald *et al*, 2006a, 2006b). The strengths of using an ICP include: delivering evidence-based care at operational level; and supporting and sustaining change in day-to-day practice. The recording of variance (i.e. any deviation from the planned care or support) which is a unique element of an ICP, and its analysis at aggregate level for cohorts of service users, supports resolution of service provision or delivery issues, either through amendment of the ICP or the development of a business case to support service development.

- Algorithms

These are sets of rules normally describing a sequence of actions at points along a pathway that are agreed by multi-agency teams and developed to standardise practice and to embed relevant national and local guidance into practice. Algorithms are succinct and simple to use. As algorithms detail standards, they provide a framework to measure care and performance. Algorithms do not act as a record of care or support, and are focused on specific or individual episodes of support so their impact may be limited in terms of service re-design across the whole patient journey.

- Pictorial or annotated pathways

These are developed for use by service users and usually in conjunction with them, as a hand-held document and/or an information leaflet/poster. They help service users, including family members, to understand and navigate services over a period of time and may include an element of standards to which services are committed at each stage of the pathway.

4.2 Principles of care pathway design

Formal evaluation of integrated pathways remains rather limited. No studies were identified for this review which dealt with the use and impact of care pathways for children or young people within non-health settings. However, some broad principles emerge from a review of the current literature on care pathways (for example, Allen et al, 2009; Ahmad et al, 2007; Evans-Lacko et al, 2010; Rotter et al, 2010; Deneckere et al, 2012):

- Pathways should be:
  - Workable and understandable for individuals, their families, partners and carers, and professionals.
  - Accessible and acceptable to all people in need of the services served by the pathway.
  - Responsive to the needs of individuals, their families, partners and carers.
  - Integrated so that there are no barriers to movement between different services and levels of the pathway.
  - Outcomes-focused (including measures of quality, service user experience and harm).
- Pathways should minimise the need for movement between different services or providers; allow services to be built around the pathway and not the pathway around the services; establish clear links (including access and entry points) to other care pathways; and ideally have designated staff responsible for the coordination of people's engagement with the pathway.
- Developing a focus on the family as a whole means that a wider network of services is likely to be involved in the pathway than has conventionally been the case.
- Specific consideration needs to be given to variance reporting and pathway review as these consistently appear as areas of weakness in operation.
- Pathways need to be locally scoped and owned and to reflect local contexts, histories and circumstances.
- A balance is needed between comprehensiveness of scope and manageability, suggesting that pathway development should be an incremental process with an

initial focus on high-level mapping and detailed work within identified areas of change that are likely to make the most difference in terms of improving outcomes for families.

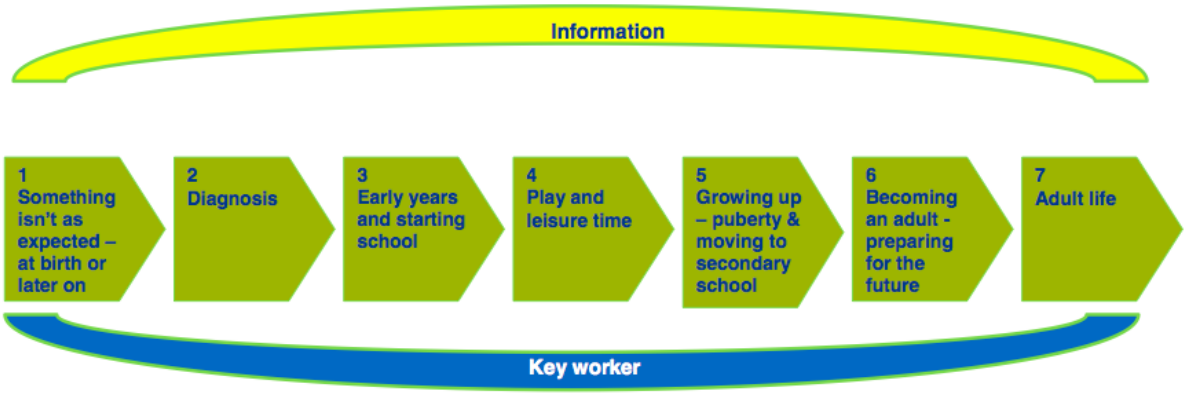
- Supporting guidance for professionals, children and young people and families' needs to reconcile comprehensiveness of detail with usefulness and usability.
- Information generated by pathways should not be simply confined to reviewing the operation of the pathway itself, but be utilised to inform broader commissioning activities.
- Pathways need to accommodate and support multiple points of entry to services.
- Shared documents, such as single assessment and family-based plans can serve as useful and powerful vehicles for integration as they draw the perspectives and contributions of many stakeholders into one coherent record.
- Developing and implementing pathways will involve change management activity. The amount of time that is required to support this kind of implementation through change management cannot be underestimated.
- Early support and intervention objectives also have implications for the skills base and workload pressures for key professional groups particularly within universal services. Training programmes designed to support implementation of a new pathway need to take account of this and to address identified deficits. In addition, a realistic assessment of the impact of new roles on workload pressures within key staff groups needs to be undertaken and made subject to routine review.

5 Models and good practice examples

This section presents examples of: a model family support pathway, 0-25 years services, and good practice transitions services.

5.1 Model family support pathway

IPC developed a Family Support Pathway model for children and young people with disabilities. The pathway shows the journey of a child and family over time, from the family's point of view. It is grouped into a series of stages. The pathway tells everyone involved what should be happening, and it can help families and professionals make sense of a complex world.



Each pathway stage in this document describes the following:

- **Event** A period of time or key event in the life of the family.
- **People involved with families** Which professionals should be involved with parents/carers and children and young people. To provide holistic services, multi-agency working will need to be a key part of this process.
- **Where** Where things should happen.
- **When** At what point in time should things happen. For example the length of time to wait for a service.
- **What can we expect?** What should happen, i.e. a list for the family and the professionals to check whether the right things have happened.

The model family support pathway is centred around a series of 7 ‘events’ representing key events, or periods of time, for children and young people with disabilities and their families. These events were drawn from interviews with families, who described significant events or periods of time in the life of their child and cited particular ‘pressure points’ along the way. These events were also informed by discussions with local professionals who cited similar events in the lives of children.

The model pathway emphasises the importance of information and the role of the key worker: ‘*The right information, given at the right time, at every stage, is very important for parents*’. Types of information needed include:

- Information about the process of support and care, including what will happen next and what is due to happen when.
- Information about the disability including diagnosis and how it will/may change over time, plus trusted and reliable websites.
- Health care arrangements.

- Services available, including entitlement to services and waiting times.
- Support options including short breaks, counselling and support groups.
- Play, sport and leisure opportunities.
- Financial information.

Key workers have responsibility for working together with the family and with professionals, and for ensuring delivery of an inter-agency care plan for the child and family.

5.2 South Gloucestershire - 0-25 Years Service

South Gloucestershire Council has established an integrated 0-25 service for children and young people with disabilities which aims to provide a seamless service. The service is composed of Portage, Early Years Worker, SEN Service, Disability Social Work Service, Occupational Therapist, Adult Disability, and Travel Trainers. The team is made up of Team Managers, Senior Practitioners, Lead Professionals, Lead Workers and Assessment Coordinators. They are split into two geographical teams.

First Point is the 'single front door' to all children and young people's services in South Gloucestershire, including the new 0-25 service. 'Needs Indicators' have been developed by the service in consultation with parents, children/young people. These are used as a guide by staff in First Point to help them screen requests for a referral to the new 0-25 service and signpost to what's available in the Local Offer.

Every referral accepted by the 0-25 service is allocated a Lead Worker/Lead Professional. The first stage involves the Lead Worker/Lead Professional working closely with the child/young person and their family to gather and review evidence to decide whether to do a 'needs assessment'. The Lead Worker/Lead Professional is supported by their manager and a multi-agency panel. The aim is that their expertise matches the needs of the child or young person.

If the decision at this stage is that the child/young person's needs would be better met via the Local Offer, then the Lead Worker/Lead Professional provides advice and support on how to access those local services. If the decision is to do a 'needs assessment', then the Lead Worker/Lead Professional contacts other relevant services, and together with the parents, as the Team around the Child (TAC) they work with the child/young person to find out their needs and personal goals and how the plan of support can help them achieve those goals and reach their potential. The aim is to develop a one-stop approach.

The local Parent Forum was actively involved in the development of the service. Questionnaires, focus groups and forums were used to engage and consult parents and young people.

5.3 Essex County Council – 0-25 Years Service

Essex County Council introduced a service to support children and young people with disabilities from 0-25 years old in July 2014. After consultation with staff and the public, four geographical teams were set up with each one incorporating the following functions:

- Children with disabilities team – supporting 0-15/16
- Young people with disabilities team supporting 16-25
- Occupational therapy – supporting 0-25
- Information, advice and guidance (IAG) – supporting 14-25
- Family and child support – supporting children with disabilities teams but due to be reviewed.

A Central team covers:

- Communication and engagement
- Service development
- Contracting and administration of the High Needs Funding budget
- Management and oversight of the IAG function
- Management and oversight of the OT function.

The structure is perceived to benefit from ensuring all teams have a dedicated team manager, providing a more local and integrated sensory service, a strengthened OT service with a reduction in waiting times, a removal of the need for a formal referral, and co-location which will enable more joined up working.

Essex has established a transition protocol which sets out the criteria for a young person to move to an adult social care team which covers education, accommodation, employment, and support.

5.4 Leeds City Council Complex Needs Service

Leeds complex needs service is for children and young people from 0 to 25 years with complex learning difficulties and disabilities, and their families. It aims to ensure that every Leeds child with a significant learning difficulty or disability will benefit from child-centred, high quality, flexible and responsive services that help them to live a successful and fulfilling life.

There are three area based complex needs teams: East North East, West North West and South. Each team works closely with families, schools and other learning providers to deliver strong support services which are coordinated around the needs of the child or young person (0-25 years) and their family.

There are five main professional areas within the complex needs service and they are:

- Special educational needs statutory assessment and provision service (SENSAP)
- Special educational needs inclusion team (SENIT)
- Educational psychology
- Sensory service
- Child health and disability (CHAD) including social work teams, occupational therapy and the regional specialist paediatric team

5.5 Transition models

Forbes and colleagues (2002) provided a review of current practice relating to the transition from child to adult health and social care which provides a framework for service development and identifies four transition models:

- Model 1: Direct transition

  The emphasis in this model is on good communication and sharing of information. Continuity results when the young person is transferred to adult care safely and efficiently. It does not address aspects of personal growth and development.

- Model 2: Sequential transition

  This model recognises that some special services will have to be provided in order to meet young people's needs as they grow older. The structure of this type of service needs to be distinct from child-orientated care and must allow the young person to rehearse and prepare for adult care. This may involve an important redefinition of the family role, with young people being given increased autonomy in making decisions about their care.

- Model 3: Developmental transition

  This model assumes that young people will need some help in acquiring the skills and support systems they need if they are to use or experience adult care effectively. The model recognises that assistance with general personal development – physically, psychologically and socially – will be required if the individual is to make a smooth transition to adult services. This model was most common in services for vulnerable young people and those with physical disabilities or learning difficulties. Model 3 has some affinity with model 2, but has an active focus on personal growth and development throughout the transition. Again, this is likely to involve redefining the family's role in providing care.

- Model 4: Professional transition

  This model differs from the other three in that its focus is on the professional rather than on the young person. It aims to ensure that the expertise that the young person has benefited from while under the care of children's services continues to be present once he or she comes under the umbrella of the adult service. The fourth model would ensure that practices were in place to make certain that the necessary skills were transferred between the child and adult teams.

These models are primarily health based. Also from health is a study which underlines that successful transition is not just about getting the model right: '*Young adults have repeatedly been surveyed and report they care more about the interaction with the health professional than the model of transition used*' (Gordon, 2012).

A couple of evaluations of specific transitions service models are presented below, along with SCIE's practice examples of local authority arrangements for early and comprehensive identification of children and young people requiring transitions services in the context of the Care Act 2014.

5.6 Multi-agency Services for Transition to Adult Services for Disabled Young People and Those with Complex Health Needs

A study of multi-agency services for transition to Adult Services for disabled young people and those with complex health needs showed that dedicated multi-agency transition services could provide a valuable service for disabled young people and their parents and have a positive impact on meeting some of their needs (Sloper et al, 2011). This was most likely to happen when transition workers worked directly with young people and families.

The main models explored in the study were services which had a transition team whose members worked directly with young people and families; and coordinating services, where a transition team or transition manager/coordinator supported existing services in working with young people through transition. Whilst there appeared to be somewhat greater advantages for families from designated teams, the coordinating model worked relatively well in an area where the transition manager supported a virtual team of social workers from children's and adult services who worked directly with the young people. This was a small area with good relationships between services and it may be that this model is more suited to that type of locality. The multi-agency transition services were largely focused on young people with severe learning disabilities.

5.7 My Way – Transition Model

My Way is a transition model for young people with learning disabilities, developed by MacIntyre, which aims to support young people to make the transition from children's services to their new adult life. The My Way approach involves holistic, person-centred support planning, the use of facilitators in a brokerage role, and a focus on outcomes.

My Way facilitators work closely with the young person as well as their family, friends, circle of support, teachers, support staff and various external organisations to gather information, create a transition plan using their personal budget, and then put the plan into action. Each young person has a dedicated facilitator who supports them and their families to design and be in control of their support arrangements. The facilitator enables the young person to access adult services and other agencies, such as housing, are encouraged to engage when appropriate. Facilitators organise their own caseloads, keeping detailed records, visiting the young person in school or college – including out of county – and, in between meetings, doing a lot of legwork to get options lined up, people on board and visits organised. Facilitators also support young people to interview providers and agree more detailed support plans with selected providers.

An evaluation suggested that the My Way approach resulted in better outcomes and had the potential for creating cost savings (Broadhurst et al, 2012).

5.8 Hampshire County Council[1]

Hampshire County Council (HCC) employs a transition team and each member has contacts with the schools in their local area. They link with what used to be youth support services and post-16 special educational needs services, building relationships

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[1] These and following case studies drawn from SCIE transition practice examples.

with parent and carer groups, children in care, disabled children and children in need teams. The team offers an assessment and if a young person meets the criteria for adult services, they will identify appropriate services and secure funding. If the young person does not meet the criteria, they are signposted to appropriate services and advice and can re-present at any time, if their needs change, through the HCC contact centre.

The transition team builds links with the local physical disability and mental health teams. Following completion of the assessment process, the team will refer an individual directly to the appropriate service prior to their 18th birthday. In addition, team members consider anyone who will be turning 18 who has complex needs, where it is not obvious who should be the lead service. They then present a written profile of the young person to a complex case panel, which is made up of a variety of managers who have the authority to agree funding. A decision is then made about which team/service they will be allocated to when their transition to adult services begins.

Each transition team member facilitates meetings between local health colleagues, special educational needs services and schools/colleges. There is also a monthly joint planning group (JPG), which is led by special educational needs services. This is where young people, who need to continue with or change their educational establishment post-18 (which could include a residential element) and whose programme of education will not finish until they are over 18, and will therefore involve adult services, are discussed. Service managers from adult services also attend these meetings so that a joint decision can be reached about the best way to meet an individual’s needs.

HCC also has a contract with an independent provider to give supported employment (paid and unpaid) to anyone who meets the adult criteria (for the learning disability team), or anyone who is borderline in meeting the criteria and is on the autistic spectrum. A group made up of provider and council representatives meets monthly to consider all applications. In terms of prevention, the community independence team (CIT) will provide time-limited support (up to 12 weeks) for young people who do not meet the criteria. The expectation is that providing this short period of support will prevent them from requiring long-term services. Support could include travel training on buses and trains, introductions to generic groups within the community, approaching job centres and so on. Hampshire has a contract to provide telecare equipment, which might be needed by people supported by the community independence team as well as those who meet the criteria. In partnership with the Department for Work and Pensions, Hampshire is also convening a strategic employment group who will co-produce an employment pathway.

5.8.1 IT and information systems

Hampshire uses a different information system to record adult user information from that used to record children’s information. The transition team can access both sets of records and has access to basic primary health care records. All the transition social workers with the exception of one are co-located within the adult services/learning disability specialist health team. This helps to improve communication and information-sharing, (although a single information system would be likely to be even more effective).

5.9 London Borough of Newham

The London Borough of Newham employs a transition service that has a particular focus on 14-25 year olds and has appointed a health care professional to this team to continue the integration agenda. This service meets regularly with special educational needs coordinators (SENCOs) to provide information about the team and the work, including the referral process. Relationships are built through regular visits to schools and via workshops for staff and parents. In addition, data are made available from the education sector on all of those identified as having special educational needs. This is added to a tracking list, which is cross-referenced with social care and health, allowing early identification to be made.

Adult social care teams in Newham are generic, meaning that they provide a service such as reablement to all the people who meet their criteria. In terms of mental health, there are good links with CAMHS and a working relationship with adult mental health services. This comes about through regular meetings with the service manager, which focus on strengthening pathways and joint working. Newham has also joined up its children and adults service workforce in relation to transitions and has appointed a new person to deal with referrals as a result of Education, Health and Care plans.

Newham holds a monthly parent forum co-chaired by an equal number of parents and staff. This group is very involved in supporting Newham to shape its services. Parents sit on strategic groups and are part of the decision-making process.

In Newham, 0–19 year olds funding decisions are discussed at a care package panel, which meets fortnightly. Information from the multidisciplinary tracking meeting supports decision-making. More complex decisions are referred to a children's integrated resource panel, which is made up of decision-makers from the health, education and social care sectors and meets monthly. Adults over the age of 18 are assessed by a funding allocations and support planning panel, which meets daily. Once a month, representatives from health attend this panel to discuss jointly funded service users.

5.9.1 IT and information systems

Newham is developing a bespoke IT system to track data on children and adults as well as an interface with other systems such as RIO (health) and software in education such as Child View. In the meantime, the transition team has access to both children and adult systems and is also able to access information systems such as RIO and Child View.

5.9.2 Early identification: looked-after children

Newham is aware that young people who are not known to social care who have been looked-after children and those who do not meet adult social care eligibility criteria could be vulnerable. Some are also known to the criminal justice system, drug and alcohol services and the homeless persons unit. Newham commissioned a study of such young people, with the intention of better understanding how to support them to achieve their aspirations, maintain their independence and keep themselves safe. Advice and guidance is offered to all at monthly drop-in meetings, youth forums and parents' groups.

5.10 Stoke-on-Trent

Stoke-on-Trent is building on its Aiming High programme using a link with the SENCO in each high school/academy. There is a regular meeting of all the SENCOs, which provides a conduit for information exchange and discussion. There are also strong links with senior managers across the authority with lead responsibility for inclusion/school achievement.

Stoke also runs an enhanced level of Aiming High that supports children and young people and their families with more complex needs, where they are on the edge of meeting the social care threshold and are likely to need longer-term support into adulthood. This enhanced service accepts cases through a short breaks resource allocation meeting, where professionals from statutory and non-statutory/voluntary and community services meet to discuss those who may meet the enhanced criteria. Information on children and young people who receive enhanced Aiming High is shared with the adult social care manager as part of the early identification process. Adult social care staff have a regular planned joint meeting with the child disabilities social care team to review and work together on cases where young people are aged over 14.

Stoke's transition forum meets monthly with partners from education, post-16 specialist learning providers, voluntary care services, health and children and adult social care services to discuss individual cases and provide a useful information-sharing network on young people as they approach the age of 17. As a result of discussions at the forum, in most cases, a referral is made or agreed in collaboration with the child social worker. Other referrals are made to post-16 learning providers or to a continuing health care panel for financial consideration. If a decision cannot be reached easily, it is forwarded to senior managers as well as the special educational needs and disabilities reform board where partners are involved. The board is the strategic overarching partnership where trends, emerging issues and future actions are agreed upon.

A weekly Education, Health and Care (EHC) panel provides an opportunity for agencies to work openly together and to assess individual cases via the planning and assessment process.

Health services are engaged and attend the special educational needs and disabilities reform board and the transition forum. Many attend the monthly short breaks resource allocation meeting.

Together with its physical health services, Stoke's education and children's social care staff are planning together to create a single new centre for services where disabled children and their families can be co-located under one roof. The purpose of this building is to ensure that services covering assessment, support, intervention, information and advice are housed together in a single building, making it easier for families, children, young people and young adults to source the advice and support they need. The joint planning for the new centre, together with the special educational needs and disabilities reforms, has encouraged health services to become more involved.

5.10.1 Local parent forum

The Aiming High Together parent forum is run for and by parents of disabled children, young people and young adults. A small amount of funding is available to this forum from a national government source. The local authority commissions small, specific pieces of work such as organising workshops on particular topics, along with wider engagement work. The forum also acts as a conduit to inform commissioning processes. The forum supports the Aiming High programme in terms of co-production, but has extended its involvement into the special educational needs and disabilities reforms, including the 'local offer' and the 'whole-life disability approach' that have been adopted throughout the authority.

The forum links to a community interest company (Crossroads Care – the lead provider of support to informal carers of people with disabilities) and meets monthly with parents, who set the agenda. Invitations are extended to children's social care, adult social care and others as the need arises. The forum has planned and hosted a workshop for families and professionals on developing a whole-life disability approach, which focused on what needs to improve and on creating an agenda for change/action plans with professionals.

5.10.2 Monthly short breaks resource allocation meeting

The Aiming High programme delivers short breaks – activities and support – to children and young people at the lower levels of social care thresholds up to the age of 20. Approximately 400 children and young people access short breaks under Aiming High or Aiming High Enhanced. Many of these do not have a social worker, hence this programme helps to fulfil Stoke's early identification and support approach to families.

The monthly allocation meeting is attended by a range of providers, including health/specialist health. All providers work through various cases where more help is needed, and advice and support are given with agreed next steps and a review process to monitor progress. Actions are logged and followed up at the next meeting.

5.10.3 Engaging with black and minority ethnic families

Stoke's universal/early identification and support services (via local resources including children's centres, housing teams, nurseries, schools, leisure services, etc) use the early help assessment process to identify additional needs and refer into higher-level services if this is needed. A proportion of referrals into Aiming High are made from these universal settings.

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