



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

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Summary Report

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

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Acronyms used

CCNUK	Care Co-ordination Network UK
DCSF	Department for Children, Schools and Families
DoH	Department of Health
NAfW	National Assembly for Wales
WAG	Welsh Assembly Government (pre 2011)

1. Introduction

- 1.1. In 2008, five pilot projects were set up to develop transition key working in Wales for disabled young people, or those with complex needs¹, aged 14-25. This report presents the findings of an analysis of the costs and benefits of transition key working in these projects.

- 1.2. Transition can be a difficult time for any young person. Deciding what to do when you leave school, where to live and who with, what employment you would like and what steps you will have to take to get it, can feel overwhelming. Disabled young people and those with complex needs, may face additional challenges in coping with multiple changes in the services they rely on. Transition key working aims to provide a named person to work with the young person and, where appropriate, his or her family to help prepare for, and successfully move through transition.

Background and policy context

- 1.3. There is a range of policy initiatives and guidance aimed at improving and co-ordinating services in order support the transitions of young people with severe and complex needs. For example, the Special Educational Needs Code of Practice for Wales (NAfW, 2004) states that all young people with statements of special educational needs (SEN) should have a transition plan prepared when they are in school year 9 (at age 13-14), and that this should be reviewed at least annually until they leave school. The code of practice also explains how schools, the education service, Careers Wales, social services and health services should all work together to contribute to these transition plans.

¹ The National Service Framework “sets out the quality of services that children, young people and their families have a right to expect and receive” (WAG, 2006:i). The Framework standard on transition 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).

- 1.4. Despite this guidance, outcomes for young people and adults with profound and multiple or complex disabilities, in terms of securing employment and independence, remain poor (NAfW, 2007). Research in Wales and across the UK has found that many young people report feeling under-prepared and unsupported following transition (*ibid*; Sloper et al, 2010).

The Transition Key Worker Pilot Projects

- 1.5. In 2007, the Welsh Assembly Government announced grant funding totalling £1.5 million to develop transition key working in Wales. In June 2008, local authorities were invited to apply to become transition key working pilot sites. Five pilots were set up. 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. In total the pilots worked with 234 young people over three years.

Key working and person centred planning

- 1.6. 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).

- 1.7. All the pilot projects adopted a person-centred planning methodology. Person-centred planning reflects a ‘social’ (as distinct from ‘medical’) model of

disability², embodies a strengths-based approach to planning and seeks to involve people as active participants in the planning process. 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). The report considers the impact of both the co-ordinating role of a transition key worker and of a person-centred planning approach.

2. The study

- 2.1. 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 intervention on disabled young people's, and their families', experience of the transition into adulthood. The focus of the study was upon young people aged 14-19 and the study ran from May to October 2011.
- 2.2. The study integrated both qualitative and quantitative research. The qualitative research focused primarily upon the costs and benefits of transition key working as experienced by the young people and their families involved in the pilot projects. The quantitative research focused primarily upon costs to the state.

² 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 n.d.). In 2002, the Welsh Assembly Government adopted the social model of disability as the foundation for its work on disability (Welsh Government, website n.d.).

- 2.3. In total, 20 young people with disabilities or complex needs contributed to the study along with 18 family members or carers. Interviews and focus groups were undertaken to discuss:
- their relationship with, and the work of, their transition key worker;
 - their transition plan; and
 - what difference, if any, the transition key working made.
- 2.4. In addition, in each pilot area, the research team met with members of the pilot delivery team to discuss the costs of establishing and operating a transition key worker service and to discuss the impact of the transition key working service.
- 2.5. The primary data collected through interviews and focus groups were analysed alongside secondary data, such as case studies, prepared by the pilots, the pilot self-evaluations, and surveys of young people or families undertaken by three of the pilots³.

Limitations of the study

- 2.6. The small sample of young people interviewed meant that the study was unable to compare benefits and costs for specific groups of young people, based on their needs. In addition, the analysis of the non-designated model of transition key working, which was piloted in only one county, was limited because it was only possible to recruit one young person and one parent for interview.
- 2.7. The study did not include any interviews with young people, parents or carers outside the pilot areas and drew its external validity from other studies on the

³ 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 used 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.

costs and benefits of transition key working, undertaken elsewhere in the UK. These showed that findings on benefits are broadly consistent with other studies, although the Welsh pilots tended to have higher costs. However, much of the difference in costs relates to differences in the context and organisation of transition key working.

3. The benefits of transition key working

The benefits for young people

Experiences of working with a transition key worker

- 3.1 The young people we interviewed were all positive about the support they received from their transition key workers and those who could remember their transition plan (11 of the 20 interviewed) were all 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.
- 3.2 Overall, the study found that although person-centred planning rarely changed what young people wanted to do, it increased awareness and understanding of their wishes amongst those working with them, helping them to support young people to achieve their aspirations.

Supporting the transition from school to college

- 3.3 In the majority of cases, the transition key workers supported young people's transition from school to college. Whilst, in most cases, the young people who went to college said that they would have gone there without the support of their transition key worker, there was evidence that the support provided by transition key workers enabled some young people to sustain their involvement in college, and/or led to them taking more appropriate courses.

Supporting the transition from post-16/19 education

- 3.4 The study illustrated gaps in post-16 and post-19 transition planning including a lack of information about what young people could do after college and what support they could expect.
- 3.5 In three pilot areas, transition key workers were reported to have played an important role in helping young people to access a range of social, sporting and cultural activities. However, after leaving college, the range of activities and experiences that young people could access were described as limited in all five pilot areas.

Supporting the transition to independent living

- 3.6 A number of factors influenced the impact of transition key workers upon independent living, including the extent to which some young people wanted to be independent. In some of the pilots, where appropriate, transition key workers played an influential role in supporting independent living by empowering young people and/or helping change their parents' and carers' attitudes and expectations.
- 3.7 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.

The benefits for families

- 3.8 The overwhelming majority of parents and carers were positive about transition key working. 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.

The impact and value of transition plans and planning

- 3.9. Although the majority of parents and carers valued the transition key worker and were satisfied with the transition plan, in some pilot areas between a third and a half reported that they did not feel the young person had been 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.
- 3.10. The parents and carers interviewed felt that the need for key working was ongoing and, rather than setting age limits on support, it should respond to need.

The benefits for the state

The impact of person-centred planning upon services

- 3.11. Participants involved in service delivery were divided about the value and impact of person-centred planning. Almost all professionals using person-centred planning were positive about it. In contrast, professionals who were not directly involved in using person-centred planning, were often more sceptical of its value, and commented on the difficulty of using the outcomes of the process in existing assessment and planning processes, which are service-centred rather than person-centred.

The impact of transition key working upon partnership working

- 3.12. Poor links between children's services and adult services were consistently identified by parents, carers and professionals as a challenge for the pilots. The need to align eligibility criteria, and better plan for support across services was seen as particularly important and there was some evidence that

transition key working helped address aspects of this. However, the effectiveness of transition key working was hindered by poorly developed links between children's services and adult services.

The benefits to society

3.13. The study identified very few specific benefits to society, over and above the benefits to young people, their families and the state. However, it is possible that the pilots could, given the right context, realise benefits for society in the future as the young people involved grow older. For example, if, as a result of the support they have been given, some of the young people are able to contribute more fully to their community, they will be helping to create a more socially integrated society.

4. The costs of transition key working

The costs to young people and their parents or carers

4.1. The only specific cost to young people and families identified by the study was their time. In addition, because young people chose to take part in additional activities, such as recreational activities, there were some consequential costs, such as for travel.

The cost to society

4.2. No specific costs to society, over and above those borne by young people, their families and the state (discussed below), were identified.

The costs to the state

4.3. 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 consequential 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 start up and operational costs, including unit costs

- 4.4. Table 1 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 within 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. Total costs have been rounded up to the nearest thousand in the table.
- 4.5. 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 group⁴) calculated by Sloper et al (2010) in the Social Policy Research Unit study of the impacts and costs of transition support. However, when all comparative calculations are included, costs in two of the service areas included in the Social Policy Research Unit study are higher than the operational costs (i.e. excluding start-up costs) in three of the pilot areas (Anglesey, Gwynedd and Pembrokeshire).

⁴ 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.

Table 1. 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 ⁵	£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

⁵ 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, when divided by the 36 young people they worked with in one year, gives a cost per case per year of £2,270.

5. Conclusion

Transition key working and person-centred planning

- 5.1. This report has presented 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 its impact upon the outcomes of transition.

Improving the experience of transition

- 5.2. The 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.
- 5.3. 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.
- 5.4. 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 previously had and that they felt better supported. Young people and families considered the additional information and support provided was likely to have made their experience less stressful.
- 9.1. Transitions involve uncertainty and this can cause considerable stress which is only partly allayed by transition key workers. 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. 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. In addition, decision-making processes need to involve young people and their families as fully as possible, ensuring that they know when a decision will be made and why it was made.

Cases where the impact upon the experience of transition was limited

- 5.5. The evidence from surveys, undertaken by the pilot projects, 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, reducing the benefits they could receive:
- some young people did not see the need for a transition key worker. Young people with autistic spectrum disorder, in particular, were identified as a group that sometimes struggled to recognise or understand their support needs and could, therefore, be difficult to engage;
 - parents and carers who were not strongly engaged in the young person's transition, including those who had learning difficulties, health problems and/or complex difficulties to manage 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 would have added unnecessary complexity.

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

- 5.6. In contrast to the strong evidence, set out above, of the positive influence of transition key working upon most disabled young people's and their families' *experience* of transition, evidence about the influence upon the *outcomes* of transition is more limited.

The costs and benefits of transition key working

- 5.7. Transition key working imposes only limited costs upon young people and on their parents and carers. There is no charge for young people using the service. Although young people, their parents and carers must spend time contributing to the planning process, most report enjoying the experience (although this does not eliminate the cost of contributing).
- 5.8. In the pilot areas, transition key working has been in addition to, rather than instead of, the work of existing services and the costs to the state relate principally to the provision of this additional 'layer' of service.
- 5.9. To date, the benefits of transition key working for the state have been relatively modest. Transition key working 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.
- 5.10. 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 likely to be less sustainable than the designated transition key working model.

Evaluating the net costs and benefits

- 5.11. It is difficult to assess the impact of transition key working upon the final outcomes of transition at this stage, because very few of the young people supported in the projects had completed transition. 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.
- 5.12. 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.

The viability of introducing and sustaining transition key working in Wales

- 5.13. 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. 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.
- 5.14. 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 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

5.15. The study has highlighted a number of areas where further research is warranted. This includes 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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