



Topical theme

Personalised Transition: A Collaborative Approach to Funding Individual Budgets for Young Disabled People with Complex Needs Leaving School

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ABSTRACT

Personalised Transition demonstrates how a collaborative approach to funding individual budgets for disabled school leavers with complex needs in Sheffield 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 according to 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. The implications of the model go far wider – to further reforms in adult social care, health care, education, children and families, and community development.

KEY WORDS

personal budgets; self-directed support; disabled school leavers; transition; personalisation; collaborative care

National research

National research on disabled young people's move to adulthood over the last 25 years

(Hirst, 1984; Burchardt, 2005) has identified some recurring themes: the struggle for young disabled people to gain recognition of their

potential, difficulties in getting paid work, the danger of transition to social exclusion (for example segregated day services) and lack of effective co-operation between agencies, despite strategic commitments to joint working. A lack of good outcomes for young disabled people and the difficulties of multi-agency 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 and 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).

Policy context

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 carers. (DH, 2008)

Talbot School model of personalised transition

The new model of personalised transition was developed by the governors and the head teacher at Talbot Specialist School, in partnership with Sheffield City Council 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.

The personalised transition model is shown in **Figure 1**, overleaf.

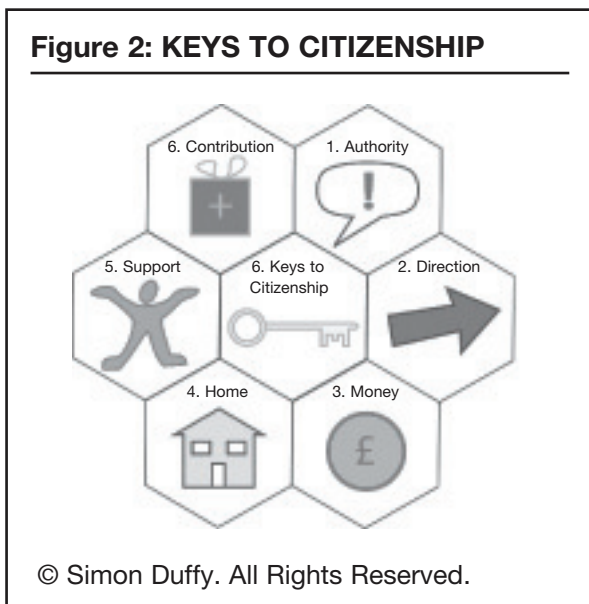
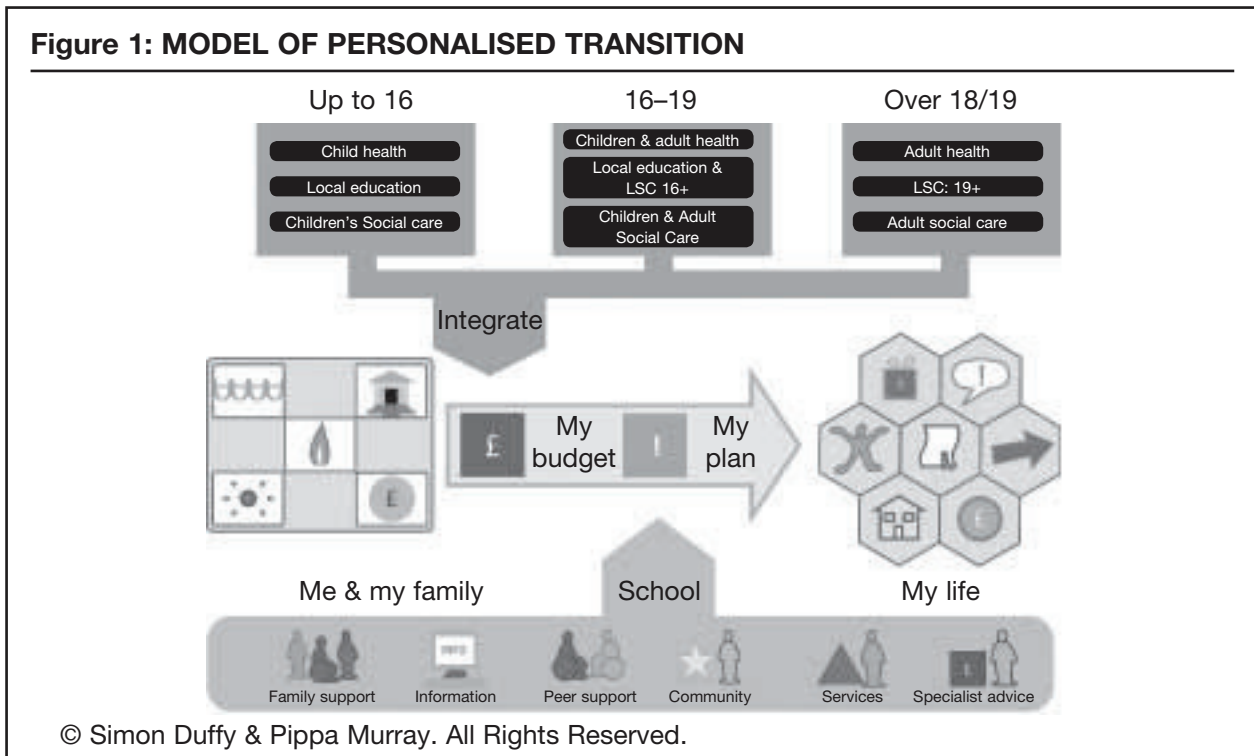
Family leadership

In Sheffield, systematic improvements in planning, communication and joint working between agencies mean 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.

Curriculum for citizenship

Education is centred on informing students about future options, giving them opportunities to try things out, making 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 (**Figure 2**, overleaf).

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.

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.

Co-ordinated 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 schools to plan and co-ordinate 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 co-ordinated and simplified. Families and young

people who have left school in the last two years and professionals have endorsed this approach.

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 have also reported some unexpected benefits of being in control, as in **Box 1**, below.

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, which has 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 among 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.

'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?' (senior manager, Sheffield City Council)

The transition liaison nurse plays a vital role in ensuring that young people's transition from children's to adult health services is as smooth as possible.

'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.' (Carolyn Western, transition liaison nurse)

Box 1: 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. The unexpected benefits of self-directed support have included 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.

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 co-ordinator 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 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 been found primarily in the improved outcomes for young people and families and in better systems of communication and planning with and between professionals. These benefits are sometimes limited by systemic factors that services are still grappling with, such as the following.

- 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.

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.

The costs of personalised transition

There is a common misconception that personalisation is inherently more expensive than traditional forms of support, despite all the evidence to the contrary (Glasby *et al*, 2010).

A simpler question is whether the significant improvements in reported outcomes can be explained simply by an increase in funding. We therefore examine all the available data on costs in **Table 1**, below, which shows average package sizes and the contribution from each funding source.

Table 1 shows 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%.

Table 1: COSTS OF PERSONALISED TRANSITION

Per capita mean	Before ¹ £	After ² £	Change %
Adult social care	19,953	11,807	-41%
NHS	8,760	15,967	+82%
Learning and Skills Council	10,798	18,870	+75%
Independent Living Fund	619	891	+44%
Total	40,130	47,536	+18%

¹ Students not using personalised transition; includes all students leaving in 2006 and 2007 but excludes students ineligible for support, and includes the one student from 2008 who wanted to use the old system of transition.

² Students using personalised transition; 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.

It is not clear to what extent the level of need differs 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 £7500 to £145,000 per year and in the 'after' group the range was from £3500 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 this suggests is that there are two, non-conflicting hypotheses to explain the increase in funding.

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

Given the uncertainties here, it is not possible to make any strong claims about 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).

Rationalising professional input

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 in 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 well 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.

Policy implications

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 that:

- 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
- a much wider, whole-of-life, policy framework for personalisation is needed.

Young disabled people with complex needs require 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.

Information

Personalised Transition (March 2010) is published by the Centre for Welfare Reform, in association with ibk initiatives. The full text is available at www.centreforwelfarereform.org.uk. Commissioned by Yorkshire and Humber Improvement Partnership.

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