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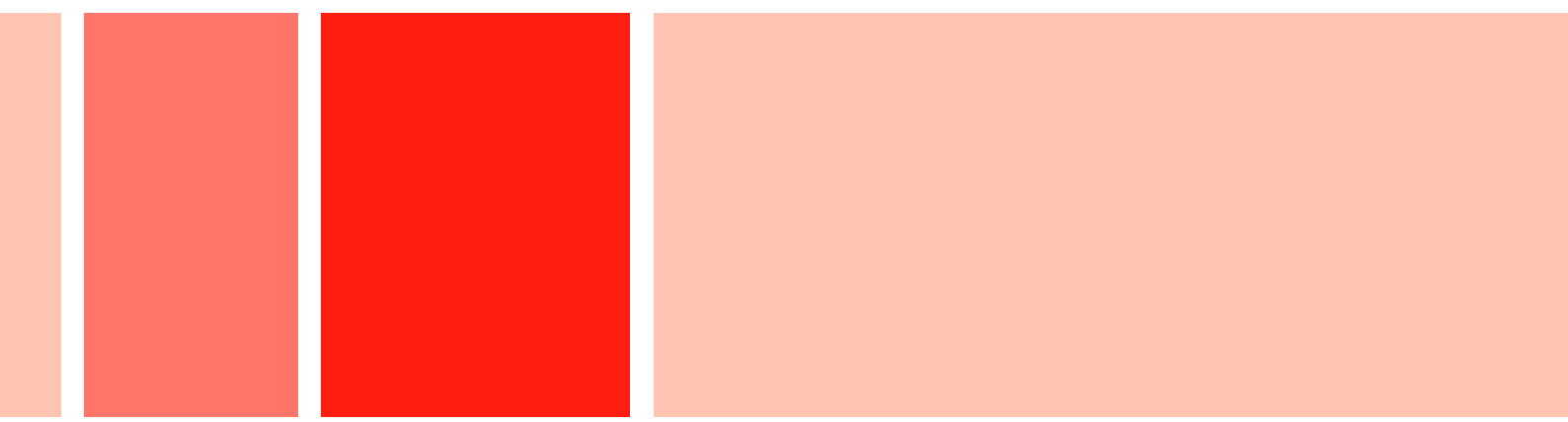


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# The Costs and Benefits of Transition Key Working: an analysis of five pilot projects

## Final Report



# **The Costs and Benefits of Transition Key Working: an analysis of five Pilot Projects**

## **Final Report**

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## **The People and Work Unit**

Views expressed in this report are those of the researcher and not necessarily those of the Welsh Government

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## Acronyms

ADHD	Attention Deficit Hyperactivity Disorder
ASD	Autistic Spectrum Disorder
ALN	Additional learning needs
CC	County council
CCNUK	Care Co-ordination Network UK
DCSF	Department for Children, Schools and Families
ELLS	Education, Lifelong Learning and Skills
ELWa	Education and Learning Wales
ESF	European Social Fund
FTE	Full-time equivalent
LA	Local authority
MoT	Moving on Together
NAfW	National Assembly for Wales
NCH	National Children's Home
NDA	National Disability Association
NHS	National Health Service
NSF	National service framework
ODPM	Office of the Deputy Prime Minister
PA	Per annum
PMLD	Profound and Multiple Learning Difficulties

SEN	Special Educational Needs
TKW	Transition key worker
WAG	Welsh Assembly Government (pre May 2011)
WAO	Wales Audit Office
WG	Welsh Government

# 1. Introduction

## Transitions for disabled young people

- 1.1. The transition into adulthood is a potentially difficult time for any young person but for those with disabilities, there are often additional challenges associated with the number and range of transitions that such young people make. The timing of these transitions, which often happen over the same period of time, also creates challenges. For example, a young person may move from their school; from their home, foster placement or a long-term residential school; from paediatric to adult health care; and from children's services to adult services all at the same time.
- 1.2. As a consequence of these multiple transitions, disabled young people and their families can face considerable uncertainty and stress. Young people with disabilities can lose the familiarity and security of home and school, and contact with workers and friends they have known for years (Janus, 2009). The multiple changes can also bring a range of new agencies and workers into a young person's life and lead to changes in entitlements and services (Sloper et al, 1999). For example, young people and families or carers are moving from the relative security of a statutory education system, paediatric health care and free social care, to discretionary services, direct payments (for some), multiple specialist adult health services and a range of learning options with, often, a lack of clarity about what these changes will entail (ibid.).
- 1.3. The challenges families experience as a result of changes in the services disabled young people receive can be exacerbated by other changes. These include shifts in the balance of control, as for many families transition is the point where young people start to take control

over their own lives and parents and carers have to let go and accept that their role has to change. In some cases, this can be a very difficult time, especially where a young person's needs have been such that families have been very protective and have fought hard to ensure adequate care. Recognising that what a young person wants, or needs, may not be what the family want or can provide can be very hard, especially where a history of conflict has resulted in families questioning the right, or ability, of services to make judgements about a young person's needs (Pascall and Hendey, 2004).

1.4. Key working is seen as an integral part of the integrated assessment, planning and support that is needed to help young people and their families to manage these challenges (York Consulting, 2010). This, in turn, will help young people make a successful transition into education, training and/or employment and to become able to live meaningful and satisfying adult lives (Morris, 1999).

1.5. In 2008, five transition key worker pilots were set up to develop transition key working in Wales for disabled young people. Key working has been defined as a:

“...service, involving two or more agencies, that provides disabled children and young people (0-25 years of age) and their families with a system whereby services from different agencies are co-ordinated. It encompasses individual tailoring of services based on assessment of need, inter-agency collaboration at strategic and practice levels, and a named key worker for the child and family giving a single point of contact” (CCNUK website).

1.6. All the pilot projects adopted a person-centred planning methodology. This has been described as:



“...a way of discovering how a person wants to live their life and what is required to make that possible” (NDA, n.d.:3).

Person-centred planning reflects a ‘social’ (as distinct from ‘medical’) model of disability<sup>1</sup>, embodies a strengths-based approach to planning and seeks to involve people as active participants in the planning process. Person-centred planning typically involves exploring, and distinguishing between, what is “important to” and “important for” a person and may also explore “what is working” and “what is not working” for a person, using a range of methods to facilitate this. Crucially, it also involves planning to meet people’s needs, preferences and aspirations in a person-centred way.

- 1.7. Adopting a person-centred planning approach extends the transition key worker role. It involves co-ordinating services for young people and their families (the traditional transition key worker role) and supporting young people to decide what they want to get out of life and then helping them work out how to get it (a person-centred planning approach to transition key working). In this report, we consider the benefits of both the co-ordinating role of a transition key worker and of a person-centred planning approach.

## **The aim of the study**

- 1.8. The aim of this study is to identify whether there are any net benefits of transition key worker (TKW) arrangements in the five pilot areas and to assess those against net cost. As part of this, the study was required to evaluate the transition key worker role and the impact of its

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<sup>1</sup> Social and medical models of disability are the two dominant models of disability. The medical model casts disabled people as the “problem” who consequently need to change and adapt in order to participate in society. In contrast, the social model views disability as a consequence of the way society is structured and organised which, therefore, needs to be changed in order to avoid excluding or marginalising disabled people (The Open University, website). In 2002, the Welsh Assembly Government adopted the social model of disability as the foundation for its work on disability (Welsh Government, website).

intervention on disabled young people's, and their families',  
experience of the transition into adulthood.

## **2. The context for the Welsh Government transition key worker pilot projects**

### **Introduction**

- 2.1. Support for disabled young people preparing for or making transitions, is governed primarily by the National Service Framework for Children, Young People and Maternity Services in Wales (WAG, 2006) and the Special Educational Needs Code of Practice for Wales (NAfW, 2004a). These documents outline the support that young people who are disabled or who need continuing care, and/or who have a statement of special educational needs, can expect to receive in preparing for, and making, the transition to adulthood.

### **The National Service Framework for Children, Young People and Maternity Services in Wales**

- 2.2. The National Service Framework for Children, Young People and Maternity Services in Wales (WAG, 2006) sets out the quality of services that all children, young people and their families in Wales have a right to expect and receive. It includes universal standards, which apply to all children and young people, and specific standards for particular groups of young people, such as disabled children and young people. These standards are underpinned by “actions” for organisations responsible for their delivery, such as a local health board or local authority (ibid.).
- 2.3. A young person is deemed to be potentially disabled and, therefore, covered by the standards for disabled children and young people, if they have a life-limiting condition as defined by the Association for Children with Life Threatening or Terminal Illnesses and their Families/Royal College Paediatrics and Child Health (ibid.: 44; ACT/RCPH, 2003).

2.4. The national service framework standard for transitions, covers:

“Young people who require continuing services, such as those who are disabled or chronically ill, young people with persistent mental illness or disorders, vulnerable young people and their families and carers, and care leavers” (WAG, 2006:54).

2.5. The actions in relation to this standard include:

- establishing an inter-agency system to identify young people who will require support in making the transition from children’s services to adult services;
- appointing a transition key worker when a young person reaches 14 years of age. The worker is responsible for co-ordinating the planning and delivery of services in preparation for transition, during transition and after transition; and is required to monitor and maintain contact with the young person until the young person reaches 26 years of age;
- preparing a joint agency transition plan that outlines support arrangements and which is reviewed at least annually;
- providing disabled young people with information about how to access information services and facilities; and
- providing aggregated information, drawn from the joint agency transition plan, to the children and young people’s partnership (WAG, 2006:54-55).

2.6. Although, as outlined above, the national service framework (ibid.), outlines the quality of services that children, young people and their families have a right to expect, only 84 of the 203 national service framework key actions required immediate delivery. The remainder are described as “developmental” and will be delivered over the lifetime of the national service framework programme (2006-2016)

(ibid.: 3). Crucially, none of the actions relating to transition were prioritised as requiring immediate action.

## **The Special Educational Needs Code of Practice for Wales**

2.7. The Special Educational Needs Code of Practice for Wales (NAfW, 2004a) provides guidance for local authorities, maintained schools, early years settings and others on meeting their statutory duties to identify, assess and make provision for children's and young people's special educational needs). As outlined in the code of practice:

'Children have special educational needs if they have a learning difficulty which calls for special educational provision to be made for them.

Children have a learning difficulty if they:

- (a) have a significantly greater difficulty in learning than the majority of children of the same age; or
- (b) have a disability which prevents or hinders them from making use of educational facilities of a kind generally provided for children of the same age in schools within the area of the local education authority
- (c) are under compulsory school age and fall within the definition at (a) or (b) above or would so do if special educational provision was not made for them.

Special educational provision means:

- (a) for children of two or over, educational provision which is additional to, or otherwise different from, the educational provision made generally for children of their age in schools maintained by the LEA, other than special schools, in the area
- (b) for children under two, educational provision of any kind' (NAfW, 2004a:1, adapted from Section 312 of the Education Act 1996).

- 2.8. The code of practice (NAfW, 2004a) outlines a step-by-step approach to meeting a child's or young person's needs. The final step is statutory assessment. If this assessment indicates that specialist help is required<sup>2</sup>, the child's needs, and the response to meeting those needs, are recorded in a statement of their special educational needs.
- 2.9. The code of practice outlines how from year nine onwards, as part of the annual review of their statement of special educational needs, a transition plan should be drawn up, and then reviewed on an annual basis (ibid.). This plan is intended to support the young person's transition to adulthood. The code outlines that the head teacher is responsible for monitoring and co-ordinating the delivery of the plan and that Careers Wales have the lead role in relation to those elements of the plan that relate to the young person's transition into further learning or employment (ibid.).
- 2.10. The code of practice also outlines the separate duty the National Assembly for Wales has, under section 140 of the Learning and Skills Act 2000, to ensure that in a young person's final year of school (typically in year 11):

“...an assessment of their needs on leaving school is undertaken and the provision identified” (ibid.:132).

- 2.11. This duty is primarily met through annual contracts with Careers Wales companies and the code of practice outlines how this assessment should be linked to the transition plan (ibid.).

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<sup>2</sup> As the guidance outlines, following an assessment, ‘The LEA may decide that the degree of the child's learning difficulty and the nature of the provision necessary to meet the child's special educational needs is such as to require the LEA to determine the child's special educational provision through a statement’. It goes on to say that ‘The LEA will make this decision when it considers that the special educational provision necessary to meet the child's needs cannot reasonably be provided within the resources normally available to mainstream schools and early education settings in the area’ (NAfW, 2004a, 94).

## The effectiveness of policy and practice

2.12. In 2003, the Education, Lifelong Learning and Skills (ELLS) Committee established a policy review of special educational needs. The review was conducted in three stages<sup>3</sup> and the final part of the review focused on transition<sup>4</sup> (NAfW, 2007a). The review found that, despite the standards laid down in the national service framework (WAG, 2006) and code of practice (NAfW, 2004a), there was:

“...often a lack of co-ordination between agencies”

and that:

“young people and their families often feel unsupported in planning for their future” (NAfW, 2007a:iii; see also NAfW, 2007b:10, 46).

2.13. The review also found that outcomes for adults with learning difficulties or disabilities, in terms of securing employment and independence, were poor, with employment rates as low as 5% for some groups of young people with learning disabilities (NAfW, 2007a).

2.14. The Equality of Opportunity Committee review into Service Provision for Disabled Young People (NAfW, 2007b) reached broadly similar conclusions, highlighting, among other things, the need for greater support and better co-ordination services for disabled young people as they make their transition to adulthood.

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<sup>3</sup> The first two phases focused upon early identification and intervention (NAfW, 2004b) and the statutory assessment (statementing) framework (NAfW, 2006).

<sup>4</sup> The committee advocated the adoption of the term “additional educational needs” and their third report on transitions is entitled “Policy Review of Additional Educational Needs” (NAfW, 2007a). However, as this phrase was not adopted by the Welsh Government, we have used the original term, special educational needs, to avoid potential confusion.

## **The Welsh Government transition key worker pilot projects**

- 2.15. In October 2007, an External Strategic Reference Group<sup>5</sup> was established by the Welsh Assembly Government to consider how best to take forward the recommendations made by the Education, Lifelong Learning and Skills Committee (NAfW, 2007a) and the Equality of Opportunity Committee (NAfW, 2007b) into the experiences of disabled young people and/or young people with learning difficulties, as they make the transition into adulthood.

In 2007, as part of the Welsh Assembly Government response to the recommendations made by the Education, Lifelong Learning and Skills Committee, a grant funding stream of £1.5 million was announced to develop transition key working in Wales. In June 2008, local authorities were invited, by letter, to apply to become pilot sites to develop the role of transition key workers in Wales for young people with a disability as part of a phased approach to develop transition key working in Wales.

- 2.16. The letter of invitation refers to the national service framework standard on transition. In particular, the letter refers to key action 5.33, which covers the appointment of a transition key worker, and requires proposals to take account of this. The invitation letter also requires proposals to take account of the Equality of Opportunity Committee (NAfW, 2007b) report Service Provision for Disabled Young People; The Education and Lifelong Learning Committee Policy Review of Special Educational Needs, Part 3: Transition (NAfW, 2007a); the Autistic Spectrum Disorder (ASD) Strategic Action Plan for Wales (WAG, 2007); and the Special Educational Needs Code of Practice for Wales (NAfW, 2004a).

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<sup>5</sup> The group is made up of representatives of young people with learning difficulties, representatives from education including further and higher education, health, social services and employers' organisations as well as Careers Wales and Skills Wales.



- 2.17. In 2008, Anglesey, Ceredigion, Gwynedd, Pembrokeshire and a regional collaboration between Monmouthshire, Blaenau Gwent and Torfaen were awarded funding. The five transition key working pilot projects began in September 2008 and ran until March 2011.
- 2.18. Each of the pilot areas developed different approaches to supporting disabled young people's transition before joining the pilot project and used the pilot projects to develop their service in diverse ways. Four of the sites established a designated key worker service, consisting of professionals specifically employed to undertake the role of transition key working. The other pilot, Anglesey, developed a non-designated key worker model. This involved either (a) professionals providing a key working service to some families, while also undertaking the role for which they are primarily employed, such as that of community nurse, or (b) parents or carers providing a key working service for their child. Further details on the background and objectives of the pilot projects are included in appendix 2.
- 2.19. In total, the pilots worked with 202 young people (see Table 1 for details).

**Table 1. The total number of young people supported by the pilot projects**

<b>Local Authority</b>	<b>No. of young people</b>
Anglesey	23
The Monmouthshire consortium	36
Ceredigion	39
Gwynedd	44
Pembrokeshire	60
<b>Total</b>	<b>202</b>

Sources: Anglesey County Council (n.d. b); Ceredigion County Council (n.d. b); Gwynedd County Council (n.d. b); Monmouthshire County Council (n.d. b); and Pembrokeshire County Council (n.d. c).

### **3. Research design and methodology**

#### **Aim and scope of the study**

3.1. As outlined in chapter one, the aim of this study is:

“... to identify whether there are any net benefits of transition key worker arrangements in the five pilot areas and to assess those against net cost. In doing so, the research should evaluate the transition key worker role and the impact of their intervention on disabled young people’s, and their families’, experience of the transition into adulthood” (WG, n.d. a:3).

3.2. In considering benefits for individuals, the study was required to consider the extent to which the benefits identified extend to all disabled young people<sup>6</sup>, or only apply to specific groups of disabled young people. The study was also required to consider the relative cost effectiveness of the pilot models, including the designated and non-designated transition key worker models.

3.3. In order to assess costs and benefits, it was expected that the experiences of young people and their parents or carers receiving the intervention of a transition key worker could be compared with the experiences of those receiving a standard transition service. However, this was not possible, as within the five pilot sites, all young people who were eligible for the service, were offered it. It was also agreed with the study steering group that it would not be appropriate to try to compare the experiences of those receiving a standard transition in non-pilot sites since there was no standard approach to provision and differences between counties would make comparisons difficult. This

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<sup>6</sup> In this context, the specification for the study refers to benefits for young people with “profound and multiple learning difficulties” rather than “disabled young people”. In the interests of consistency and to minimise the risk of confusion, we have used “disabled young people”, in line with the aims of this study, the aim of the pilot projects and the National Service Framework (WAG, 2006) standard on transition.

has important implications for impact attribution, which we discuss further below.

- 3.4. In assessing costs and benefits, it was also agreed with the study steering group that it would not be appropriate to attempt to calculate a financial value for the identified benefits. There are established approaches for calculating the financial value of benefits, such as increased wellbeing. However, where there is no market price, such as, “willingness to pay” (HM Treasury, 2011), the work required to interpret qualitative benefits such as life changes into their financial value, was judged to be beyond the scope of this study.

### **Approach to impact attribution**

- 3.5. In considering the costs and benefits of the transition key working arrangements in each area, it was important to assess the contribution that the transition key working arrangements made to the outcomes. That is to say, it was necessary to evaluate the impact the transition key working arrangements had upon the observed outcomes, such as the costs and benefits experienced by individuals, the state and society.
- 3.6. The standard approach to empirical impact evaluation involves an estimate of the counterfactual, what would have happened in the absence of the intervention, using either control or comparison groups (ibid.). However, as outlined above, it was not possible to use comparison groups who received the standard transition service, and no scope to use control groups, to estimate the counterfactual. Because an experimental or quasi experimental design, using control or comparisons groups, was not feasible, in line with the Magenta Book: guidance for evaluation (Ibid.), the study drew upon a process evaluation and case studies. Whilst this approach did not enable the study to quantify any observed impact nor did it allow an assessment

of the extent to which any observed impact was attributable to the pilots, it enabled judgements about the likely benefits of the pilots to be made (ibid.).

- 3.7. The judgements made in this study about impact are based primarily upon the accounts and perceptions of three groups of stakeholders – young people, their parents and carers and the professionals working with them, such as transition key workers. This data was drawn from interviews conducted for this study and from other sources, such as case studies and surveys of young people and their families, undertaken or commissioned by the pilot projects. We present the evidence from each of these sources in appendices 3-5.
- 3.8. In order to evaluate the accounts and perceptions of stakeholders, we first compared them. This enabled us to assess the consistency of accounts and perceptions across specific groups of stakeholders and sources (data and methodological triangulation). Where there were differences, or discrepancies, we explored these in order to determine their causes. For example, in Monmouthshire, transition key workers tended to report a lower level of impact than young people, parents and carers. We concluded that this was probably because participants interpreted and measured success in different ways, with transition key workers having higher expectations of impact than young people, their parents and carers.
- 3.9. Once we had compared the accounts and perceptions, and explored differences and discrepancies between them, we then considered how credible the accounts were as an explanation of impact. In order to assess credibility, we drew upon a process evaluation (described below) and the descriptions of how transition key working and person-centred planning were expected to operate, such as the national service framework standard (WAG, 2006) and the National Health

Service Wales and Welsh Assembly Government (2002) practice guidance for person-centred assessments. We also draw upon evidence of the type of outcomes that could be expected, outlined in the review of the benefits of transition key workers (WG, n.d. c). In making judgements about impact, this enabled us to:

- evaluate the extent to which the transition key working arrangements met the expected standard and could, therefore, be expected to have contributed to the expected outcomes;
- consider the contexts for the work<sup>7</sup>, the problems that were encountered and the impact these were judged to have had upon the effectiveness of the transition key working arrangements in each pilot area; and
- evaluate the credibility of individual stakeholders' accounts of how, and why, particular outcomes were or were not realised.

### **The analytical framework: foreshadowed problems**

3.10. The “foreshadowed problems” framework (Hammersley and Atkinson, 1995), adopted for this study, is based upon a model adapted from grounded theory (Glaser and Strauss, 1967). It ensures that researchers are open to unexpected findings, whilst providing some degree of structure to help organise data collection and analysis. It involves the identification of issues of interest to the study that informs data collection through, for example, topic guides. The data generated is then grouped and categorised to assess the extent to which it supports, or fits with, the issues and themes that were identified (i.e. the “foreshadowed problems”). The issues and themes are then refined, added to, subdivided, combined or discarded, in order to fit

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<sup>7</sup> We use “contexts” here, to describe the key characteristics of the situations or places in which transition key working arrangements were implemented, which influenced how transition key working operated and the outcomes it achieved. They include, for example, the capacity of, and relationships between, the different services that transitions key workers sought to co-ordinate.

the data (rather than trying to fit the data to the theory identified before the fieldwork began).

- 3.11. This approach was adopted as it aimed to provide sufficient flexibility to enable the research to respond to the needs and perspectives of the stakeholders participating in the research. It also enabled the identification of unexpected issues and themes, whilst maintaining sufficient commonality across the pilots and groups of stakeholders to enable comparisons of relative net cost and benefits for specific groups, areas and models to be made.

*The foreshadowed benefits of transition key working and person-centred planning*

- 3.12. In 2011, Welsh Government social researchers undertook a literature review of the Benefits of Transition Key Working (WG, n.d. c). This review identified a key benefit of transition key working to be the co-ordination of fragmented service provision. This, in turn, was seen to improve access to services by broadening awareness, within and between services, of what each could offer (Glendinning, 1986) and to reduce the burden on families created by having to maintain multiple service contacts (Sloper et al, 1999).
- 3.13. Benefits were also identified in the long-term relationship a transition key worker can forge with families, providing the scope to develop a deeper understanding of their needs (Liabo et al, 2001; Carnaby et al, 2003). This understanding enables transition key workers to help families better communicate their needs to professionals, or to act as advocates (Greco et al, 2005; Sloper et al, 1999), resulting in improved and more effective partnership working between agencies and families (Greco et al, 2006). Better identification of needs is also seen as leading to greater consistency and continuity of care, resulting in fewer unmet needs (Mukherjee et al, 2006, Sloper et al, 1999) and

a reduction in the waste of resources through misunderstanding and duplication (Greco et al 2005).

3.14. Finally, the literature review identified a benefit in the reduction in stress experienced by families and by young people during transition periods (Greco et al, 2005; Liabo et al, 2001).

3.15. In the light of this, and other research and reviews, the literature review (WG, n.d c) identified the following expected benefits for:

**individuals** – improvements in outcomes such as:

- independent living and increased health and wellbeing;
- access to higher or further education and employability based on the needs of each individual learner; and
- benefits to families including higher levels of satisfaction with services and reduction in stress on family life;

**the public sector** – reductions in local authority, and other organisations, expenditure on services through:

- better forward planning, resulting in more learners able to remain in the community and have their needs met locally;
- greater possibility for shared commissioning of services;
- greater ability to re-configure services to meet the needs of young people and their families;
- reduction in bureaucracy and duplication of roles across services; and
- a sustainable multi-agency transition key worker service with the commitment of all relevant agencies at a local authority or regional level; and

**wider society** - including benefits for the wider community as individuals access the services they need in their local area, thus improving community cohesion” (adapted from WG, n.d c).

The expected benefits identified by the Welsh Government were used to inform the “foreshadowed” benefits of the pilots. For example, benefits for individuals were further broken down into benefits for young people and benefits for young people’s families, primarily parents and carers.

3.16. The “foreshadowed” benefits also included the benefits that might be expected to result from the pilot projects decision to adopt a person-centred planning approach for their transition key working arrangements. As outlined in chapter one, person-centred planning aims to help a young person make decisions about what they want to get out of life and to then help them work out how to achieve this. The benefits that might be expected to flow from this approach included:

- a better and more balanced understanding of the young person including who they are and what is important to them, rather than, for example, an understanding rooted in the problems or difficulties the young person has;
- the identification of a young person’s ambitions and aspirations;
- the development of an action plan ‘owned’ by the young person, to enable the young person to work towards realising their ambitions and aspirations, and to enable services to support young people in this; and
- the empowerment of a young person, by celebrating their achievements and abilities and focusing upon the possibilities, rather than the problems they face (NHS Wales and WAG, 2002).



### *The foreshadowed costs*

3.17. The expected costs of transition key working arrangements included:

- costs for young people and their families - such as increasing demands upon their time, the costs of travelling to education, training and/or employment and the costs of increasingly independent living; and more intangible costs such as a sense of insecurity or vulnerability that may flow from the changes that make up the transition process;
- costs for the public sector - such as the start-up costs of establishing new services (for example, training and recruiting staff) or reconfiguring and/or rationalising existing services (for example, the costs of redundancy and institutional restructuring), the operational costs and the costs of developing key working arrangements (for example, additional staff costs). Moreover, key working arrangements may create demands for new services and may involve the reallocation of costs from one service to another service and from future to current budgets (for example, where key working leads to earlier intervention than would otherwise have occurred), or vice versa; and
- costs for society – there were no foreshadowed costs for society.

### *Additional foreshadowed problems*

3.18. The “foreshadowed” costs and benefits identified for the study were also intended to enable researchers to understand how and why costs and benefits for specific groups and pilot projects might vary. Therefore, in addition to the expected costs and benefits, the “foreshadowed problems” identified for the study, included those factors expected to influence the effectiveness of the transition key

working arrangements in each pilot area. These included, for example:

- young people's level of involvement in developing their transition plan, including the use of person-centred planning methods; and
- problems transition key workers may face in co-ordinating multi-agency involvement in the development and implementation of a transition plan.

3.19. We discuss the issues of foreshadowed problems in more detail below.

### **Evaluating the benefits of a person-centred planning approach to transition key working**

3.20. In considering costs and benefits, we do not seek to systemically distinguish between those that flow from transition key working, in line with the national service framework standard (WAG, 2006), discussed in chapter two, and those that follow from the adoption of a person-centred approach to transition key working. This is because the two aspects of transition key working arrangements in each pilot area were integrated and it would, therefore, be extremely difficult to try to separate out the contribution of each. For example, person-centred planning might be used to identify a young person's aspirations, which inform the development of an action plan. This plan might then become the basis for the inter-agency plan required by the national service framework standard (*ibid.*), used by the other services supporting that young person, to ensure they meet his or her needs. As required by the national service framework (*ibid.*), the transition key worker might then co-ordinate and plan the delivery of services, in line with the inter-agency plan, and provide information to the young

person that will help the young person realise their plan and, therefore, their aspirations.

3.21. We draw a broad distinction between the benefits of the transition key worker upon young people's and their families' experience of transition and the outcomes of transition, such as entry into further education or employment, and/or independent living. In some ways, this reflects the distinction between transition key working as required by the national service framework (WAG, 2006), which should improve the experience of transition, and a person-centred planning approach to transition key working, which might be expected to lead to the development and identification of aspirations and ambitions and, therefore, different choices about transition and outcomes as a result of that process. However, the distinction is not clear cut. For example, even in the absence of a person-centred planning approach, by better co-ordinating services and providing better information for young people, transition key working in line with the national service framework standard, could lead young people to make wider and better informed choices and could contribute to outcomes, such as entry into further education or employment, and/or independent living. Young people might, for example, be more aware of the choices open to them and be more willing to make particular choices, if they felt supported in doing so.

### **Overview of the study phases**

3.22. The study ran from May to October 2011 and was structured into three phases:

- inception and scoping (May-June 2011);

- data collection and fieldwork, including qualitative interviews with a range of stakeholders and analysis of quantitative data (June-October 2011); and
- analysis and reporting (August-October 2011).

3.23. The phases were carefully sequenced to ensure that each phase could inform later phases. For example, the inception and scoping was used to inform the fieldwork and analysis and there was on-going 'dialogue' between the overlapping fieldwork and analysis phases, ensuring that emerging analysis could inform and enrich the fieldwork.

3.24. The study integrated quantitative and qualitative research. The qualitative research focused primarily upon the costs and benefits of transition key working experienced young people with complex needs and their families. The quantitative research focused primarily on the costs to the state of transition key working. Further details about the methodology are included in appendix 6.

### **Inception and scoping**

3.25. The scoping review included a meeting with the project advisory group; consultation with the pilots<sup>8</sup>; a review of key project documentation (listed in appendix 1); and a review of the benefits of transition key working prepared by Welsh Government Knowledge and Analytical Services (WG, n.d. c).

3.26. One of the key issues identified through the initial scoping work, was the risk that the research would duplicate other research in this area, most notably, doctoral research being undertaken by Sally Rees of Care Co-ordination Network Cymru<sup>9</sup> (CCN Cymru)<sup>10</sup>; the evaluation

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<sup>8</sup> Each of the pilot project managers was contacted in order to introduce the research team and discuss the proposed approach.

<sup>9</sup> Formally part of Care Co-ordination Network UK (CCNUK).

of the Reach the Heights programme<sup>11</sup>; and the on-going evaluation of the Real Opportunities project (formerly known as the Regional SEN Transition to Employment project)<sup>12</sup>. The biggest potential risk of duplication was judged to be in relation to Sally Rees' research. The research team worked closely with Sally Rees to minimise this and considered a number of options for combining elements of the two studies, such as using data from Sally Rees' study and the research instruments developed for the study. Following the review of the options, this was judged not possible. An extract of the options appraisal is included in appendix 3.

3.27. The outcomes of the inception and scoping phase were summarised in an inception report and agreed with the study steering group in June 2011.

### **Data collection and fieldwork**

3.28. In each pilot area, the research team met with members of the pilot delivery team to:

- discuss the costs associated with establishing and operating transition key working within their service (for example children's services);

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<sup>10</sup> Entitled, Moving on Together: evaluating the experiences, processes and outcomes for disabled young people receiving support from a transition key worker. Research objectives are to: explore the disabled young person's and their parents'/carers' experiences of the key worker model through transition to adulthood; evaluate the outcomes of the key worker model through comparison with standard transition services; investigate possible differentiation of outcomes between the designated and non-designated model(s); and compare outcomes for young people with an autistic spectrum disorder (ASD) who receive transition key worker services with those who do not have an ASD (Rees, n.d.). The research started in March 2011 and is due to complete in 2014.

<sup>11</sup> The programme is funding the development of transition key working across the ESF convergence area. The final evaluation of Reach the Heights is taking place between June 2012 and May 2013.

<sup>12</sup> The Wales Centre for Learning has been commissioned to undertake an external evaluation of the effectiveness of this project. This evaluation started in February 2011 and is due to complete in September 2012.

- discuss the impact of establishing and operating transition key working on the costs of providing other services, such as health and social services;
- identify the data pilot projects were able to provide on the costs of transition key working to their services (such as children's services) and to other services (such as adult and health services). This data included project budgets and financial accounts; and
- where possible, discuss with members of the pilot project the data analysis undertaken by the research team, in order to refine and validate the analysis<sup>13</sup> (more details on this are included in appendix 6).

3.29. In addition to discussing and identifying data on costs in each pilot area, the research team met with pilot project managers to identify:

- between five and ten families, including young people and/or parents and carers, who had experience of transition key working and who, it was felt, might be willing to take part in the study;
- professionals, such as representatives from adult services and health services, who it was judged could contribute to the study; and
- secondary data, including self-evaluations, case studies and surveys<sup>14</sup> of young people, parents and carers conducted by the pilot projects, which could be used to help evaluate the costs and benefits for young people, their families and the state.

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<sup>13</sup> Not all local authorities were able to provide this data in time to enable our analysis to be discussed with them and refined.

<sup>14</sup> The surveys in Pembrokeshire included a telephone survey of 14 families undertaken by the pilot in September 2011 and feedback forms completed by 15 families in February 2011; in Gwynedd, the surveys consisted of interviews with 44 young people and 48 adults, conducted by an independent consultant in 2009 and 2010; and in Ceredigion, a baseline survey of 16 parents and a follow up survey of 11 parents was undertaken by the pilot.

3.30. Interviews and, in one project, focus groups<sup>15</sup> were then set up with stakeholders who were willing to participate in the study. It was necessary<sup>16</sup>) for the pilot project staff to make the initial contact with young people and their families. The introduction by project staff, who were known and trusted by young people and their families, was extremely valuable. Project staff then sought permission from young people and their families or carers for us to contact them, and in the case of Pembrokeshire, convened a focus group on our behalf. Table 2 summarises the fieldwork that was undertaken in each pilot area.

3.31. When we discuss the data collected, we distinguish between type of stakeholder (such as young people, transition key workers, health or social care professionals and parents or carers) and data sources (such as interviews and surveys). By presenting the data from specific stakeholders and sources in this way, we illustrate the commonalities and differences in stakeholders' accounts and perceptions of the process, costs and benefits of transition key working arrangements. We also consider the number of stakeholders making the same or similar points when considering the weight to be attached to a particular perception or judgement, and identify the number of people making particular points. However, in order to protect the anonymity of those who contributed, in general we do not identify the sectors participants work in or their job titles<sup>17</sup>.

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<sup>15</sup> In Pembrokeshire, Action for Children recommended that this would be more appropriate and effective than one-to-one interviews.

<sup>16</sup> Data protection laws restrict the sharing of personal information, such as contact details.

<sup>17</sup> The exception to this is in the case of Anglesey, where there was a clear divide between the views of professionals from children's services and professionals from adult services. The divide was in our judgement worthy of note and interviewees from both services were aware of the difference of opinion between the two services. We judged therefore, that the risk that interviewees would be identified because we report the service they represent, was small.

**Table 2. Summary of the fieldwork with stakeholders**

Pilot area	No. of young people	Profile of the young people	No. of parents, siblings and carers involved	Total No. of families involved	Professionals involved in the pilot
Anglesey	1	Since only one person was interviewed, the profile has been omitted to protect the young person's privacy.	1	1	<ul style="list-style-type: none"> <li>- Transition key working champion</li> <li>- Manager, specialist children's services</li> <li>- Joint operations manager, adult learning disability services</li> <li>- Community nurse, learning disability services</li> </ul>
Ceredigion	4	<p>Aged 17, 18, 19, and 20.</p> <p>Two attend local college, one attended local school and another was in employment.</p> <p>Their conditions include mild learning difficulties and physical disabilities.</p>	4	4	<ul style="list-style-type: none"> <li>- Corporate manager for social services</li> <li>- Manager, child development service</li> <li>- Key worker</li> <li>- Key worker</li> </ul>
Gwynedd	4	<p>Aged 16, 18 and two aged 19,</p> <p>Two attend college, one a specialist college, and one volunteered part-time.</p> <p>Their conditions include mild learning disabilities, communication difficulties, and a physical disability.</p>	4	5	<ul style="list-style-type: none"> <li>- Service manager</li> <li>- Transition key worker</li> <li>- Education officer</li> </ul>
Monmouthshire consortium	3	<p>Aged 16, 18 and 19 years.</p> <p>Two attend college, one is in a specialist provision, and one is in school and hopes to move to a residential college next year. Two young people, aged 19 and 26 were represented by their parents.</p>	6	5	<ul style="list-style-type: none"> <li>- Project manager</li> <li>- Transition co-ordinator (key worker)</li> <li>- Transition co-ordinator (key worker)</li> <li>- Project board member</li> <li>- Manager, Future of Statements Project</li> <li>- Team manager, children services</li> <li>- Team leader, Careers Wales Gwent</li> <li>- Continuing care manager, Aneurin Bevan Health</li> </ul>



		<p>One young person is looked after by the state.</p> <p>Conditions include mild and severe learning difficulties, behavioural difficulties and severe physical disabilities.</p>			<p>Board</p> <ul style="list-style-type: none"> <li>- Learning disabilities community nurse, Aneurin Bevan Health Board</li> </ul>
Pembrokeshire	8	<p>Four young people were aged 16, one was 17, one was 19, one was 20 and one was 21.</p> <p>Three young people attend a special school, four attend college and one was not in employment, education or training (NEET).</p> <p>Their conditions include mild and severe physical disabilities, social, emotional and behavioural difficulties, learning difficulties and communication difficulties.</p>	3	8	<ul style="list-style-type: none"> <li>- Service Manager, The Hawthorn Project, Action for Children</li> <li>- Principal educational psychologist</li> <li>- Member of the learning disabilities team</li> <li>- Transition key worker</li> <li>- Transition key worker</li> <li>- Contributing transition key worker</li> </ul>
<b>Cross-cutting</b>					<ul style="list-style-type: none"> <li>- Wales manager, Contact a Family</li> <li>- Community services and project manager, Regional SEN Transition to Employment Initiative (now called Real Opportunities)</li> <li>- Wales manager, CCN Cymru</li> <li>- Representative of Welsh Government</li> </ul>
<b>Total</b>	<b>20</b>		<b>18</b>	<b>23</b>	

Source: Transition key worker pilot projects

3.32. As outlined above, the interviews were informed by a “foreshadowed problems” research framework. The topics (or foreshadowed problems) covered in interviews with young people and their families included:

- their relationship with, and the work of, their transition key worker;
- their transition plan; and
- the difference the transition key worker and the transition plan made.

3.33. Over the course of the fieldwork, these topics were further refined and developed. As expected, a number of issues which had not been fully foreseen (or foreshadowed) emerged in the course of the fieldwork with young people and their families. These included:

- the close relationship some young people developed with their transition key workers;
- the difference between the benefits young people identified as important to them and the benefits that their parents or carers identified as being important to the young person;
- young people’s wellbeing and optimism about the future, despite often difficult transitions; and
- the variations in the role that transition key workers took in influencing the attitudes and aspirations of parents and carers.

3.34. The interviews with young people, parents and carers were semi-structured, covering the topics outlined above. The young people, parents and carers who participated in the research had a wide range of interests and abilities. To facilitate full participation, a range of open and closed questions, prompts and visual cues, were used. Copies of the schedules are included in appendix 9.

- 3.35. In order to ensure young people were supported, and were able to contribute, interviewers consulted with practitioners working with the young person - teachers, support staff and/or care workers - prior to conducting the interview with the young person. The consultations included a discussion about the most appropriate approaches to take to involve young people given, for example, the young person's interests, preferences, abilities, means of communication (including, for example, how they communicate yes and no answers) and attention span.
- 3.36. It was not possible to spend sufficient time with any of the young people to reach the point where they felt comfortable with someone they did not know, or to spend time observing how they felt most comfortable communicating. For this reason, the young people were sometimes accompanied during interviews by people they knew, most frequently parents and carers, and sometimes these people acted as intermediaries, helping to interpret or encourage answers. In two cases, a parent chose to respond on behalf of the young person because of communication difficulties and in two others parents interpreted the young person's response to questions asked by the interviewer.
- 3.37. Most interviews took place in the young person's, or family, home. In a small number of cases, parents or carers chose to be interviewed on the telephone and two small focus groups were run on the premises of one of the pilot projects. In order to ensure that people's consent was informed, interviews began with an explanation of what the study was about, why it was being undertaken and how their answers would be used. Young people and families were told that they would not be named in any report, but given the small numbers involved in each

county it would not possible to guarantee total anonymity<sup>18</sup>. If there was anything participants did not want reported, they were advised to let the researcher know. The researchers informed participants that involvement was voluntary and that they could stop the interview at any time.

3.38. The interviews with professionals, such as transition key workers and others working with young people experiencing transition including health and social care professionals, were more structured than the interviews with young people and their families, but were still semi-structured, enabling the interviewers to vary the order in which questions were asked, and to ask supplementary or follow-up questions where appropriate. The topics covered in these interviews included:

- young people's level of involvement in developing their transition plan, including the use of person-centred planning methods;
- problems transition key working may face in co-ordinating multi-agency involvement in the development and implementation of a transition plan; and
- the extent to which having a transition key worker impacted on the experience of transition, including making it less stressful.

Copies of the original schedules used are included in appendix 9.

3.39. As with the interviews with young people and their families, over the course of the fieldwork these topics were further refined and

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<sup>18</sup> The concern regarding anonymity stemmed from the small numbers of young people in the target population together with the detailed knowledge transition key workers have about the young people, who participated in the research, and their situations. It is likely, therefore, transition key workers will be able to attribute reported views to specific young people. The research team have, however, taken all possible steps to ensure that this is not the case where a young person has made a sensitive comment.

developed. For example, a number of issues which had not been foreseen (or foreshadowed) emerged in the course of the fieldwork with professionals we interviewed (including transition key workers). These included:

- the differing impacts individual transition key workers had upon the experience and outcomes of transitions;
- the contribution local opportunities and services made to the impact of transition key workers;
- the inherent uncertainty associated with transitions;
- the polarised judgements on the value of person-centred planning between those using and those not using this method;
- the differences in the way designated transition key workers operated in the four pilot areas which adopted this model;
- the limited impact of transition key workers upon the costs of providing other services (consequential costs); and
- the difficulty of identifying a clear point at which transition, or points at which different aspects of transition, ended or were completed.

3.40. To add breadth to the study, as outlined above, where available, the study also drew upon a range of secondary data including research undertaken by pilot projects including self-evaluations, case studies of young people, and data collected in surveys of young people, parents and carers undertaken by the projects in Ceredigion, Gwynedd and Pembrokeshire. This provided data on the experiences of a larger number of young people, parents and carers, complementing the data generated by interviews undertaken for this study.

3.41. The secondary data was diverse. Although, for example, the self-evaluation reports typically covered a range of areas including a discussion of both outcomes and barriers, the level of detail varied

considerably. This reflected, in part, the amount of research, monitoring and evaluation the pilots undertook or, in one case, commissioned. For example:

- Anglesey undertook six case studies of young people;
- Ceredigion completed a baseline survey of 16 parents and a follow-up survey of 11 parents; and collected feedback from 33 young people who attended a one-day event for sharing information on transition issues;
- Gwynedd commissioned an independent consultant to undertake a baseline and follow-up survey of young people's attitudes and experiences. This included interviews with 44 young people and 48 adults (Forshaw, 2010);
- Pembrokeshire undertook a telephone survey of 14 families in September 2011 and distributed feedback forms, which were completed by 15 families in February 2011; and
- the Monmouthshire consortium undertook detailed case studies of 22 young people, as well as feedback from young people, parents and carers and professionals (Monmouthshire County Council, n.d. b).

3.42. The quality of research, monitoring and evaluation also varied. For example, the case studies prepared by some pilots, such as the Monmouthshire consortium, were more detailed than those prepared by other pilots. The use of an independent consultant, who interviewed young people in Gwynedd, produced richer data than the self-completion questionnaires used by other pilots.

3.43. The differences in the quantity and quality of research, monitoring and evaluation, meant the secondary data about the experiences of young people and families in some areas, such as the Monmouthshire consortium, Gwynedd and Pembrokeshire, was stronger than the data

available about the experiences of young people and their families in Anglesey and Ceredigion.

## **Strengths and limitations of the research design**

### *Internal validity*

- 3.44. This research is primarily a qualitative study into the benefits of transition key working arrangements in five pilot sites. It involved interviews with 23 families, including 18 parents, carers or siblings and 20 young people with complex needs, a group which can be challenging to engage and involve in research (Lewis and Kellet, 2004). For example, a recent major national study, only secured interviews with six families<sup>19</sup> (Sloper, et al, 2010). However, it was not possible for this study to involve the target of 30-35 young people from across the five pilots. For example, only one family was involved from the Anglesey pilot. Although the research team worked with pilot areas to engage potential interviewees, this was limited by the quality of the relationships pilots had with young people and their families and the willingness of young people and their families to participate in the study.
- 3.45. In addition to its small size, the sample of young people and other family members was limited in other ways. It was purposefully selected, by pilots, following consultation with the study team and limited by the willingness of young people and families to participate.
- 3.46. To reduce the limitations of the sample of young people, parents, carers and other family members, as outlined above, the study triangulated findings from other participants, such as professionals working with families and project staff, and secondary data. The

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<sup>19</sup> In three of these cases, young people also participated. The study originally intended to recruit 30-40 families – equivalent to five or seven in each of the sites studied, however, delays in the recruitment led them to reduce the target number to around 10 families.

secondary data, including the pilot case studies and surveys of young people, parents and carers, was particularly valuable, as it provided information about the experiences and perceptions of a larger sample of young people and/or their parents and carers. It included, for example, more evidence about negative experiences of, or dissatisfaction with, transition key working, than the interviews with young people, parents and carers undertaken by this study. Taken together, the data provided a more balanced, or rounded picture, of the experiences and perceptions of young people, their parents and carers.

- 3.47. Nevertheless, because the number and range of young people and their parents and carers and other family members involved in this study was more limited than expected, and the secondary data did not include sufficient information about young people's needs, there was no scope to directly compare costs and benefits for specific groups of young people based on their type of need.
- 3.48. The fact that only one young person and one parent/carer was interviewed in Anglesey, was particularly problematic because this was the only area that piloted a non-designated model of transition key working. As a consequence, the study was reliant upon secondary sources, including other research studies, monitoring and evaluation carried out by the pilots, and the assessments of the professionals, such as key transition workers, we interviewed. This increased the risks that some of the costs or benefits of the non-designated model were not identified, were over-estimated or were under-estimated.
- 3.49. Because, as outlined above, it was not possible to compare the experiences of young people, their parents or carers receiving the intervention of a transition key worker with the experiences of those receiving a standard transition service, it was not possible to quantify



the impact of transition key working. Nevertheless, as outlined above, by drawing upon multiple sources of evidence, it was possible to make inferences about the benefits of transition key working by comparing the findings from the primary and secondary data against the benefits and impact of transition key working reported in literature.

- 3.50. The assessment of the costs of transition key working arrangements for young people, their parents and carers, drew primarily upon qualitative data. The length of time that had passed since the pilot projects ended (March 2011) and the fieldwork was undertaken (June-October 2011) caused particular problems. In particular, many young people, parents and carers struggled to remember exact details of the transition key working arrangements and their experiences of it including, for example, the time they spent involved in transition planning. Nevertheless, because these costs were considered to be small, the inability to precisely assess the size of these costs is not a major limitation.
- 3.51. The assessment of the costs of transition key working arrangements for the state, drew primarily upon quantitative data supplied by the pilot projects. The data that each pilot area was able to provide differed markedly. Moreover, in some cases, the data was provided too late to fully discuss, refine and validate our analysis with the pilots. The gaps in the costs data meant, in many cases, the costs to the state had to be estimated. Nevertheless, most costs that could not be quantified related to the cost of establishing and operating a transition key worker service, and in most cases the cost of a comparable service could be used.

## *External validity*

- 3.52. The study did not undertake any primary research outside of the five pilot sites. Therefore, the assessment of the external validity of the study (that is, the extent to which the findings on costs and benefits could be expected to be found in other areas), is based primarily on findings from other studies about the costs and benefits of transition key working in other areas of the UK. There is more evidence about the benefits of transition key working than there is about its costs<sup>20</sup>.
- 3.53. As outlined in the following chapters, the benefits identified through this study are broadly consistent with other research studies in this field, as identified in the literature review undertaken by the Welsh Government (WG n.d.b). Therefore, it is reasonable to expect that the findings on benefits can be generalised to local authority areas not included in this study. The findings on costs are more complex. As we outline in chapter six, the cost incurred by the pilots are higher than those found in other transition key working projects. However, much of the difference in costs reflects differences in the way transition key working is organised. Inevitably, how transition key working is organised, the existing infrastructure and how that can be utilised, and the scale and range of local needs and provision will impact on costs, and so findings from the local authorities involve in the pilot can not be assumed to apply to those local authorities not involved in the pilot.

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<sup>20</sup> The evidence of benefits is summarised in the Welsh Government literature review, The Benefits of Transition Key Working (WG, n.d. c). The main evidence of costs comes from Sloper et al (2010) Models of Multi-Agency Services for Transition to Adult's services for Disabled Young People and those with Complex Health Needs: impact and costs.

## 4. The benefits for young people

4.1. In this section, we discuss the benefits of the transition key working pilots for young people. The discussion is based on three sources:

- interviews with young people, their parents, carers and siblings (this includes both direct data from young people and indirect, or reported evidence, from their parents and carers);
- interviews with professionals working with young people, their parents and carers; and
- other sources, primarily secondary data, including surveys of families undertaken by the Ceredigion, Gwynedd and Pembrokeshire pilots<sup>21</sup>.

4.2. The discussion is restricted to the benefits for young people so, for example, where we talk about the transition key workers' biggest impact, this is their biggest impact in relation to the perceived benefits for young people. This should not be taken to mean that transition key workers are perceived to have had a bigger impact upon young people's experiences than, for example, upon parents' or carers' experiences. We consider the relative benefits of transition key working upon young people, their parents and carers, the state and society, in the conclusions.

4.3. We summarise the key findings from the five pilots, and include a more detailed discussion of the evidence from each pilot, in appendix 3.

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<sup>21</sup> Surveys were not conducted in the other two areas – Anglesey and the Monmouthshire consortium.

## **Summary of the benefits for young people across the five pilot areas**

### *Experiences of working with a transition key worker*

4.4. The 20 young people we interviewed, and the two young people whose experiences were reported by their parents, were either positive or very positive about the support they received from their transition key workers. This finding was supported by professionals we interviewed (including transition key workers), and by surveys of young people or their parents and carers, conducted in Ceredigion, Gwynedd and Pembrokeshire. In many cases, young people stated they had developed a close relationship with their transition key worker, and usually described the transition key worker as having provided emotional and practical support during, what was often, a difficult period in their lives. However, in a small number of cases, young people had not engaged with their transition key worker and/or the planning process. In some cases, this was because they felt that they did not need the support or because they felt they already had all the support they needed. For some young people, the introduction of a transition key worker was not welcomed because the complexity of their problems resulted in a large number of professionals working with them. In such cases, the transition key worker was viewed by parents, carers and some young people as an additional professional and, thus, an additional complication.

### *Transition plans and planning*

4.5. Overall, transition key workers, parents and carers were identified by young people we interviewed as the most important sources of information and support. This was particularly evident within Pembrokeshire and Ceredigion. There were relatively few examples of other professionals, such as social workers or careers advisors, being identified as significant sources of information or support. Almost all young people wanted more information and

support than had previously been provided and this made transition key workers particularly important to them.

- 4.6. Of the 20 young people we interviewed, 11 could remember their transition plan. These 11 young people were all generally satisfied, or very satisfied, with their plan. There were, however, marked variations in the significance young people attached to their plans and to person-centred planning processes, across the five pilot areas. Awareness was highest amongst the young people we interviewed in Ceredigion, Gwynedd and the Monmouthshire consortium area. Young people attached considerable significance to the importance of their plans in shaping and directing their experiences of transition in both Gwynedd and the Monmouthshire consortium areas.
- 4.7. Person-centred planning had a bigger impact on helping young people plan and follow a 'route', rather than in identifying a different end 'destination'. That is, although the planning process rarely changed what young people wanted to do, it increased the awareness and understanding of professionals working with them about their wishes, and helped professionals support young people to achieve their aspirations and reach their 'destination'.

#### *Supporting the transition from school to college*

- 4.8. In the majority of cases, the greatest benefit of the transition key workers was supporting young people's transition from school to college. All the young people interviewed, who had made this transition, valued the support transition key workers provided. The evidence from young people, project managers and other professionals suggests that in most cases, young people who went to college would have gone there without the support of their transition key worker. However, two young people reported that they doubted that they would have gone to college unless their transition key worker had supported them. Nevertheless, the benefit for most young people was related more clearly to the experience of this transition rather than to its outcome,

since they had not yet completed their college courses. The transition key workers played an important and valued role in providing emotional support, including work to enhance young people's confidence; and practical support including helping to organise equipment and the support needed for a young person to attend college.

- 4.9. Although in most cases, transition key workers may not have changed young people's aspiration to attend college, it is possible that their support has enabled some of the young people to sustain their involvement in colleges and complete the next step in their plan for realising their aspirations. There is, for example, evidence that transition key workers helped young people settle into courses and in some cases, change courses. However, it was not possible in this study to measure the counterfactual. That is, what would have happened to these young people without the support of a transition key worker.

#### *Supporting the transition from post 16-19 education*

- 4.10. Overall, transition key workers had a more limited influence upon planning and supporting young people's transition from post 16-19 education. The majority of the young people we interviewed were either in school (n=7) or college (n=10) and many of those who were in college were anxious about what would happen once they completed their courses. This anxiety reflected, in part, an inherent uncertainty about the future but was also linked to a lack of information about what they could do after college and what support they could expect to receive. One young person, within our sample, had secured paid employment and attributed this, to a large degree, to the support provided by the transition key worker.
- 4.11. In three pilot areas, transition key workers were reported to have played an important role in introducing young people to, and helping them access, a range of social, sporting and cultural activities during both the week and weekends. However, across all five pilots, transition key workers' ability to do

so was reported to be constrained by the range of opportunities available locally. In general, after leaving college, the range of activities and experiences that young people could access were described as being limited. Most students were attending courses especially designed to cater for their needs and frequently leisure and social activities were linked to college or school facilities. Finding suitable activities outside of college for young adults was seen as a challenge in all areas.

### *Supporting the transition to independent living*

- 4.12. A number of factors influenced the perceived impact transition key workers had upon independent living. For some young people, their needs meant that their independence was necessarily limited and transition key workers' impact was primarily upon the nature of their placement. For others, their prospects for independent living were limited by other factors including their own skills and self-confidence and their parents' and carers' attitudes and expectations. In some of the pilots, transition key workers played an influential role, empowering young people and/or helping change their parents' and carers' attitudes and expectations.
- 4.13. Despite the problems many young people had experienced, and the anxieties they often felt about the future, the majority of those interviewed in the course of this study were happy with their lives. Therefore, whilst most of the young people who participated in the research had not completed their transitions as they were, for example, still completing their education, they were happy with the progress they had made so far.

## **5. The benefits for families**

- 5.1. In this section, we discuss the findings about the benefits of transition key working for families. The data was collected from: interviews with families, interviews with professionals working with young people, and other sources, primarily secondary data such as the surveys of families undertaken by the pilots.
- 5.2. We summarise the key findings from across the five pilot sites and discuss the evidence from each area in detail in appendix 4.

### **Summary of the benefits for parents and carers across the five pilot sites**

#### *The experience of having a transition key worker*

- 5.3. The overwhelming majority of parents and carers were positive or very positive about transition key working. They appreciated the support the pilots provided to the young person and, in particular, nearly all parents and carers felt that the young person (and themselves) was listened to. In all five cases, there was evidence that the pilots had taken pressure off parents, lessening the time and effort that they needed to put into managing the young person's transition. This assistance included:
- providing practical help – including telephoning individuals, such as college admissions tutors, who could help a young person realise their plan; investigating learning, social and leisure opportunities; and helping families to complete forms (e.g. to apply for direct payments);
  - acting as an accessible point of contact – parents and carers viewed the transition key worker as someone they could easily access. Only in Gwynedd did parents explicitly refer to the transition key worker as a single point of contact. In other areas, the worker was seen as an intermediary who worked with, and liaised with, other agencies on behalf of the family;



- smoothing transition – less time was wasted by parents and carers. In addition, in some cases, parents and carers felt that services worked more effectively as a result of better information and that the transition key worker provided a quality control function; and
- offering continuity – transition key workers were described as offering continuity (at least during the life of the pilot) at a time when many of the workers involved with a young person were changing. This allowed a supportive relationship to develop between transition key workers and the young person's parents or carers.

5.4. In addition, parents and carers in the Monmouthshire consortium and Pembrokeshire talked about how transition key workers were able to help them work more effectively with service providers. For example, transition key workers helped parents and carers respond less emotionally to service providers by listening to their frustrations, and as a result, parents and carers were less likely to take their frustrations out on service providers; and helped by providing explanations and information to parents and carers. This emotional support helped reduce the stress that parents experienced during their son's or daughter's transition.

5.5. The quality and nature of the relationship a parent or carer has with the transition key worker, was considered very important. However, the nature of the relationship between transition key workers and parents or carers varied between pilots. In the Monmouthshire consortium and in Pembrokeshire, transition key workers were credited with having helped parents and carers to reconsider their preferred options for the young person's future, acting as a critical friend who might encourage and challenge their perceptions. In other pilots, transition key workers were more likely to be described as offering more reactive support and information, rather than taking this more active role.

5.6. Although, as noted, the study was not able to use comparison groups, to assess the counterfactual, there was limited evidence from young people,

parents and carers about the experience of transition without a transition key worker<sup>22</sup>. This evidence indicated that transition was more stressful and difficult without the support of a transition key worker. This finding is consistent with findings from other studies (see, for example, Sloper et al, 2010). Such studies indicate that the continuing weakness in transition planning and support, in the absence of a transition key working service, can generate significant human and financial costs as a result of a poor or difficult transition.

### *The benefits of transition plans and planning*

- 5.7. Surveys of young people, parents and carers, conducted in Ceredigion, Gwynedd and Pembrokeshire<sup>23</sup> indicate that the majority of families were happy with their son's or daughter's transition plans. However, the importance parents and carers placed on the role of the transition plan in their son's or daughter's transition, varied significantly across the pilots. Most parents and carers from the Monmouthshire consortium pilot regarded the transition plan as a valuable tool. In contrast, in the other pilots the plan was barely remembered by many of the parents and carers interviewed. The parents and carers that most valued the transition plan, talked about how it gave young people confidence, as the plan showed what was important to, and for, the young person; and how the plan helped parents to be clear about what needed to be done, in order to help young people realise their ambitions and ensure their needs were met.

### *Factors that limited the benefits of transition key working*

- 5.8. Transition key working provides support and information. Whilst the support and information helped parents and carers manage a common set of issues or problems, it was not always sufficient to enable parents and carers to resolve or overcome them. Reasons given for this included:

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<sup>22</sup> These included some young people who began their transitions before the project started, or who were continuing their transitions after the project had ended.

<sup>23</sup> Surveys were not conducted in the other two areas.

- the clarity of information from, and between, services about what would happen at transition – service providers and transition key workers reported that services themselves frequently did not know, until the last minute, what their involvement would be and that this significantly limited the potential to involve parents in planning;
- differences in the assessment and eligibility criteria used by individual services to identify and meet need, which meant that despite the co-ordination role provided by a transition key worker, young people (along with their parents and carers) still had to go through multiple assessments and planning routes; and
- gaps in the range and accessibility of therapeutic services, suitable learning provision, and cultural and sporting opportunities for those over 18 years of age was considered by all types of respondents to limit what a young person could do and, at worst, to lead to parents and carers having to 'fight' to secure what was available.

5.9. Although, as noted, the majority of families valued their transition key worker and were satisfied with the transition plan, in some pilot areas, where there was sufficient data from surveys to enable experiences to be assessed, between a third and a half of families reported that they did not feel their son or daughter was adequately prepared for transition. A number of factors contributed to this:

- in many cases, transition key workers did not start working with young people until they were close to, or at the point of, leaving school;
- many parents and carers felt they did not have enough information; and
- many parents and carers were anxious about a future that was inevitably uncertain.

### *The potential long-term role for transition key workers*

5.10. The parents and carers we interviewed felt that the need for transition key working was on-going. Although there was recognition of a particular need around the time of transition from school, having invested in developing a strong relationship with the transition key worker, many parents and carers felt that they and the young people would benefit from long-term contact with their transition key worker. In the Monmouthshire consortium, three young people had completed transition, in that they had settled into permanent adult domestic settings, and were engaged in non-age specific and sustainable activities. Nevertheless, in the two cases where parents were still involved they felt that knowing they could have occasional contact with a transition key worker, if needed, would be very helpful. In Ceredigion and Gwynedd, two parents we interviewed also raised concern about transition key worker support stopping. In Monmouthshire, because the pilot project had finished there<sup>24</sup>, families that had experienced the support of a transition key worker expressed regret that they could no longer access this support. In other areas, parents were concerned about losing the support when the young person had become an adult and would, therefore, no longer qualify for transition key worker support<sup>25</sup>.

5.11. As identified above, transition from school is just one step in a young person's life and needs do not end when a young person starts a college course. Parents and carers, in all five pilot areas, raised concerns about the future for the young people they care for, including who would be working with them and the level, and type, of support they would receive in the future.

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<sup>24</sup> The project ended because it was not in the Convergence area and, unlike the other pilot sites which are in the Convergence area, Monmouthshire was not, therefore, eligible for European Social Fund funding.

<sup>25</sup> In line with the National Service Framework (WAG, 2006) standard, transition key worker support is usually only provided for young people aged 14-25.

## **6. The benefits for the state**

- 6.1. In this section, we discuss evidence of the benefits for the state from two key sources: interviews with professionals and, primarily, secondary data such as surveys of young people, parents and carers. We do not discuss evidence of benefits for the state from young people, parents and carers where no specific benefits were identified by them.
- 6.2. We summarise the key findings from across the five pilot sites and discuss the evidence from each area in detail in appendix 5.

### **Summary of the benefits of the five pilots**

#### *The aims of pilot projects*

- 6.3. The ambition of the individual pilot projects, in relation to changing services, varied. Some, such as the Monmouthshire consortium, set out with an explicit agenda which focused on developing multi-agency working across the consortium whilst others, like Pembrokeshire, focused primarily upon extending and developing an existing and well-established support service.

#### *The benefits of transition key working for services*

- 6.4. A range of expected benefits were identified by the pilots, which included:
- contributing to the development of more effective assessment and planning processes with the aim of facilitating services to provide for needs more efficiently and effectively (Anglesey, the Monmouthshire consortium and Pembrokeshire);
  - saving time by integrating structures and processes (Ceredigion and the Monmouthshire consortium);

- improving efficiency by increasing the take-up of services<sup>26</sup> (Gwynedd and Pembrokeshire); and
- improving the extent to which families engage with services (all areas).

6.5. Three young people involved in the study had very complex multi-agency involvement (for example, one young person had over 20 agencies attending their last review meeting). Their parents and carers reported that as a result of the transition key worker, meetings were more productive and useful, and services were more effective.

*The benefits of person-centred planning upon services*

6.6. Participants involved in service delivery were divided about the value and impact of person-centred planning. Almost all professionals using person-centred planning were very positive, or positive, about it, reporting that person-centred planning helped them better understand and meet young people's needs. At the same time, however, professionals acknowledged they could not engage every young person through person-centred planning. In contrast, professionals who were not directly involved in using person-centred planning, were often more sceptical of its value and sometimes struggled to use the outcomes of the process in existing assessment and planning processes, which are service-centred rather than person-centred.

6.7. There was also evidence of some other agencies, such as adult day services and schools, taking up person-centred planning approaches and training as a result of the pilots in Ceredigion and the Monmouthshire consortium.

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<sup>26</sup> For example, where there are significant fixed costs associated with delivering a service, such as when much of the cost is covered by staff salaries, but the variable costs are small, the cost of each additional person using the service is small. In this case, increasing the number of people using a service can increase efficiency, by reducing the cost per person using the service.

### *The benefits of partnership working*

- 6.8. The often poor links between children's services and adult services was consistently identified by parents, carers and professionals as a challenge for the pilots. The pilots, and the work of transition key workers, helped highlight some of the problems but they struggled to close or bridge the gaps. The need to align, and better plan for, differences in eligibility criteria for support across services was seen as particularly important. The Monmouthshire consortium considered this an issue for national policy and one that local partnerships could have limited impact upon.
- 6.9. Transition protocols and multi-agency transition groups have been established in many of the pilots, but it is too early to say what impact this will have. Professionals recognised that these structures and processes will need to improve the long-term planning of service provision to meet need, if the new protocols and groups are to produce savings in commissioning services and responding to complaints.

## 7. The benefits for society

- 7.1. The study identified very few specific benefits for society, over and above the benefits for young people, their families and the state. However, whilst it is possible to state that the pilots, to date, have realised limited benefits for society, it is not possible to state with any certainty that the pilots could not, given the right context, realise benefits for society in the future as the young people involved grow older.
- 7.2. If, as the findings to date suggest, the influence of transition key working upon the *experience* of transition is greater than the influence upon the *outcomes* of transition, wider benefits for society are likely to be limited. For example, if transition key workers do not have an impact on the number of disabled young people whose transition to adult life leads to improved integration into society, the potential benefits of transition key working for society will be limited.
- 7.3. As previously discussed, in the majority of cases, the pilots were constrained from influencing the outcomes of transitions, in terms of the destinations made by young people leaving school. It is not clear, however, whether transition key workers have influenced the outcomes of destinations, in terms of supporting the sustainability of destinations.
- 7.4. Since, in the majority of cases, transition key workers supported young people who aspired to attend college, it is not possible to draw conclusions about the influence transition key workers may have had on their employment outcomes, nor the extent to which they would be able to live independently, on leaving college.



7.5. The one young person, however, who gained employment during the pilot lifetime, considered this would not have happened without the support of the transition key worker.

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## **8. The costs for young people, their families and society**

8.1. The only specific cost to young people and families identified by the study was their time. For example:

- Gwynedd revised their planning process in response to feedback from young people that the initial process was too lengthy; and
- one transition key worker highlighted problems with the IT system used for planning. The system was reported to be difficult to use because of its encryption and frequently crashed, causing the loss of data.

8.2. In addition, because some young people chose to take part in additional activities, such as recreational activities, there were some additional costs consequent upon this, such as travel costs.

8.3. In Anglesey, two parents worked as non-designated transition key workers, which is likely to have increased the time they spent on transition planning, because they took on the responsibilities of a non-designated transition key worker<sup>27</sup>.

8.4. It was also reported by one professional that the establishment of the pilots raised expectations amongst families, expectations that were not always met because, for example, young people did not fit the pilots' eligibility criteria or were not living in one of the counties covered by the pilots. Moreover, the loss of support when, for example, a young person reached the age of 25, or funding for the project ended, was

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<sup>27</sup> Although a parent or carer would be expected to contribute to transition planning for their child, the role of a transition key worker implies taking on additional responsibilities that a parent or carer would not necessarily be expected to undertake. Nevertheless, in the absence of a transition key worker, many might take on some or all aspects of the role of transition key worker, such as providing information and liaising with the services supporting their child.

often keenly felt. In effect, by improving experiences, the project had raised expectations, that could not be met over the long-term.

- 8.5. No specific cost to society, over and above those borne by young people, their families and the state (discussed above) were identified.

## **9. The costs to the state**

### **Introduction**

9.1. The study focused upon three types of costs to the state:

- start-up costs - the costs of establishing a transition key working scheme;
- operational costs - the cost of operating a transition key working scheme; and
- consequential costs - the consequent costs to other services of having a transition key working scheme (e.g. where a transition key worker makes a referral to another service).

### **Summary of costs, including unit costs**

9.2. Table 3 summarises the start-up and operational costs for each area. Costs are not directly comparable, because some areas provided additional detail, which we have included where available. For example, costs in Gwynedd are increased by the inclusion of the post of a person-centred planning officer in their budgets. If the cost of this post was excluded (no other pilot included costs for this type of post) the total operational cost for the period of the pilot in Gwynedd would fall by over £100,000. Full details of the start-up and operational costs identified by the study are included in the appendix 7.

**Table 3. Estimated total cost per case per year**

Area	Estimated start-up costs	Estimated operational costs over the lifetime of the project	Total cost (start-up and operational costs) over the lifetime of the project	Total number of young people supported	Duration (months)	Estimated cost per young person, per year, excluding start-up costs	Estimated cost per young person, per year including start-up costs
Anglesey	£32,000	£185,000	£217,000	23	24	£4,022	£4,717
Ceredigion	£51,000	n/a	n/a	40		n/a	n/a
Gwynedd	£47,000	£577,000	£624,000	75	36	£2564	£2,773
The Monmouthshire consortium <sup>28</sup>	£44,000	£444,000	£488,000	36	29	£5,103	£5,609
Pembrokeshire	£30,000	£231,000	£261,000	60	24	£1,925	£2,175

<sup>28</sup> These costs are notably higher than the cost per case calculated by the Monmouthshire consortium in their final project report (Monmouthshire County Council, n.d. b). This is because their costs are only based upon the salaries of the project manager and transition key workers (excluding for example, the cost of meetings and training) and only include a proportion of each salary, a proportion based upon the time they estimated was spent working directly with young people and their families - 70% of the transition co-ordinator's time and 20% of the project manager's time. This gives a total annual figure of £81,755, which divided by the 36 young people they worked with in one year, gives a cost per case per year of £2,270.

## Comparisons with the costs of transition key working estimated by the 2010 Social Policy Research Unit study

- 9.3. The unweighted mean cost per case per year, including start-up costs, for the four pilot areas where we have sufficient data, is £3,404, rising to £3,819 if start-up costs are included. These costs are considerably higher than the mean cost of £1,890 per case per year (including the cost of a steering group<sup>29</sup>) calculated in Models of Multi-agency Services for Transition to Adult Services for Disabled Young People and those with Complex Health Needs: impact and costs (Sloper et al, 2010).
- 9.4. However as Table 4 illustrates, the Social Policy Research Unit study mean cost conceals a very large range, with the study calculating costs of between £560\* to £3,610 per young person per year for the five areas it studied in-depth.

**Table 4. Service level costs for five transition services**

Service	Total cost per year including staff and steering groups (2007-08 prices)	Total number of young people support per year	Cost per case per year	Cost per case per year 2010/11 prices**
A	£204,800	183	£1,119	£1,205
B	£113,670	72	£560*	£603
C	£166,310	184	£904	£974
D	£274,450	76	£3,611	£3,889
E	£197,230	52	£3,460	£3,726

\* A figure of £460 is quoted in the report, however, this appears to be a typographical error.

\*\* Assuming inflation of 2.5% per year.

Source: Sloper et al, 2010

<sup>29</sup> The study included costs with and without the cost of steering groups. We have cited costs including the steering group, as they are more directly comparable to the costs calculated by this study.

9.5. The majority of the difference in cost between the five transition key working pilots in Wales and the Social Policy Research Unit findings reflects the much higher ratio of young people to transition key workers in three of the five service areas included in the Social Policy Research Unit study (A, B and C). Because staffing accounts for the bulk of the cost, this reduces the costs per case in each area and the mean cost per case. Table 5 summarises the ratio of whole team equivalent (WTE) staff to young people in the five service areas included in the Social Policy Research Unit study.

**Table 5. Ratio of staff to young people in the five service areas included in the Social Policy Research Unit 2010 study**

Service	Total number of young people supported per year	Staffing (WTE on transition)	Ratio young people to WTE staff	Cost per case per year
A	183	4.7	39	£1,119
B	72	1.78	40	£560
C	184	3.5	53	£904
D	76	5.98	13	£3,611
E	52	4.55	11	£3,460

*Source: Sloper et al, 2010*

9.6. Higher caseloads in service areas B and C in particular, only explain some of the gap between the mean costs identified by the two studies. Differences in the approach used also explain some of the gap. In particular, the Social Policy Research Unit study (Sloper et al, 2010) does not include any of the start-up costs of establishing a transition key worker service and a number of operational costs, including:

... “clerical and administrative support, office-related costs, other staff costs such as travel, client-related service costs, building costs and

overheads payable to a managing organisation for section- or department wide functions...” (ibid.:217).

- 9.7. The range of costs in the five service areas included in the Social Policy Research Unit study is, therefore, narrower than the range of costs included in this study, and limited primarily to staffing costs, which account for the bulk of the costs of providing the service, and the estimated costs of steering groups.
- 9.8. In order to enable the costs calculated by the two studies to be compared, as Table 6 illustrates, we first excluded the start-up costs in the four pilot areas where figures are available. However, as Table 6 illustrates, the cost per case still remains markedly higher than those in three of the five service areas with high caseloads per worker (A, B and C), although more comparable with the other two service areas (D and E), with much lower caseloads per worker.
- 9.9. We then included an estimate of the likely cost of the other operational costs that the Social Policy Research Unit study excluded. The Social Policy Research Unit study estimated that:

“Direct costs (travel, training, equipment) are equivalent to at least ten per cent of salary costs; managers and administrative staff add a further ten per cent; and capital overheads (land and building) account for an additional six per cent”<sup>30</sup> (ibid.).

This would increase the total costs by just over a quarter. Although this is not included in the Social Policy Research Unit headline figures (discussed above), even if they were included, the mean cost per case would rise to £2,382 per case per year. This would still be markedly lower than the mean cost per case per year (excluding start up costs)

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<sup>30</sup> These estimates are based upon the data for child and adolescent mental health teams, reported in Curtis (2007).



calculated by this study (£3,404). Table 6 illustrates the impact of this upon the range of costs identified by the study.

**Table 6. Service level costs for five transition services, including estimated costs for administrative support, office, staff, building and management costs**

Service	Cost per case per year excluding estimated costs	Cost per case per year including estimated costs for admin support, staff, building and management costs*
A	£1,119	£1,410
B	£560	£706
C	£904	£1,139
D	£3,611	£4,550
E	£3,460	£4,360

\* A multiplier of 1.26 (26%) has been used.

Source: Sloper et al (2010)

- 9.10. If these additional costs are included, costs in two of the service areas included in the Social Policy Research Unit study (D and E), are higher than the operational costs (i.e. excluding start up costs) in three of the pilot areas (Anglesey, Gwynedd and Pembrokeshire).
- 9.11. In interpreting costs, it is also important to bear in mind that in addition to providing a direct service to young people and their families, some areas also focused on developing systems and processes and staff training to promote person-centred planning and transition support. Although the majority of these costs fall within the start-up costs, not all costs did, and this will have further inflated the cost per case in the pilot areas.

## **10. Conclusions**

### **Transition key working and person-centred planning**

10.1. In this report we consider the benefits of the co-ordination and support provided by transition key workers, and the benefits of adopting a person-centred planning approach, upon young people's and their families' experience of transition and upon the outcomes of transition.

### **Improving the experience of transition**

10.2. This study found that transition key working offers important benefits for the majority of young people. Most young people value the emotional and practical support transition key workers offer, during what is often a difficult period of their lives.

10.3. The study found that the projects have improved most young people's experience of the transition from school to college and improved the experiences of those who are making, or have made, the transition from education into adult life.

10.4. All the young people and families interviewed, and a significant proportion of those surveyed by the projects, said that transition key workers had helped provide them with more, and better, information than they had previously had and that they felt supported. Young people and families considered the additional information and support provided was likely to have made their experience less stressful. The transition key workers were not able to remove stress altogether though. In line with other studies, we found that young people and families still had some concerns, but those that still had access to a transition key worker felt that there was someone 'on their side' explaining things and helping them to cope with disappointments and uncertainty. Those that were no longer in contact with a transition key worker missed the support and co-ordination provided by the transition key worker.

10.5. Transitions inevitably involve uncertainty. As one transition key worker put it, they don't have a "crystal ball" and the degree of uncertainty many young people and their families report, despite the support of a transition key worker, is a significant cause for concern for families. In many cases, transition key workers have not been able to ensure that there is transparency and clarity about decision-making at transition, or that adequate notice is given about decisions. For example, young people with a transition key worker still talked about the possibility that they would not know about whether they could attend a college until as late as a week before term starts; others did not know if they would have a social worker in future, and most of those in college were unsure what would happen when their course ended, and in some cases, were anxious as a consequence. This would suggest that in order to further reduce stress around transition, there needs to be better long-term planning, with key decisions made well in advance of transition points such as from school or from college, and decision-making processes that involve young people and their families as far as possible, ensuring that they know when a decision will be made and why it was made.

### **Supporting parents' and carers' transitions**

10.6. Transition is also often a difficult time for young people's parents and carers and some of the transition key workers described helping families to manage the changes in young people's lives, aspirations and behaviour as a major part of their work. There were also examples of young people being supported into more suitable environments and activities, resulting in their behaviour becoming calmer and easier to manage, with a resultant lessening of parental stress. In some areas, there was evidence that the transition key worker had helped parents and carers to recognise young people's changing needs and to go through a very difficult journey towards meeting them (in effect, a transition of their own).

10.7. Evidence from this study suggests that the capacity of a transition key worker to make a difference to a family, by supporting the transitions young people, their parents and carers make, is defined by the availability of suitable provision and the funding to finance it; the agreement of key staff to work together to achieve such a change; and the relationship that the transition key worker is able to establish with the young person, their parents and carers.

### **Cases where the benefits for the experience of transition was limited**

10.8. The evidence from surveys, undertaken by the pilot projects, indicates that the majority of young people and families were very positive about having transition key worker support, although a minority were dissatisfied with aspects of the transition key working services.

10.9. The evidence from surveys, undertaken by the pilot projects, also indicates that a small number of young people, parents and carers did not engage fully with the transition key working service. The evidence from the Monmouthshire consortium, where we have the richest evidence, suggests three broad reasons why some young people, their parents and carers did not engage with their transition key worker and the benefits were, therefore, reduced:

- some young people did not see the need for a transition key worker. Young people with autistic spectrum disorders were identified as one group that might struggle to recognise or understand their support needs and could, therefore, be difficult to engage;
- parents and carers who were not strongly engaged in their young person's transition, perhaps because they themselves had complex difficulties in their lives; and
- cases where a professional was already taking on a *de facto* key working role, and where introducing another worker to the family just made things more complicated.

## **The benefits of a person-centred planning approach to transition key working upon outcomes for young people**

10.10. In contrast to the strong evidence of a positive influence upon most disabled young people's and their families' *experience* of transition, evidence about the influence upon the *outcomes* of transition for disabled young people, such as continuation in education or training, finding a job and living independent lives, is more limited. In part, this was because few of those interviewed for this study had completed their transition, so that the evidence on long-term outcomes was necessarily more limited. Nevertheless, the qualitative evidence indicates that the influence on intermediate outcomes, such as continuation in education or training, was limited. The qualitative evidence from this study indicates that most young people would have followed the same transition pathway - in most cases, the transition from school onto a college course - even if they had not been supported by a transition key worker. It is not clear, however, whether the support of the transition key worker had helped to sustain involvement in college. That is, prevented young people from dropping out. Crucially, it is the next stage of transition, from college into the adult world, which is more uncertain and challenging for this group of young people. It is too early to say what impact transition key working arrangements will have upon this, because, as noted, so few of those we interviewed had completed their transitions.

10.11. For eight of the 20 young people we interviewed, transition key workers have had an influence on the outcome of their transition. This includes four young people with very severe and complex needs who have moved into permanent adult residential placements; encouraging and enabling young people, who would not otherwise have done so, to access college courses, as was the case for three of the 20 young people we interviewed; or employment, as was the case for one of the 20 young people we interviewed.

10.12. There are a number of reasons why, despite the adoption of person-centred planning, the benefit of transition key working upon young people's choices about transition were limited. These factors include:

- the extended nature of the transitions young people were making;
- the often limited choices or options open to young people locally; and
- the limits of a person-centred planning process.

*The extended nature of the transitions young people were making*

10.13. Traditionally, young people's transition was identified through the achievement of a set of recognised 'markers' of adulthood, that is transition to employment, their own home and their own family (Wallace 1987; Jones 1995).

10.14. Transitions for disabled young people, particularly those with complex needs, are typically quite different, and the concepts of 'fragmented' and 'extended' transitions (ODPM, 2005; Jones, 1995), are useful here in describing and understanding their transitions. These concepts emphasise the range of transitions that young people may make at different ages and the total length of time during which they may be involved in transitions, which we feel, offer a useful framework for looking at the transitions of disabled young people.

10.15. The concept of an 'extended' transition, implies an end point of achieving adulthood and independence, albeit one that can take a long time to reach. For some young people, particularly those with complex needs, the 'markers' of transition to adulthood may be less clear cut, meaning it is difficult to identify a point at which their transition is 'complete'<sup>31</sup>. These markers may include:

- on-going involvement in meaningful activities with support in place to ensure it is sustained and sustainable<sup>32</sup> - this could include employment or volunteering for some, however, others will not be able to work and

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<sup>31</sup> The campaign group PMLD Network highlights the unsuitability of the majority of people with profound and multiple learning difficulties for paid employment, as more than 50% of adults with PMLD are reliant on day care.

<sup>32</sup> Involvement in a time limited activity, such as a college course, would not constitute a marker of completed transition but rather a step towards transition to adulthood, requiring planning for what happens at the end of the activity.

their adult life may be focused around stimulating therapies, accessible social networks and good quality supported living;

- settled housing suitable for adult and long-term needs - this could include independent living, supported accommodation, paid assistants and plans in place to manage any long-term changes needed (for example, when a parent dies); and
- a social and cultural life - this could include relationships with partners and forming a new family but also sustainable access to social networks and friendships.

10.16. This study focused primarily upon the experiences of young people aged 16-19 and illustrates that by the age of 19, most of the young people involved in the pilots were only part way through their transition to adulthood<sup>33</sup>. Their transition may not be 'complete' until they are in their mid-twenties and, even then, may require a permanent support structure. Moreover, the likelihood of most young people making a transition from education to employment is at best uncertain, especially since most were involved in non-vocational college courses that focused more on living skills than preparation for employment.

10.17. Moreover, because the transition key worker pilots ran for less than three years, inevitably, the transition key workers could only support young people for a portion of their transition. The study, therefore, raised questions about the point (or age) at which all the costs and benefits of transition key working, including those associated with changes in outcomes for young people, would or could be realised (and assessed). The study also raised questions about the benefit of transition key working upon young people who were already mid-way through their transitions where the benefit was affected because the transition key workers were helping to address problems which, if they had worked with the young person from an earlier age, might have been avoided.

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<sup>33</sup> The focus of this study was upon the benefits for young people aged 14-19, although as some pilots worked with young people up to the age of 25, we have considered benefits for these young people.

10.18. The fragmented and extended nature of many young people's transitions clearly had implications for the scope of transition key working. It meant that it was difficult to justify a pre-determined cut-off point for ending the support provided by the transition key worker and there was some evidence that the idea that the transition key worker's support would be withdrawn at some point was, in itself, causing concern to young people and families around what would happen in the 'transition from transition support'<sup>34</sup>. Moreover, even amongst those young people who had 'completed' their transitions, young people and their families often still expressed a desire for continuing support.

### *The choices young people can make*

10.19. Limited resources and choices have been identified, by transition key workers and other professionals, as key factors which constrain the impact of transition key working upon the choices young people make. For example, in many cases, the only options for disabled young people leaving school were a limited range of courses in a local college, attending an adult day centre or to become unemployed. Post-college options were often even more limited for those who would not be able to work. This inevitably limited the impact of person-centred planning upon outcomes for young people.

10.20. In addition, structural barriers, such as poor joint working between children's services and adult services and the existing statutory assessment and planning process, have limited the choices young people can make and, consequently, have also limited the benefits of transition key working.

10.21. Unless these structural barriers, and the often limited range of options for young people are addressed, the impact of transition key working upon outcomes (as distinct from experiences of the process) is likely to be limited.

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<sup>34</sup> The negative effects of withdrawing support are also highlighted by PMLD (2009).



### *The limitations of person-centred planning*

10.22. Person-centred planning worked well with many, but not all, young people. In some cases, the young people were already well supported and had a clear idea of what they wanted. In other cases, young people's difficulties in communicating, or in understanding their needs, limited the effectiveness of person-centred planning despite the fact that transition key working allows the time for workers to be able to meaningfully involve young people and develop an effective relationship.

10.23. Judgements on the value of person-centred planning were often polarised. In general, the greatest level of scepticism about person-centred planning came from those who were not directly involved in it. This may, in part, reflect a misconception. It is easy to dismiss person-centred planning if the value is seen only in terms of identifying what a young person wants. If, however, it is viewed as a planning tool that helps empower and enable young people to achieve their aspirations and ensure their needs are met, its value is much greater. Its impact has also been limited by the factors outlined above. These include the limitations imposed by difficulties in using person-centred planning to inform existing assessment and planning processes, and by the limited options for many young people once they had completed college courses. This has also contributed to scepticism about the value of person-centred planning.

### **The transition key worker role**

10.24. The study illustrates how the role of an effective transition key worker is person-centred, developmental and supportive. Ideally, it involves:

- using a person-centred planning methodology to help young people decide what they want to get out of life and to plan how to get it;
- working with others to co-ordinate support for this plan;

- pro-actively seeking out and identifying opportunities and activities that help meet young people's wants and needs;
- supporting young people and their families through periods of change and uncertainty - what might be described as 'hand-holding'; and
- empowering young people, building their support networks and their social and emotional skills and dispositions so they are better able to cope with change and uncertainty.

10.25. The five roles should complement each other. The first involves planning a transition, the second role should help 'smooth' out transitions, the third should help people realise their aspirations, whilst the fourth and fifth roles contribute to strengthening young people's 'resilience', their ability to cope with adversity (including change and uncertainty) during transition.

10.26. Whilst the work should always be person-centred, not all young people, and not all families, will need equal amounts of support. Some young people, for example, will have clear aspirations, strong social and emotional skills and dispositions, and a well planned and co-ordinated package of support, but others will not. It is, therefore, crucial that transition key workers have the flexibility, skills and knowledge to respond to young people's diverse needs. Therefore, we would expect that transition workers would undertake diverse roles when working with young people and families.

10.27. Nevertheless, the available evidence, whilst partial and incomplete, suggests that the extent to which transition key workers took on all five roles outlined above differed across the pilot areas, and that this was not only attributable to differences in the needs of the young people they worked with. In some areas, young people and families had clearly discussed 'what next' scenarios and were involved in updating the transition plan to map out what needed to be done and when. In this way, the plan became a basis for proactively seeking out opportunities and options. In other areas, there seemed to have been less forward planning done and work appeared more focused on helping young people cope with what was currently happening. In these latter cases,

transition key workers appeared to be adopting more of a support worker role, perhaps in the absence of anyone else who could take this work on.

### *Co-ordinating support and managing transitions*

10.28. Young people and families particularly valued the support the transition key worker role provided, but it appeared to be most effective when it was offering more than support. In particular there was value where:

- the worker was actively involved in helping to co-ordinate the work of agencies on the young person's behalf - for example, not just attending review meetings but intervening to make the meetings more effective, and helping to hold service providers to account;
- the worker was focusing across the domains of transition, supporting young people's learning, health, social, emotional, and practical needs holistically; and
- the worker was able to help the young person tap into a range of resources including voluntary sector programmes and direct payments - there was considerable variation across the pilots on the options made available to young people. However, the extent to which these variations reflected local differences or were down to the skill of a worker in identifying and helping a young person access them, was not clear.

### *Supporting young people and families through periods of change*

10.29. Transitions are often stressful and, in most cases, transition key workers played an important role in providing emotional support. In some cases, the worker was able to help parents and carers to 'let go' where appropriate - that is, to stand back from an entrenched view of what the young person needed and review options - enabling young people to make transitions. Again, however, there were variations across the pilots in the role transition key workers played with parents and carers.

## *Empowering young people*

10.30. In addition to providing practical and emotional support, in some cases, transition key workers were able to help empower young people, by building their support networks and their social and emotional skills and dispositions so they were better able to cope with change and uncertainty.

### **The costs and benefits of transition key working**

10.31. The benefits realised by transition key working determines the net costs and benefits for young people, their families, the state and society. The study did not set out to calculate a financial value for these costs and benefits, such as increases in the demands upon people's time, improvements in their wellbeing and improvements in partnership working that, unlike items such as salary costs, are not directly expressed in monetary terms. Therefore, it is not possible to subtract total net costs from total net benefits in order to see if the financial value of benefits outweighs the financial value of costs for specific groups.

### *The costs and benefits of transition key working for young people*

10.32. Transition key working imposes only limited costs upon young people. There is no charge for young people using the service. Although young people must give up time to contribute to the planning process, most report enjoying the experience (although this does not eliminate the cost of contributing). Some also incurred modest costs in terms of, for example, charges for text messages and phone calls to transition key workers. Because transition key working rarely changed the outcomes of the transition process, the additional, or consequential costs of the choices young people make about aspects of transition, are also rare. While young people may highlight their anxiety (an emotional cost) about making the transition from school to college, it is likely that they would have made this transition without the intervention of their transition key workers, and potentially have faced greater costs without the

additional support since, as noted, the emotional and practical support offered by transition key workers helped reduce their anxiety. However, the close relationship many young people forged with their transition key workers, whilst a benefit, may also result in an emotional cost when support is withdrawn.

### *The costs and benefits of transition key working for families*

10.33. Transition key working offers important benefits for the majority of families.

Most parents and carers value the emotional and practical support transition key workers offer. Benefit was experienced directly by parents and carers feeling more supported themselves, and indirectly through the improvement of young people's experience of transition which improved their parents' and carers' experiences. Transition key workers also directly improved most parents' and carers' experience by providing information, practical help, an accessible point of contact and providing continuity at a time of change. For a small minority of parents and carers, the benefits are less clear and they have expressed dissatisfaction with transition key working.

10.34. Transition key working imposes only modest costs upon most families. There is no charge for young people using the service, but families must give up time to contribute to the planning process. They may also incur modest costs in terms of charges for text messages and phone calls to transition key workers, but this may have been offset by a reduction in contact with other services<sup>35</sup>. Some parents described how in the past they may have spent many hours on the phone trying to find the right person to deal with a problem, but were now able to just ring the transition key worker and rely on him or her to deal with the issue. Because transition key working did not change the transition process for most, there were few additional or consequential costs of the choices their son or daughter made about aspects of transition. Moreover, whilst, for example, a young person choosing independent living as

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<sup>35</sup> It is difficult to estimate the net costs here though, as some of the calls made to transition key workers may have been made to other services, if there was no transition key worker and by acting as single point of contact, transition key workers may have contributed to a reduction in the number of contacts.

a consequence of the intervention of a transition key worker might lead to a loss of state benefits for the family, in principle, these should be offset by lower costs for the family.

10.35. It is possible that if transition key working improves experiences and raises expectations of a level of support that cannot be met once the service is withdrawn, the emotional costs that flow from this may outweigh the emotional benefits experienced whilst the service was provided. It was, however, too early to judge whether this was the case or not. Although this could be considered a cost, it is best considered to be an example of a cost related to a previously unmet demand, and as such, is not a new or additional cost.

10.36. The model in which a parent acts as non-designated transition key worker is an interesting one. The available evidence is too limited to draw definitive conclusions. However, on paper, it is likely that many of the benefits of transition key working for both young people and families, such as the benefit of having someone independent from the family who can not only co-ordinate services and provide information, but can also ensure that the young person's interests are put at the centre of planning and help parents review the young person's changing needs, will be more difficult to realise<sup>36</sup>.

#### *The costs and benefits of transition key working for the state*

10.37. To date, the benefits of transition key working for the state have been relatively modest. It has contributed to improvements in assessment and planning, and improved parental engagement with services. However, the evidence indicates that the pilot projects struggled to bridge or close divides between children's services and adult services. Moreover, many of the benefits of improvements in assessment and planning may only be felt in the medium to long-term. For example, it may reduce the dependence upon expensive out-of-county placements and reduce the risks of placements

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<sup>36</sup> A parent or carer may, for example, find it difficult to disentangle their interests and expectations from those of their child.

breaking down or non-completion of college courses, which should in turn save money (cf. WAO, 2007)<sup>37</sup>.

10.38. The costs of transition key working to the state relate to the provision of an additional 'layer' of service being provided to families as, in general, transition key working has been in addition to, rather than instead of, the work of existing services. This has resulted in problems such as parallel planning. The mean, unweighted cost per case in the pilot areas, £3,402 (excluding start-up costs), is much higher than those estimated by the Social Policy Research Unit research into the costs of key working (£1,890) (Sloper et al, 2010). The difference in cost reflects the very high ratios of young people to transition key workers in three of the five sites included in the Social Policy Research Unit study (which had a substantial impact on the mean cost). They also reflect differences in methodology, which means this study included a wider range of operational costs<sup>38</sup>. If allowance is made for these factors, the differences in cost are not so great.

10.39. To date, the services have not generated significant consequential costs by, for example, identifying previously unmet needs or creating new demands upon resources, but neither have they generated significant cost savings by, for example, improving forward planning for how best to meet need. Transition key workers can contribute to this, but the study suggests that realising these types of benefits will depend upon other reforms to assessment and planning for young people's needs being implemented. Other research (Sloper et al, 2010, DCSF 2007) has highlighted the variation in provision across local areas and service providers as an area for attention<sup>39</sup>.

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<sup>37</sup> The Wales Audit Office reports that "Good forward planning can lead to higher expenditure in the short-term. However, higher levels of initial investment have the potential to reduce costs in the longer term by reducing the number of pupils placed in expensive out-of-county provision, and by increasing schools' capacity and confidence in catering for SEN" (p. 8, WAO, 2007).

<sup>38</sup> The Social Policy Research Unit study, *Models of Multi-Agency Services for Transition to Adult Services for Disabled Young People and those with Complex Health Needs: impact and costs*, does not include start-up costs, such as training, and only includes estimates for operational costs such as overheads, which are lower than those calculated by this study.

<sup>39</sup> Research by Sloper et al. (2010) suggests that "transition services have varied considerably in how they are structured, which agencies are involved and the support they provide for young people and their families".

10.40. Although the evidence is more limited, the study suggests that the non-designated transition key working model generated fewer benefits without significantly reducing costs, and is also judged likely to be less sustainable than the designated transition key working model.

*The costs and benefits of transition key working for society*

10.41. The study identified relatively few specific costs or benefits for society, over and above those incurred or experienced by young people, their families and/or the state. In particular, the relatively limited impact of transition key working upon the outcomes of transition meant that potential benefits for wider society, such as increasing social inclusion, were limited.

*Evaluating the net costs and benefits*

10.42. As outlined above, it is difficult to assess the impact upon the final outcomes of transition at this stage, because these outcomes relate to the completion of transition and very few of the young people supported in the projects have yet reached that point. In contrast, the benefits in relation to the process or experience of transition are clearer. Given the levels of stress, the uncertainties and the multiple changes associated with it, the impact of improving the experience of transition should not be undervalued. For example, as one interviewee put it:

“...even if it's [the destination is] not that different at the end, if you get there through a less rocky path...if things are not left to the last minute, with all the stress of feeling like you're going to fall off a cliff...[you shouldn't] minimise that”.

10.43. Moreover, it was striking that despite the problems many had experienced, almost all the young people who contributed to this study were happy with their lives.



10.44. Although to date, transition key working has not generally created significant cost savings for the state, the study suggests that if combined with other changes to the assessment and planning of, and for, young people's needs, it could contribute to savings over the long-term. Transition key working and approaches such as person-centred planning bring important benefits, but are not a panacea that ensures that services work efficiently and effectively. There was, however, optimism amongst many of the professionals we interviewed, that if combined with other changes, they could contribute to cost savings, and the frustration of many stakeholders with the inefficiency and ineffectiveness of many existing services was clear.

### **The viability of introducing and sustaining transition key working in Wales**

10.45. This study has identified both clear benefits for the majority of young people and their families and significant costs for the state as a consequence of the introduction of transition key working. Crucially, the study also suggests that the benefits of transition key working and the potential cost savings are severely constrained by structural factors, including:

- often limited options for young people once they have left school, options which tend to become even more constrained after they complete college courses;
- weakness in the long-term planning for need, which means that the decision-making process is often poorly understood by young people and their families and decisions are sometimes made late in the day, contributing to poor value for money for the state; and
- weaknesses in partnership working between services.

10.46. Although the benefits of transition key working are much valued by young people and their families, unless and until the structural problems are addressed, the impact of transition key working will be curtailed and the net costs to the state will remain high.

10.47. The on-going reform of the statutory framework for young people with special educational needs aims to address some of these structural problems, most notably in relation to the assessment and planning of need and partnership working to meet that need. In principle, this should contribute to an increase in the benefits of transition key working and a reduction in net costs. However, unless and until reform takes place, these will remain potential, as opposed to actual, benefits and net cost savings.

10.48. The study also indicates that, given the 'extended' and 'fragmented' nature of transitions, there may be a case for extending support to the age of 25 years and potentially beyond. It is likely that the support needs of young people aged over 20 would be lower and would tend to decline over time, and that the intensity and frequency of support offered by transition key workers - the major cost of providing the service - would be lower.

### **Areas for further research**

10.49. The study has highlighted a number of areas where further research is warranted. These include, more research into:

- the impact and effectiveness of the non-designated model of transition key working;
- the relative cost-effectiveness of independent and local authority managed transition key working models;
- the cost-effectiveness of extending transition key working to the point where young people are settled into a sustainable adult life, which in some cases may mean support up to age 26, or beyond, if required;
- the effectiveness of adult services planning for young people's needs as they approach the age of 18, including the transfer of information about young people's needs from children's services to adult services;
- ways in which the impact of transition key working upon the outcomes of transition could be enhanced, including models of effective inter-agency and multi-agency collaborative working;

- the effectiveness of current programmes focusing on employment preparation and work experience for young people with severe and complex needs;
- the extent to which formal and informal educational provision, social, artistic and sporting provision for young people with complex needs, who have completed further education, meets their needs;
- the extent to which existing statutory assessment and planning arrangements limit the potential to use person-centred approaches; and
- ways of increasing clarity around transition including how to make routes through transition more transparent and accessible to young people and families, so that people know what options are going to be available and can plan well in advance.

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