

PERSONALISED TRANSITION

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NOVEMBER 2011



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CONTENTS

1. INTRODUCTION	2
2. CONTEXT	3
3. THE MODEL	4
4. OUTCOMES	7
5. COSTS	10
6. RATIONALISING	12
7. CONCLUSION	13

1. INTRODUCTION

Personalised Transition demonstrates how a collaborative approach to funding individual budgets for disabled school leavers with complex needs has led to more positive, individualised outcomes for the young people and their families. The approach allows young people and their families to be in control of support planning and organising their lives beyond school with a mix of funding from health, social care and education depending on individual needs. The focus is on the young person as a citizen with a contribution to make – not as a service user.

The model is already being used in five other local authority regions in Yorkshire and the Humber. And the potential implications of the model go far wider - to further reforms in adult social care, health care, education, children and families and community development.

2. CONTEXT

National research about disabled young people's move to adulthood over the last 25 years has identified some recurring themes (Hirst, 1984; Burchardt, 2005). A lack of good outcomes for young disabled people and the difficulties of multiagency working have frequently led families to talk about falling into a 'void' at transition (Morris, 1999). Responses to these messages in the past have merely shifted responsibilities between agencies – they have consistently failed to lead to better outcomes. During this time there have also been clear, consistent messages from young disabled people about their aspirations - wanting a job, a home of their own and personal relationships – in other words, a life like any other (Morris, 2002).

Collaborative working is central to government policy on the transformation of social care:

Local authority leadership accompanied by authentic partnership working with the local NHS, other statutory agencies, third and private sector providers, users and carers and the wider local community to create a new, high quality care system which is fair, accessible and responsive to the individual needs of those who use services and their carer.

(DH, 2008)

3. THE MODEL

The new model of Personalised Transition was developed by governors and the head teacher at Talbot Specialist School, in partnership with Sheffield City and NHS Sheffield, and is the most radical form of personalisation in the UK. It offers an innovative model of bringing together funding from three sources to support young people with complex support needs moving into adulthood in the supportive environment of the young person’s school. It’s a good example of how creative thinking and partnership working can successfully transform the life chances of disabled school leavers. From 2007 for the first time ever, young people and families have been able to control individual budgets from social care, health care and education. In the first two years 23 young people and their families received an individual budget.

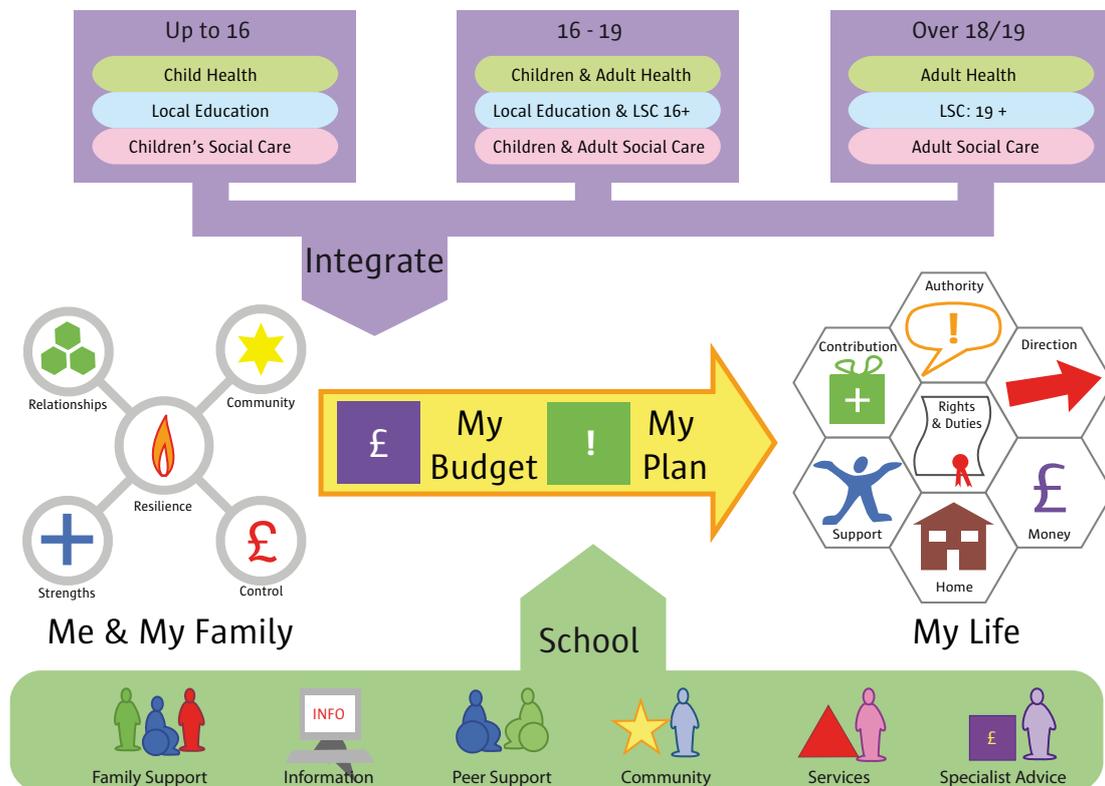


Figure 1. Personalised Transition

The four essential elements of the model demonstrate this further:

- 1. Family leadership** - In Sheffield systematic improvements in planning, communication and joint working amongst different agencies meant that the right of young disabled people and families to be in control of planning their move to adult life is respected and has become the foundation on which Personalised Transition works. This means a new and different relationship between young people and families and people working with them.
- 2. Curriculum for citizenship** - Education is centred on informing students about future options; giving them opportunities to try things out; make informed choices; and equipping them for adult life and for being active citizens. Learning from this experience means that from the school year 2009/10 the School has taken the lead in supporting their students to plan for positive and fulfilling futures. The School is now using Simon Duffy's Keys to Citizenship (2006) as a framework for all its work (See Figure 2). Person-centred transition planning, introduced through the curriculum, helps to ensure that the young person's gifts, skills, needs, wishes and natural supports and friendships are built on rather than looking for a response within traditional services. Working towards an empowering, person-centred way of working (including person-centred reviews) throughout the School and not just at transition has gone hand in hand with the culture of young people having a voice and having choice and control.
- 3. Individual budgets** - If young people are entitled to support, funding or access to particular services then these entitlements must be clear and transparent so that people can evaluate what is available, plan effectively and know how best to use any resources they can control. Talbot School supports each student to compile an 'All about Me' folder with photos, a one page profile and a practical summary of the student's communication skills with any relevant advice to readers. People who know the students well contribute to the booklet. These are live documents, intended to be updated as needed.
- 4. Coordinated expert support** - Personalised transition planning is school based and focuses on the young person. Professionals from social care, health and Sheffield College come together with school to plan and coordinate support to young people and their families. The aim is to have a key professional working with each young person and their family to maximise empowerment and minimise interference and complexity. The support must be coordinated and simplified. Families and young people who have left school in the last two years and professionals have endorsed this approach.

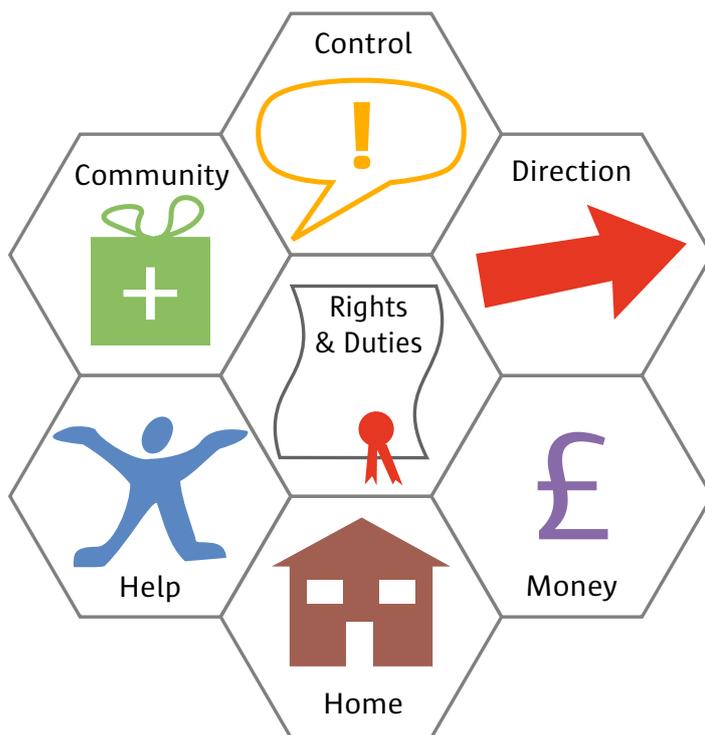


Figure 2. Keys to Citizenship

4. OUTCOMES

The outcomes have made a significant difference to the lives of these young people and their families. Young people with severe impairments are finding work, getting more involved in community life and having better lives. Families also reported some unexpected benefits of being in control.

Katrina's story

Katrina's son, Jonathan, who has high support needs, is now aged 21 and has had an individual budget since he left school in July 2008. Katrina says that despite all the difficulties along the way, self-directed support has been a life-changing experience for Jonathan and all the family.

Katrina says Jonathan is much more mature and more active now – doing ordinary things like travelling on buses and trams, meeting up with friends to go to the pub, making choices about what to have for dinner, going to art workshops, and Katrina says he comes home with a smile on his face every day.

Some of the unexpected benefits of self-directed support have been the improvements in Jonathan's health because he is more active now. A knock-on effect is that he needs less attention at night which in turn means the rest of the family get more sleep (Alakeson and Duffy, 2011).

Katrina says school is where transition planning should be based because they know the young people and their families well and families feel comfortable there. They can pull in other professionals as necessary. Katrina also says she couldn't have managed without the person-centred planning coordinator and transitions team at social services:

It was a big culture change and it was a big relief knowing there were people there who could direct you. The support we had was excellent.

The idea of individual budgets for learning was very new and this was a way to test defining learning in more creative ways. For example, one young man has spent three days at college and employs a personal assistant (PA) to support him to research setting up a microenterprise for the other days.

Since April 2010 the funding in Sheffield has been administered by Sheffield College who have appointed a member of staff to look specifically

at new college and community based learning opportunities for young disabled people. Issues of accreditation and whether providers are recognised learning providers have still to be resolved.

In Sheffield the genuine commitment amongst senior managers and operational staff in all agencies to improve support planning, advocacy and empowerment enabled some families to create innovative and exciting solutions with a shift towards citizenship and involvement in the community, and a move away from residential and institutional care. As one senior manager at Sheffield City Council said:

One family told us how (having an individual budget) has transformed their lives. They considered that if they could do it for their son, who has high support needs, anyone can ... Once you've heard that story how can you do things the old way?

The transition liaison nurse, Carolyn Western plays a vital role in ensuring that young people's transition from children's to adult health services is as smooth as possible, she says:

People work very hard to achieve the right pathways for the young people. If we get it right for people with the highest support needs, other people will also benefit.

The transition strategy has worked best when agencies have listened to each other with mutual respect, acknowledged each other's roles and embraced each other's issues – in other words, worked in a person-centred way with each other. And where they have put young people and their families at the centre of their working. This means that the young person is in charge of their own move to adulthood and that any transition pathway guides, but does not rule this move. Individual champions in each agency help to keep self-directed support at transition on the agenda.

The immediate benefits of personalised transition have primarily been found in the improved outcomes of young people and families and better systems of communication and planning with and between professionals. These benefits are sometimes limited by systemic factors that services are still grappling with (for example, the hard work necessary to introduce individual budgets, limited market development, limited peer support and the ongoing need to overcome tendencies to bureaucratise or control decision making).

Financially the improvements have been broadly cost-neutral. But better use of limited professional staff and a significant reduction in the use of expensive residential or segregated services outside the City signals the

possibility of further economic benefits.

Some limitations still to be overcome include:

- Standard services are still used by most families and family confidence is low regarding self-directed support.
- Market development has been limited.
- There is no framework for peer support for young people and their families after school.
- Learning and Skills Council funding (now the Young People's Learning Agency (YPLA)) has now moved to local authorities which should make it simpler to give individual budgets for education.

5. COSTS

There is a common misconception that personalisation is inherently more expensive than traditional forms of support despite all the evidence to the contrary.

(Glasby, 2010)

A simpler question is to ask **whether the significant improvements in reported outcomes can simply be explained by an increase in funding.** We can therefore examine all the available data on costs below.

Before – Students not using personalised transition. This includes all students leaving in 2006 and 2007 but excludes students ineligible for support, but including the one student from 2008 who wanted to use the old system of transition.

After – Students using personalised transition. This includes students leaving Talbot in 2008 and 2009 but excludes students ineligible for support and the one student whose family chose not to use personalised transition. For these groups we found that the average package sizes and the contribution from each funding source were as follows:

PER CAPITA MEAN	BEFORE £	AFTER £	CHANGE
Adult Social Care	19953	11807	-41%
NHS	8760	15967	+82%
Learning and Skills Council	10798	18870	+75%
Independent Living Fund	619	891	+44%
TOTAL	40130	47536	+18%

Overall this shows that there was an increase in the overall package cost of 18% although interestingly there was a reduction in the local authority’s per capita spending of 41%.

It is not clear to what extent the level of need is different between the two groups. It is important to note that needs vary significantly between individuals within the group and between years so it would be a mistake to generalise too much from these early experiences. For example, in the ‘before’ group services ranged from £7,500 to £145,000 per year and in the ‘after’ group the range was from £3,500 to £111,000.

There have also been other important changes in funding, in particular the application since 2008 of a new policy for funding 'Continuing Health Care' attempting to make it much clearer when the NHS should fund services and to what extent. The significant increase in overall NHS funding may therefore have been influenced by this policy change.

Learning and Skills Council (LSC) funding was also subject to some one-off factors that make straightforward comparisons more difficult. In the past the LSC would fund residential colleges for people with significantly greater needs. In 2008 the LSC in Sheffield began to use a tool for allocating resources as part of the Learning and Living Project which was applied in Sheffield. There were also considerable funds attached to this project.

What all of this suggests is that there are two, non-conflicting hypotheses for why funding increased:

- The 'after' group had higher needs and therefore this led to increased levels of expenditure by the NHS and LSC. For it is usually the case that additional funding of the type used here would only be available to people with the highest needs.
- The policy changes at the NHS and the LSC have tended to trigger entitlements at lower levels than they would have done previously.

Given the uncertainties here it is not possible to make any strong claims as to the meaning of the economic impact of personalised transition. There have been improvements in outcomes and increases in cost, but the increases in costs are most plausibly explained by either the changes in policy or the increased levels of need of the 'after' group (or a combination of the two factors).

6. RATIONALISING

What is clear is that there is now increasing awareness at operational and strategic levels that the central task is not to increase spending on the transition process. Instead the priority is to simplify and rationalise professional input while further empowering young people and families. If well managed, this may have the potential to increase process efficiency.

Perhaps the most important change of all within personalised transition is the shift of control to the young person and their family. This shift is important for four reasons, each of which goes way beyond the immediate advantages or disadvantages of personalised transition:

- **Dignity** – Young people and families feel they have more dignity and command greater respect from others when they are in control.
- **Well-being** – Feeling more in control of our lives increases emotional well being and the ability to respond to crises and difficulties when they arise
- **Efficiency** – Being more in control enables individuals to connect the money and services to other natural, personal and community resources creating ongoing opportunities for increased efficiency and effectiveness.
- **Quality** - Being in control lets you change what is not working more quickly.

7. CONCLUSION

This innovation may seem small in scope – focusing on people with some of the highest needs in our community – but it is actually one of the most radical and potentially far-reaching reforms of recent times, for it indicates:

- Shifting control to citizens and families can resolve the ongoing difficulty of integrating different and competing services.
- Education and health care are just as capable of being radically personalised as social care.
- There is a need for a much wider, whole-of-life, policy framework for personalisation.

Young disabled people with complex needs need strong allies to achieve a successful transition. Personalised transition requires commitment from family members, other informal supporters and the professionals involved. An equal partnership - based on respect, inclusion and self-directed support – between the young person, their family, the school and a well-motivated professional can be very powerful. It can make the difference between an exciting, fulfilling life and a ‘good enough’ one.

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If you are interested in the detailed thinking behind the ideas set out in this paper then the best report to read is *Personalised Transition* by Alison Cowen which is available to download directly from The Centre for Welfare Reform website (www.centreforwelfarereform.org).

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This article originally appeared within the Journal for Integrated Care.
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First published November 2011

ISBN download: 978-1-907790-21-8

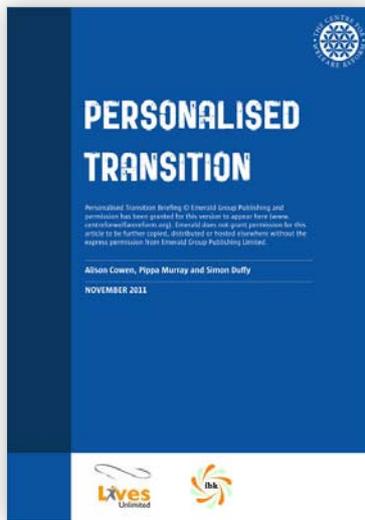
19 pp.

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