



Personalised Transition

Innovations in health, education and support

by Alison Cowen

with additional material by Simon Duffy and Pippa Murray





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A report exploring the co-production and implementation of Personalised Transition at Talbot Specialist School in Sheffield and the cross-city collaboration to improve support to young people and families from 2006 to 2009.

Published by the **Centre for Welfare Reform** in association with **IBK Initiatives**



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Alison has worked widely in the voluntary and statutory sectors at local and national levels. She is a freelance writer – special interests currently include independent living, self-directed support and young disabled people. Her work is informed by the values of person-centredness and inclusion, and by her personal and family experiences of impairment. Recently she supported her son, Tom, to live in a place of his own with a team of personal assistants and to set up a fair trading and music gig micro-enterprise, funded by a personal budget. Alison was a member of the York Learning Disabilities Partnership Board for 6 years until 2008 and worked as Information Manager at the Family Fund for several years. She has also worked for the Social Policy Research Unit, University of York, Norah Fry Research Centre, Joseph Rowntree Foundation, the Foundation for People with Learning Disabilities and Inclusion North. She enjoys gardening, walking and spending time with family and friends.

Simon Duffy

Simon is Director of the Centre for Welfare Reform. He developed the concepts of an individual budget and self-directed support and has been active in promoting shifts in power and control towards citizens and families since beginning to work in public services in 1990. As a Harkness Fellow he studied welfare reform and inclusive education. He founded and led Inclusion Glasgow and In Control and is the author of Keys to Citizenship. In 2008 he was awarded the RSA's Prince Albert Medal for his work on personalisation. He lives in Sheffield with his wife Nicola and their son Jacob, and he is a governor at Talbot Specialist School. He loves skiing, windsurfing and trying to learn Latin.

Pippa Murray

Founder of ibk initiatives, Pippa focuses on using the voices of disabled children, young people and their families as a key tool for organizational development. Her work is based on, and inspired by, her family experience of living with impairment and disablement. Following the death of her son in 1998, Pippa completed a PhD looking at ways to support disabled families live ordinary lives. Over the past ten years she has worked with universities, local authorities, schools and organisations in the statutory and voluntary sector across the country. She also works directly with disabled young people and their families, and is a governor at Talbot Specialist School. Pippa enjoys spending time with family and friends. She loves swimming in the sea, lying under the stars and playing with her beautiful baby granddaughter.

With thanks for the generous
support and encouragement of:



Sheffield Health and Social Care **NHS**

NHS Foundation Trust
[Joint Learning Disabilities Service](#)



Publishing information

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Preface © Cath Roff & Katrina Ellershaw

Executive Summary, Introduction, Policy Implications © Simon Duffy & Pippa Murray

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First published 8 March 2010

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Version 1.0 of Personalised Transition published by the Centre for Welfare Reform, Sheffield UK

This document is available for download from

www.centreforwelfarereform.org

68pp.

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Preface

“Jonathan’s started to do things I would never have dreamed he could do. Having choice and control has been a positive, life changing experience for all the family, especially Jonathan.” Katrina Ellershaw, Parent

The outcomes from Personalised Transition since 2006 are very exciting. What this model offers is an innovative, holistic plan bringing together funding from social care, health and learning funders to support young people with complex needs moving into adulthood, based within the supportive environment of the young person’s school.

It means that in the last year of school young people can finalise their plans for the future with individual budgets agreed. The outcomes to date show that young disabled people are achieving happier, more fulfilling lives than school leavers in the past.

Sheffield City Council, the Learning and Skills Council (LSC) and NHS Sheffield have worked closely together with Talbot Specialist School to develop this innovative and holistic approach which puts young people and their families in the driving seat. It focuses on the young person as a citizen with a contribution to make rather than purely a service user.

When we first started this work we did not have a clear view of what was needed but we were always clear on the outcomes we wanted to achieve. True models of personalisation mobilise citizens to be co-producers of the support they want and need. This leads to a better and more valued support system for each individual. Everyone involved has made this journey together, young people, their families and staff - we have learnt about each other and from each other, building trust, taking risks and reaping huge rewards as people have exceeded their aspirations.

The achievements are a celebration of many people working effectively together. We’re looking forward to seeing this approach adopted as the way transition to adulthood happens and more importantly the way that young people get a valued life in their community and will do our best to support its further development and extension in the months and years ahead.

Katrina Ellershaw and Cath Roff | March 2010

Summary

This report describes a new way of organising support to disabled young people and their families that is called Personalised Transition. Personalised transition is a system for enabling young people with complex needs to leave school and to achieve active citizenship within their communities. Personalised transition was first developed at Talbot Specialist School in Sheffield in 2006 as part of a collaboration between families, school, Sheffield City Council, NHS Sheffield and the Learning and Skills Council. The model began to be used in 2007 and is now being further developed and extended for use across the whole city.

The four key components of personalised transition are:

- 1. Family Leadership** - Families are recognised as the proper foundations for planning and developing the education and support that young people need as they take on adult lives. This means overcoming the paternalistic culture that has been dominant in services for people with disabilities, offering appropriate support and making sure that families can work together to realise more positive futures.
- 2. Curriculum for Citizenship** - Schools can work with young people to prepare them for active citizenship, helping them personalise their learning experience in a way that gives them a positive focus on all that life after school has to offer. This means an increased focus on self-advocacy, communication, work and active participation in community life.
- 3. Individual Budgets** - It is important that families have early information about what they will be entitled to before the young person leaves school and that no ambiguity opens up between the responsibilities of education, health and social care. This means that systems have to be developed which allow for an early identification of needs and a corresponding budget.
- 4. Co-ordinated Expert Support** - Professional support is important, but it must be co-ordinated, simplified and appropriate to the needs of the young person and their family. This means that the school has a key role in ensuring that meetings are designed around families and that professional input is shaped to suit the family's needs.

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The combination of this clear model and a spirit of genuine commitment to overcoming historic difficulties has led to an array of benefits, including:

- Improved advocacy, planning and empowerment for most, exciting innovations for some
- Systemic and evolving improvements in planning, communication and joint-working
- Shifts away from residential and institutional care, increased focus on citizenship and community

There is still much to do and the development of flexible systems and responsive markets will only take place as the numbers controlling their own budgets increase and as systems of peer support grow.

This innovation has arisen in an area of public policy that is renowned for its on-going and entrenched complexity and resistance to reform. Despite an array of policy initiatives and imperatives it has seemed impossible to make significant improvements.

This suggests a series of policy lessons:

- Transition - Effective integration and successful transition can be achieved when citizens and families are given clear entitlements and control of key resources.
- Adult Social Care - Further progress in personalisation in social care needs to be protected from the dangers of unnecessary bureaucratic controls and the lack of peer support.
- Health Care - Personalisation in health care is a feasible and successful approach which needs practical leadership in order to develop on the ground.
- Education - Personalisation in education could be a real source of improved standards and increased innovation. There are indications that it would be useful to assign individual education budgets, at least for some groups - but this will require identification and support for early innovators.
- Schools - Schools can play a much more positive role in leading change and co-ordinating the different supports to families and young people if they are helped to see possibilities of a wider role - beyond managing education inputs.
- Children - Developments in adult services should be mirrored in services for disabled children and families and early years care, with local leaders prioritising the development of a whole-of-life approach to personalisation.
- Local Government - Personalisation offers an important strategy for rethinking the wider role of local government and commissioning. It is important that it is integrated into new thinking about the commissioning of public services at a deeper level and its place alongside other strategies should be tested and refined.

The Journey



The Journey

BY SIMON DUFFY & PIPPA MURRAY

Personalised transition is a community-led innovation. It was developed in a special school through a powerful partnership of families, young people and professionals. It is still evolving and it is important to see that a radical innovation like this can be developed and implemented by local leadership, as long as we have faith in people's capacities (including our own) and are willing to work together with honesty and integrity.

As Alison will describe in the main body of this report the development of personalised transition has been a community-led process. This is how exciting innovations usually happen, but it is not how we usually think they happen. In the main we imagine that new ideas, policies and systems are created by politicians, civil servants or someone else 'up there' who then makes us do them - 'down here'. We have a tendency to think of any change in public services as a 'top-down policy' that we experience as disempowering. Such an approach inevitably undermines the possibility of human, organisational and community development.

The reality is both more complex and positive. We constantly find we cannot await smart and rational solutions to emerge from 'on high'. Instead we need to work on the ground to create new solutions, to help other people get excited by these possibilities and then to make them happen. Nothing helps the spread of a good idea more than making that idea work! This is what we, along with colleagues and allies in Sheffield, have done at Talbot Specialist School.

Seeing the problem

The problem of the 'transition' from school to adult life for people with learning disabilities is well known to families, professionals and policy-makers. Indeed, transition is a

word that seems to now be always accompanied with a groan! For many working with disabled young people and their families transition is understood as the time disabled young people move from children's to adult services, rather than a natural stage of life that includes leaving school, starting work, going to college or university, leaving home, trying out new experiences and making new friends. The model we outline in this report is a step towards allowing disabled young people and their families to reclaim this stage of life, with the support they need.

The majority of young disabled people leaving school discover that, in addition to all the normal emotional challenges of adolescence and the need to work out what they want to do after school, they face an extra set of challenges. These challenges do not come from their impairment, but are created by the services and systems put in place to help them.

To take just a few of the problems:

- They have to end a relationship with three different children's services (health, social care and school) and begin a totally new relationship with the three corresponding adult services - continuity is rare and hard to achieve.
- Meaningful advice about funding and support after school is difficult to provide. Any entitlements are obscure and only become clear long after the young person

has left school and has entered the next stage of life - this makes planning within school next to impossible.

- In order to facilitate joint planning and greater continuity a series of bureaucratic steps are put in place to ensure all the different professionals talk to each other and prepare for the 'transition' - but this often has the effect of crowding out the voices of the young person and their family.

These problems and the negative impact they have were already well known. But one other thing struck Simon when he joined the board of Governors of Talbot School:

"At the first meeting I attended there was no report about the young people who had just left the school - this struck me as strange. Now I realise that this was not because the school didn't care. It was quite the opposite - they cared so much that it became too painful to think about changes that were so often negative, confusing or uncertain. The school was burdened by a sense that it could not really help young people prepare successfully for adult life - so it put its head down and focused on trying to make sure their students did well during their years at school. In other words, I sensed that the 'transition problem' was undermining the meaning and value of school life - schools need to believe that they are preparing young people for something good and meaningful."

Sharing his feelings with the head teacher and other governors, Simon discovered there was both an awareness of the problem and a willingness to try and change things. So Simon was given the support of the governing body to call together a group of governors and professionals in the city to develop a new strategy for managing transition.

Understanding the problem

Knowing there is a problem is not the same as understanding that problem; and the problem of transition, because it has to respect the valid perspectives of so many different people and professionals, does not allow for simple solutions. It is all too easy to slip from sharing our own perspective about the problem to blaming others.

We worked hard to avoid the temptation of pointing the finger at others:

- To blame the school for not having a focus on helping young people learn about adult life
- To blame the city for not having the right set of services ready and waiting for the young people
- To blame the NHS for not supporting young people's health needs appropriately
- To blame the college for offering limited and segregated services
- To blame families for not being positive about their children

The blame game had to be stopped. Instead we have worked together and tried to identify the strengths and gifts that everyone can bring to developing a new solution. Of course this doesn't mean blaming has totally gone away - we are not capable of perfection - but usually we find that if blaming begins it is because people are not communicating effectively and do not fully understand the perspective of the other people involved. Increasingly everyone is learning to manage their own behaviour better.

Part of what made this change possible is that we began to identify an hypothesis about the real nature of the transition problem - an hypothesis that did not blame anyone - an hypothesis that explained the systemic failures that created the problem.

Our hypothesis was that transition was flawed because of:

- **System-centred thinking** – Young people and their families must be at the centre of services - problems begin when we put services and systems first, as opposed to thinking about how to help the young person and their family direct their own destiny.
- **Obscure entitlements** - People with disabilities often need support and services, sometimes such support is vital to their very existence, but if you do not know what you are entitled to then you cannot plan and are reduced to falling back to wait for others to provide solutions.
- **Complex professional support** - If there are too many people trying to help you at once, however good they are, you will not feel supported. Often there were more professionals involved in the transition process than there were young people leaving school.

It is important to understand that, if a problem is created by bad systems, then those systems can be changed. But, even more importantly, people need to be able to distance themselves from the problem - to see that *they* are not the problem. Instead they are part of a solution; a solution that is just waiting to come to life.

Finding a solution

The solution we have developed is described in more detail in the report, but in essence, what we have called personalised transition has the following four components (Figure 1).

1. **Family Leadership** - enabling the young person and their family to be at the heart of planning for their future
2. **Curriculum for Citizenship** - helping the school realise its role as a valuable resource to support the student's preparation for life as a citizen

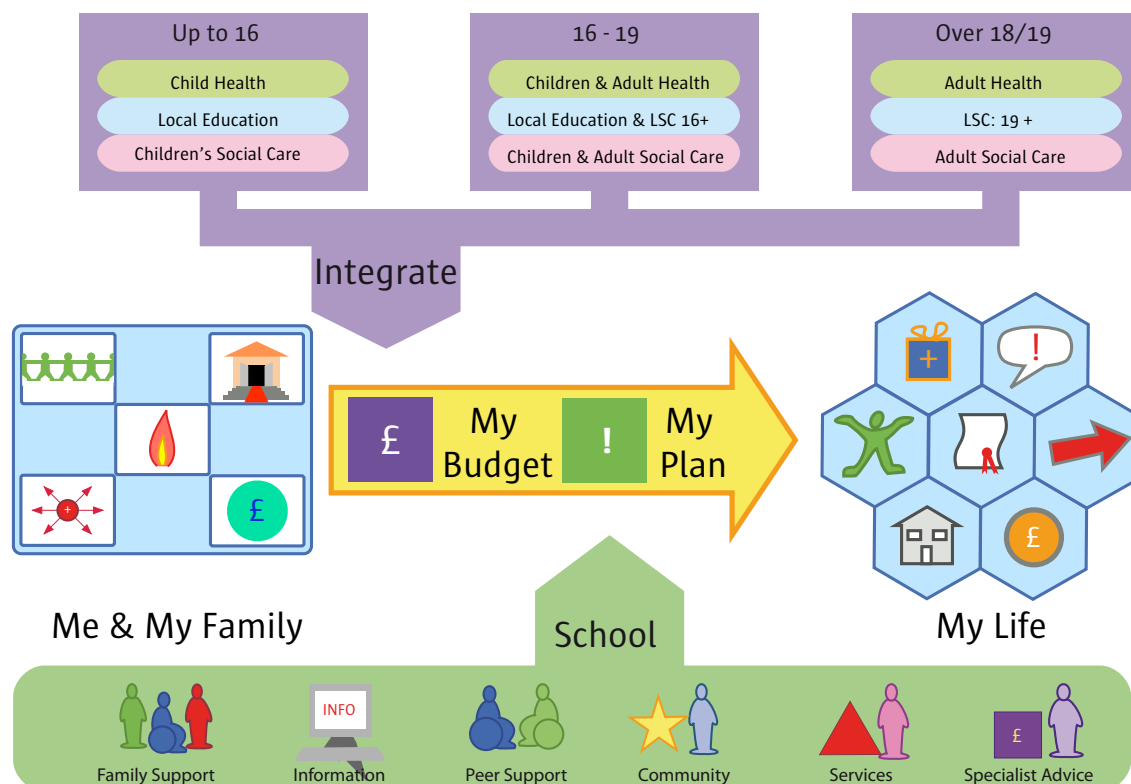


Figure 1 - Personalised Transition

3. **Individual Budgets** - enabling people to have clear entitlements - from health, social care and education
4. **Co-ordinated Expert Support** - getting people the right support, at the right time, with professional leadership and co-ordination

Like all solutions to human problems this may not be the only model - and our own model has been developed and improved over time. In the following section we share some of the thinking that underpins our model, because some of our choices and ideas may seem foreign.

One aspect of our model that raises concern is the way it validates the role of the family - not just the young person. This was important to us because families tell us they feel like they suffer from a kind of professional prejudice that treats them as the source of the problem in a young person's life. This is despite the fact that, in the last analysis, it is almost always the family that will be there to support the child, the young person and the adult through their whole life. This does not mean ignoring the voice of the young person - but it does mean avoiding naive simplifications of child-adult-family dynamics and respecting families as one of the foundation stones of a good life.

Another complex issue has been our attempt to see the school as much more than an education device. For us the school is a community - it is a real place and a real group of people - and it plays an on-going and powerful role in the life of the child and the family. It makes sense to us to treat the school as a kind of natural support system and to build into the way the school works different kinds of opportunities to strengthen the young person and their family - in particular by creating opportunities for both to come together with others. The school is therefore a natural hub for peer support. Of course, our assumption may be framed by our starting point - the innovation started within the school - but we believe other schools and other systems should take this possibility seriously, for it offers a very practical role for the school

which puts it at the beating heart of the real transition story.

Individual budgets continue to be controversial for many, and although the idea was first tested in England with young people, it is seen by some as an innovation that is only appropriate for adults. Our sense, and this has been reinforced by our learning over the last three years, is that the setting of clear budgets not only helps families and young people but it also helps professionals. In particular we think that the increasing clarity about the financial responsibilities of different statutory services is one of the underlying causes of improved collaboration and increased communication. This system takes away the bitter game of trading or bluffing that goes on when services try to define the financial costs of meeting someone's needs. It is often too easy for the person to be lost, or for their needs to become distorted, when the rules for clarifying entitlements are ambiguous.

Finally our approach may be considered controversial because we have avoided trying to locate the primary responsibility of offering support for transition with one group. In recognition that individual need and context make it difficult to generalise, our process focuses on getting the simplest system and most appropriate expert support for each family. No one professional group is dominant; what is critical are the skills and expertise they each bring. All professional groups have to take more responsibility for co-ordinating the support of others and making sure the family does not drown in professional input.

Realisation

It took us a year to develop a model of personalised transition that everyone was willing to try. We then created a Strategy Group (chaired by Simon) and an Operations Group (chaired by Pippa).

This system worked well in that the Strategy Group could make sure that the commitments that everyone gave at the beginning of the process would be followed through. In the

second year we were able to close the Strategy Group and in the third year the governance of the process has been integrated into the school's own system of sub-committees.

The Operations Group is open to professionals from school, local authority, health, Connexions and Sheffield College. In addition to developing ways of working that allow for personalised transitions, the group initially had to find ways to mend fractured relationships between agencies. Pippa recalls the difficulties facing the group in the early days:

"Facilitating those early meetings was extremely challenging. We spent a lot of time talking about different roles and responsibilities, desperately trying to find common ground. It was easy to agree we all wanted disabled young people to have better outcomes when they left school. But it was much more difficult to create an environment encouraging everyone to take responsibility, in whatever role they happened to be in, for making something different happen. Although we had lots of practical tasks to be getting on with, building trust was my primary aim in those early days. I was aware that in order to build trust, I first had to earn the trust of the group. I did this by trying to be consistent in my manner, doing what I said I would do, and always going the extra mile. I don't facilitate that group any more, but occasionally go to a meeting. It makes my heart sing as I listen to their discussions, feel their enthusiasm, sense their genuine regard for each other, and observe the pride they are rightly taking as they see young people and their families having greater control over what happens when they leave school."

Opportunities

When the Operations Group first met we had a clear idea of what we wanted to achieve but did not know how we were going to get there. The process was very much one of finding out as we went along, and adapting our programme of work accordingly.

We were extremely fortunate that South Yorkshire, along with Essex, was chosen as an area to develop individualised learning opportunities for young disabled people as they left school. This project (called Learning and Living Now) brought energy and resources – including a project worker and a facilitator for support planning – into the city. It gave the development of personalised transition for young people in Talbot a way of getting started. And this opportunity naturally led to others.

For example, senior managers in health embraced the opportunity to look at ways of giving one young man an individual budget to meet his needs; Sheffield College began to look at accrediting learning outside of college buildings; providers in the city realised they would have to develop new ways of working and provide different services if they were to support young people to lead the lives they chose; the manager of the Transitions Team commissioned ibk initiatives to bring parents of disabled young people together to think about planning for the future, and to work with some young people to find out what they wanted to do when they left school; and Talbot School commissioned ibk to pilot a personalised work experience project with a small number of students in Post 16.

Another invaluable resource was the manager of Self Directed Support for Sheffield City Council – Jeanette Thompson. Jeanette was an important member of both the Strategy and Operations groups, providing information, advice and hours of 'behind the scenes' work enabling individual budgets to move forward in health, education and social care. Other key posts supporting work on the ground were the transitions liaison nurse – Carolyn Western – and a person-centred planning coordinator in the Transitions Team – Niki Marshall.

Although the Operations Group struggled with the lack of clear connection between these different initiatives and individuals, they all contributed to the growing momentum around the development of personalised transition.

How our learning developed

The monthly meetings of the Operations Group gave an opportunity for a multi-agency group to agree on necessary actions, to make sure those actions happened within an agreed timescale, and to solve the numerous problems we encountered.

Our learning developed as we went along - trying things out and noting what worked well and what did not. For example, it has taken us three years to develop a planning process with families that all parties are happy with; we are still developing ways of sharing information between agencies – the monthly meetings have helped enormously with this as we often start with an update on each student leaving; and although we struggle with the different organisational timescales for assessments and planning, we are developing a clearer understanding of what needs to happen to overcome those barriers.

We have not yet succeeded in finding a way to combine the leaving school support planning process with planning for young people leaving social care provision at the age of 18, but are encouraged by a pilot taking place for individual budgets for children. This will allow a small number of children (under the age of 5) and young people (aged 14 -18) to be offered an individual budget through social care, so paving their way for life. And, in spite of encouraging developments and a positive relationship with Sheffield College, our planning around college placements and learning opportunities continue to be thwarted by the relatively late allocation of college places.

In the early days, in addition to the formal monthly meetings, we spent time talking with staff at Talbot School about their experience of transition generally and work going on in school with students and families. These smaller discussions provided a space for private conversations about the new ways of working. It emerged that some staff were concerned that asking students what they

wanted to do when they left school raised expectations and made them vulnerable to disappointment. Staff worried about developing person-centred approaches. Pippa recalls those early days:

"I remember leaving school one day, having listened to staff talk about their worries, knowing I had to find a way to show them, students and parents, that something else is possible. To my way of thinking traditional approaches denying voice, choice and opportunity are cruel. But I knew I had to listen to their concerns because they knew and cared about their students. It took me a few days to come up with the idea of a work experience pilot, but when I did I went straight to Judith and asked if we could go ahead. She agreed to fund it and we went ahead. Within a relatively short space of time students, staff and parents were buzzing. There was magic in the air as we pulled off some of the most unlikely placements and they all worked beyond our wildest dreams!"

Listening to the views of others, taking their perspective into account, allows informal and on-going learning to take place on all sides. At the end of each year we have facilitated more formal evaluation workshops bringing key players together to reflect on our achievements, look at the barriers we encountered along the way, and draw up an action plan for the next year.

Spreading the word

As success stories from young people and families filtered back to school and allied agencies, professionals grew in confidence about the part they were playing in personalised transition. And as that confidence grew, those professionals became more proactive in their efforts to support young people and their families achieve their choice of a future.

For example, the Transition Team appointed two new social workers who embraced a personalised approach; staff at Talbot organised an information event for families –

contacting as many providers as possible who then came into school with information about the services they offer; the leadership group at Talbot gave responsibility for developing personalised transitions to a senior member of staff who is passionate about improving outcomes for young people and now facilitates the Operations Group. Recently a small group of key professionals from Talbot School, the Transition Team and the NHS delivered a workshop to a regional conference about their success. These and other relatively small steps contribute to a shared sense of ownership, responsibility and pride in our achievements.

Keeping it alive

We are aware that although the experience of leaving Talbot and moving into adult life is being transformed, we have a long way to go before we achieve our vision of disabled young people moving into an adult life full of meaningful opportunities and fun. In keeping with the approach taken so far, our only hope of keeping the development alive is to listen to the experience of young people and their families, and to keep our focus firmly on the issues they identify as demanding further change.

For example, young people tell us (through their behaviour if not their words) that they require energetic support workers who listen well to them; find ways to develop their experiences; and give them choices. Parents tell us they are anxious about aspects of personalised transition because they see it as bringing additional responsibilities. As a result, many parents at Talbot have chosen to use their budget to purchase a service rather than to directly manage their own package of support to access mainstream activities and community resources.

Transition is a scary time for parents of disabled young people. As well as all the practicalities that need sorting out, it is a time when they are confronted with the fact that they, as well as their son or daughter, are getting older. Thinking about what will

happen to their child when they are no longer there is very much at the forefront of parents' minds as they make transition plans. We have to pay attention to this if we are to make personalised transition work for all family members. We have to listen to their hopes and fears, hold to our vision, come up with practical solutions and find ways to move forward together.

As we move forward we understand the importance of each person taking part in the process of change. We have learned that ultimate success depends on our ability to bring people together in ways that recognise and acknowledge our common humanity. We have seen how, when we do this, barriers between agencies dissolve and deep-seated prejudices can be suspended. It is the development of this environment that helps us find solutions to the challenges around transition and which will allow our achievements to grow and develop.

What's next?

The publication of this report marks an important next step for all of us in Sheffield. We hope that this success in Sheffield prepares the way for a set of new challenges and bigger opportunities:

- **To extend personalised transition across the country** - We recognise that local people will want to think carefully about how they adapt this model to use locally. But personalised transition is not an unrealistic top-down policy - it was developed by local people and it has worked - and with some more hard work it could work even better. We hope that, particularly in the Yorkshire and Humber Region, we can turn transition from an unwieldy and damaging process into the natural process of human development and personal choice it should be.
- **To make personalisation work across the whole of life** - The development of personalised transition shows that

integration does not need to be done by merging organisations. We have been able to create opportunities for personalised integration: the next step is to build this way of operating into services for children, adults and older people. It would be very exciting if some authorities in Yorkshire and Humber were willing to test out a model which took the principles of personalised transition back to the birth of the child and to see greater use of technologies like individual budgets for young people.

- **To increase the extent of personalisation within education** - It has been very exciting to see schools, colleges and young people start to identify individual

education budgets and explore ways in which the whole educational process can be revitalised, personalised and made relevant to young people. For, although personalisation began in social care, it may be that its greatest impact will be felt in education.

We will try to take these ideas forward and we are both grateful for the leadership, wisdom and support we have received from young people, families and professionals across the City of Sheffield. We would especially like to thank Alison Cowen, the researcher and author of the report, who has vividly captured the achievements, challenges and story of all our work to date.

Personalised Transition



Personalised Transition

BY ALISON COWEN

Over recent years a number of factors came together which led to the need for a new approach to supporting young disabled people in their move to adulthood. A general dissatisfaction with the present system, typified by its lack of planning and last-minute arrangements causing stress for young people and families, led some families to demand that things be done differently.

A national problem

National research over the last twenty five years about disabled young people's move to adulthood has identified some recurring themes.

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. Responses to these messages in the past have merely shifted responsibilities between agencies – they have constantly failed to lead to better outcomes. During this time there have 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.

In 1984, in a survey of 1000 young severely disabled adults aged 16–21, Michael Hirst talked of:

"...a considerable gap in access to paid employment for young people with disabilities compared with young people in general; ...and the transition from school to further education, training, employment, unemployment or day care can be difficult."

HIRST, M. 1984

Fifteen years later Jenny Morris picked up a similar theme:

"...young people in transition to adulthood are in danger of experiencing a transition to social exclusion if their needs are not better addressed."

MORRIS, J. 1999

Three years later, developing her explanation of the difficulties around transition Jenny identified a significant gap between the rhetoric of government policies and the experience of young disabled people:

"There are still significant differences between the intention of inter-agency working expressed at government and policy level and the experiences of disabled young people and their families. Strategic commitments to joint working are rarely translated into effective co-operation in practice."

MORRIS, J. 2002

And, more recently, Tania Burchardt stated:

"It has been a struggle for young disabled people to gain recognition of their potential and to develop positive aspirations for playing useful roles in adult life..."

BURCHARDT, T. 2005

In response to such studies and the repeated difficulties reported by young people and their families, *Aiming High for Disabled Children*, (2007), highlighted the need to improve and co-ordinate services for young disabled people

in transition to adult life. As a result the National Transition Support Programme was set up to raise the standards of transition in all local areas and this programme includes:

- The National Transition Support Team - run by the Council for Disabled Children and partner organisations - who coordinate their work with local authorities, the NHS and regional advisers and other experts; and
- Support for change at local level through direct grants and regional adviser activity.

The strategies for improving transition are published in the good practice guidance on effective transition - *Transition: Moving on Well* (2008). This guide was intended to help ensure that the young person and their family are better prepared for the move to adult health care and that the adult care team has been involved in planning for the transfer. Evidence of the benefits of planned transition is now emerging and, in particular, it is clear that a good transition can improve the health and well-being of young people with complex health needs and disabilities.

Well-planned transition, sensitive to underlying needs, improves health, educational and social outcomes for young people. Good planning that puts the young person at the centre will prepare them and their family for the move to adulthood and the transfer to adult health and social care. In addition early engagement with adult health services and continuing links with the GP reduce the risk of over dependence as young people and families move on from comprehensive children's services.

A local solution

In 2005 two Governors at Talbot Specialist School, Simon Duffy and Pippa Murray, brought together a group of local professionals involved in transition to discuss a strategy for the school. The aim was to empower young disabled people and their families and

enable them to plan a self-directed move to adulthood. Parents were consulted about the Strategy and began to be offered more information about what the transition process was likely to involve.

The Governors agreed the *Talbot Transition Strategy* (2006) and in its first two years two groups met regularly – one a strategic group with senior managers from social services, Connexions and the School, led by Simon Duffy and the other an operational group with members of the social services Transitions Team, transition liaison nurse, person-centred planning coordinator and Connexions personal assistants, led by Pippa Murray. As at January 2010 there is now one group, chaired by the Transitions lead at School supported by Pippa Murray, and focusing on operational matters.

The Strategic Group provided a framework from which the school and professionals from other agencies could develop self-directed support at transition to ensure that young people and their families were in control and had the best possible chance of leading the lives they chose.

Experience at Talbot School has shown that as a few young people achieved very different, more creative person-centred opportunities, they acted as role models for others. In particular, the idea of having an individual budget, enabling families to individually tailor opportunities for their sons and daughters, meant they could start to think differently about their futures.

However the pace of change is gradual and only over time is it likely that families will demand more innovative person-centred services and opportunities that reflect holistically the needs and aspirations of the young person rather than tapping into services that are already there. Self-directed support in itself cannot transform the market – it's only likely to change as young people and families think about and demand holistic and different opportunities.

Personalised transition is the basis of a living and developing strategy designed to enable disabled school leavers to have power

and control of their lives and have the best possible lives as young adults.

At the heart of the personalised transition model are four essential elements:

- 1. Family Leadership** - The young person, with the support of their family, has the right to be in control of their own life and to make their own decisions. It is important that the whole process of transition respects and strengthens people in the exercise of this basic human right.
- 2. Curriculum for Citizenship** - Expressing preferences, making choices and decisions are recognised to be the fundamental aims of post 16 learning. Education is centred on informing students about future options; giving them opportunities to try things out and make informed choices. Transition planning becomes school based and person-centred - focusing on the young person rather than on a bureaucratic process.
- 3. Individual Budgets** - Following the relevant supported self-assessments, young people and their families are told how much they have to spend from relevant funding agencies. As far as possible agencies work together to ensure individual young people receive the amount they are assessed for, and are able to use that funding in ways that meet their interests and needs.
- 4. Co-ordinated Expert Support** - As far as possible, having just one professional partner working with the young person and their family to maximise empowerment and efficiency and minimise complexity for young people and families.

Top Tips: Getting started

- The Talbot model is one way to achieve successful transition. But other schools will need to adapt the model to their own local circumstances.
- The school head teacher and governors need to have ownership of the transition strategy and take the lead by listening to young people, families and professionals.
- It is powerful to help clarify the entitlements that young people and their families can expect.
- You must start from where you are now with transition, building on current strengths and tackling major weaknesses.
- Change will not happen without leadership, and leadership must be found at every level.
- Work out a clear structure - a model won't tell you how to do everything but it will help you to set out a logical process.
- The fundamental principle is that young disabled people and their families should be in control of planning for life after school - with as much support as is needed but no more than necessary.
- The more transparent are our entitlements from education, social care and health care then the easier it is to plan.
- Administrative and planning systems should be designed around young people and their families.
- An empowering, person-centred culture in school giving young people a voice - not just at the point of transition is vital.
- Encourage leadership from families - the families that can demonstrate leadership will inspire others.
- Keep listening to young people and families about new learning possibilities.

Part 1 - Family Leadership

The aim of the developing model is that young people and their parents lead the way. Families are given information about available options and the process they need to follow to achieve their goals for life after school. Young people and their parents are encouraged to say what they want to happen, regardless of availability of activities, support or services. Professionals working with families are encouraged to feed this information up to senior managers and commissioners in both children's and adult services.

Senior managers within statutory services are starting to hear the voices of young people and families and to see them as partners rather than as recipients of services. Some parents are championing self-directed support.

Katrina's story

Katrina Ellershaw insists that she is 'just a mum' wanting the best for her son - she is also a parent champion of self-directed support not only for her son, Jonathan, but also for all school leavers at Talbot School and beyond. 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 positive and life-changing experience for Jonathan and all the family.

"All our kids are individuals and we should treat them as individuals. Our expectations sometimes get in the way... We need to be willing to look outside the box."

Since Jonathan left school Katrina says "everything has changed" for him; he has matured and is now really grown up. She says she never imagined he'd be able to do things like painting, cleaning and lots more. 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.

Many of the things that Jonathan does are very ordinary – art and craft workshops, travelling on buses and super trams, meeting up with friends to go to the pub, making choices about what to have for dinner, cooking and so on. Jonathan also makes decisions about things he doesn't want to do.

Jonathan's team of personal assistants (PAs) were recruited by word of mouth. His teaching support worker from school helped with interviewing and Katrina trains the PAs along with specialist nursing staff. Katrina does all the admin work for Jon's support which means she can keep an eye on all Jon's arrangements.

The planning and organising for Jonathan's leaving school began at a Planning Live day in school. Katrina says the planning really got her thinking.

"Just because our children have a disability why should we put obstacles in their way?"

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 the Transitions Team from 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."

As more young people have their own individual budget, providers will have to listen to young people and families and respond to demand if they are to stay in business.

Josie Bennett, Head of Learning Disabilities 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?"

By establishing this as the culture within school right from the start, staff at Talbot can enable young people and families to take the lead in planning their future. Having this power and control can be both exciting and scary. Most of all leaving school can be a time for celebration and a time when new possibilities and new doors open.

Daniel's story

As part of Daniel's preparation for leaving school, Alan Martin – a disabled activist with a history of breaking free of traditional services to a life of employment and independence made possible through self-directed support – was invited into school to work with the leavers group. **The main purpose of the sessions with Alan were to:**

- Help the young people present their aspirations to an audience of family, friends and professionals from children's and adult services, and
- Provide the young people and their families with a positive role model - an example of what is possible.

During the workshops Daniel listened intently to the words of a poem written by Alan – the poem was a plea to others to see Alan as a

person rather than a body in a wheelchair. On the night of the presentation, as Alan recited his poem to the audience, Daniel moved towards him and slowly danced to the music and the words.

Daniel's mum was moved to tears as she realised her son understood the words and was expressing the same sentiment in his own way. Seeing her son express himself so eloquently allowed her to recognise his potential and gave her the courage she needed to embark on the path of self-directed support with energy, enthusiasm and hope.

Months later, Daniel's mum told us this had been a powerful moment which allowed her to see Daniel as a capable adult. The practical expression of her new approach has been to give her son a greater degree of independence than she had ever thought possible. Daniel is flourishing!

In practice many young people and their families have chosen to use their individual budget to fund traditional services – partly because the market as yet is undeveloped in terms of more innovative opportunities and partly because having choice and control is new and sometimes challenging. Some more traditional services have started to improve the support they offer; a few young people have chosen to employ PAs to support them in learning and leisure opportunities. As role models emerge, others are seeing how more positive, creative possibilities can be developed.

A few have chosen to employ their own PAs to support their chosen activities but the culture of employing PAs has yet to be developed. The experience of one young man in Sheffield (not a Talbot student) is that PAs themselves are often the catalyst to young people getting involved in new opportunities.

Andrew's story

Although not a Talbot student, Andrew has undoubtedly benefitted from the focus on self-directed support for teenagers at transition. Andrew's individual budget has enabled him

This chair is not me

What do you see when you look at me?
An ugly metal chair with wheels to run
around?

This chair is not me.

What do you feel when you pass me by-
A shudder of distaste or there but for the
grace of God go I?

This chair is not me.

What do you say when my back is
turned?

Do you laugh or call me names?

This chair is not me.

I drink, I am one of the boys.

I laugh, I cry, I have a sense of humour
And rules that I live by.

This chair is not me.

I have wants, I have needs,

I have hopes and I have dreams.

Some will bear fruit,

Others will not come to be.

But whatever happens in my life,

This chair will never be me.

This wheelchair is not me, It's just my
way of getting around.

I am me!

Just because my legs don't work,
Doesn't mean my brain can't.

Please see me as a person.

I can think.

I can see.

I can hear.

I can feel.

I can make decisions.

I am not a baby.

Don't treat me as a baby.

Some people treat me as if I were rubbish.

I am not rubbish!

I am worth as much as the next person.

Some people treat me as if I were mad.

Maybe I am mad, but in a happy kind
of way.

Please see me.

Please talk to me.

Please hear me, listen to me.

Please take time to get to know me,

Because I would like to get to know you.

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to build up a team of PAs who support him throughout the week (Monday to Friday 8.30 – 5pm), for two evenings and one day over each weekend. The team have worked together to put a programme in place that allows Andrew to follow his interests, extend his learning, contribute to his community and expand his network of friends. Given Andrew's interest in dog walking, one PA regularly supports him to take a friend's dog for a walk. They are hoping to support Andrew to take responsibility for more dog walking.

Another PA noticed Andrew's fascination for posting things – anything from letters, keys, drawings, socks etc! The PA saw this as an opportunity to give to others by offering a small recycling service to neighbours and friends unable to go take their plastic and glass to a recycling centre. Plans are in place to develop this idea and so give Andrew another opportunity to do something he enjoys at the same time as making a contribution to his community.

A key factor of the success of PAs taking responsibility for finding activities is monthly group supervision where the PAs, with a facilitator, meet to discuss how things are going. These meetings often produce ideas of ways to take things forward.

Giving parents the information they need

An initial consultation with parents highlighted the lack of information about available options open to young people as they left school. A significant number of parents were unaware of:

- the benefits their son/daughter were entitled to claim at the age of 16;
- the possibility of self-directed support;
- existing services;
- and the processes needed to access services.

Clear and accessible information about services, resources and community options needs to be made regularly available and constantly updated if families are to lead

Top Tips: Working with young people and families

- Getting good information is the key to developing successful family leadership.
- Families, schools and others often see adult services as an alien world and it is vital that both sides work together to make clear how new systems will apply.
- Once family members have sufficient information to understand the world their children are entering they can influence, demand and offer constructive criticism with confidence.
- Put the young person at the centre of their planning and really listen to them and their family to find out what will work.
- Working in partnership with young people and their families is essential.
- Act on what young people and families say! If people tell you reviews are intimidating, find ways to make reviews more person-centred and friendly.
- Be prepared to work flexibly if you are a professional - accept that you may not be the key person in someone's life.
- Make sure you really hand choice and control over to young people and their families - don't just say it.
- Empower young people and their families to write their own support plans with support from relatives, friends and professionals who know them best.
- Celebrate the successful outcomes for school leavers and learn from them.
- Connect people to people - it is the support and experience of other families that will often be the most important source of support for a family

the way. It is particularly important that the information needs of people from black and minority ethnic (BME) communities are addressed. In order to address this gap Talbot School now hold an annual information day for parents where professionals from the statutory and voluntary sector are invited to set up stalls outlining what they have to offer.

In addition, staff put on regular workshops where information about self-directed support, the process of planning for a future with self-directed support, the experiences of families going before them, and the options

available to them are shared with parents. In recognition of the fact that informal networks of other parents and disabled people are usually the most useful source of information, ex-students and their families are invited into school to talk with younger students and parents whose children are coming up to the age of leaving school.

Effective planning can only be done on the basis of accurate, up to date, accessible information across a whole range from leisure and social opportunities to micro-enterprises, benefits, housing and further education.

Part 2 - Curriculum for Citizenship

Transition planning is about equipping young people for adult life and for being active citizens. In the past many schools have not seen this as their responsibility – a view often reinforced by the involvement of many other professionals and by seeing ex-students go on to lead institutionalised, unfulfilled lives. Over the last two years Talbot School has been making, with others, significant changes to the way that young disabled people prepare for life beyond school.

Person-centred transition planning, introduced through the curriculum, helps to ensure that the young person's gifts, skills, needs, wishes, natural supports and friendships are built on, rather than looking for a response within traditional services. Person-centred planning is a tool to ensure that the focus person is always at the centre of any plans, decisions or choices about their life.

In the early stages, as a result of the Learning and Living Now Project, Talbot School received support from social services and outside consultants to help with person-centred planning. A lot of work was done with students by the person-centred planner in the transition team alongside ibk initiatives to enable the young people to make their voices heard. Listening to students' voices has gradually been embedded into the school curriculum. The school is now using the *Keys to Citizenship* (2006) as a framework for all its work (see Figure 2).

Making decisions and choices is an essential part of planning for the future. Talbot aims to develop students' skills in this by using tools such as talking mats, objects of reference, photographs, DVD, communication grids – whatever is most meaningful to the student. Establishing a person-centred way of working throughout the school and not just at transition has gone hand in hand with developing a culture where young people have a real voice

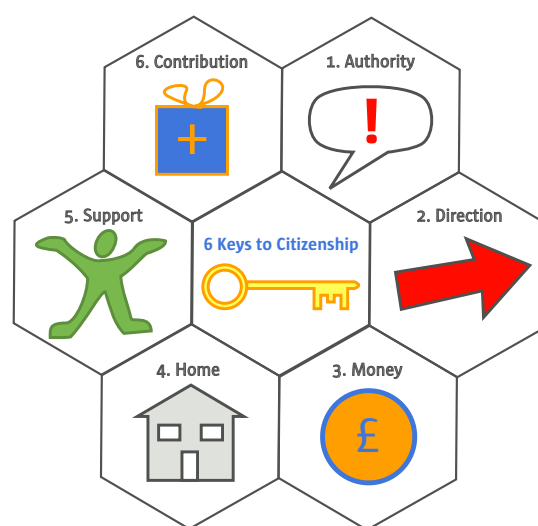


Figure 2 - Keys to Citizenship

and genuine choice and control. The school is already working towards this, although it is recognised that it will take time for it to become fully embedded.

Support Planning

Within support planning there is a crucial link between funding and planning. A person-centred plan without funding is just a dream.

Person-centred planning must be central to all the planning that is carried out. If young

people are to plan for the future they need to be offered tools or support to develop plans that genuinely reflect their aspirations and support needs.

People must be assumed to have capacity and where individual support is needed this must be coordinated and agreed as part of a clear and transparent plan.

In the first two years families were invited into school with their son or daughter to a Planning Live day. Each young person and their family were supported by teachers and other professionals from social services, health, Connexions, the Learning and Skills Council to draw up a support plan which identified what they wanted to do when they left school and how it would be paid for using their individual budget.

Inviting the right people to be round the table to support young people to plan is essential – people who know them well, perhaps other family members, people who know what the options might be and people who will ensure that the young person

remains at the centre of discussions about their future. Families are encouraged to bring as much information to the table as possible – this may include the pathway plan carried out by social services at age 18 for young people receiving short term breaks.

The learning from the first two years of Planning Live sessions was that students would benefit from more preparation to take part and to ensure that their voice was truly heard. The school has responded by supporting 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 (see Figures 3 and 4). People who know the students well contribute to the booklet. The school's speech and language therapist plays a proactive role in supporting young people's communication, for example, through communication grids, communication passports and producing symbol cards for planning. The 'All about Me' folders are live documents, intended to be updated as needed with copies made available to the young person and their family to pass on to anyone who will be working with them in the future. They are an essential part of any support planning the young person does.

For young people with complex impairments communication is always of crucial importance and is a significant part of the person-centred planning. Speech and language therapy staff at Talbot ensure that, as part of their person-centred plan, young people have simple and clear information about how they communicate which is accessible to everyone, and which they take with them when they leave.

Once the support plan is finished it is presented to a panel that makes the final decision on funding. Some parents have presented the support plan themselves which has the advantage of putting them in control and also means that panel members hear first hand from families about plans for supporting their young person's life choices.

Ownership of support plans remains with the young person and their family. Now



Figure 3 - One Page Profile

Communication Chart			
At this time...	When I do this...	We think it means...	What we do...
When I can't stand the noise	I start singing in my own language and I make loud noises	Your concentration span has reached its limit	One of the TA's takes you out on the roof terrace for five minutes
When I need something (i.e. water)	I take an opportunity to run as fast as I can	You enjoy exploring familiar areas and attention seeking	The fittest of the TA's would catch up with you and bring you back. You will have the biggest smile on your face if you have achieved your goal
During lesson time	I am laughing hysterically and spinning round	You are not comfortable working with unfamiliar staff	We let you work with a familiar face
During lesson time	I squeeze the staff's or students' arm, I spit or run around	You are either unhappy, unwell, or work is too hard	Staff will sit opposite you and talk to you calmly, repeating simple phrases like 'calm down Wakas' or similar. We also change the activity to help you calm down

Figure 4 - Communication Chart

that Talbot students are starting to plan at an earlier age it is likely that – for those students who use short term breaks - their plans can inform statutory pathway planning at age 18. Equally it's likely that the pathway plans can inform support planning in Year 14.

While both pathway planning and support planning are important it will be essential to ensure that each informs the other and that young people and their families have one single plan which they own and which is a living, developing document that can be added to at reviews or whenever they wish.

In these early days of developing new ways of working, Talbot School recognises that some families, including those from BME communities, may find support planning in school too stressful. The school's BME teacher supports colleagues to find the best way of planning with these families. Planning with families at home may be one option. For particularly complex plans a series of meetings may be necessary – support planning is understood to be a flexible process based around the individual.

Developing a person-centred culture

How the school equips its students for life is now recognised as an important measure of success. Learning from the transition work in school over the last two years has convinced Judith Smith, Head Teacher at Talbot School, that person-centred working is the way forward both for school leavers and for the culture within the school.

In the third year of the school's transition strategy Judith is ensuring that the school takes responsibility for playing its part in securing positive transitions for all students. But she is under no illusions about the scale of the work involved and expects it to take at least five years before staff, students and families are on board.

However the Talbot transition work is already informing the culture and work in the rest of the school. The emphasis is on what the students **can** do, their skills and abilities. Empowering young people to have a voice,

make choices and take decisions is at the heart of what Talbot is now aiming for. Local self-advocacy groups have been into school to talk to students with very positive feedback from students.

“Students have blossomed as we have taken this different approach. If a student makes a plan we stick to it... if we can’t, we need to find out why.”

And some parents of younger students, having seen the outcomes for the last two years’ leavers, are now asking when they will get to talk about transition for their son or daughter.

Person-centred reviews

Reviews are held in high regard and either Judith or her Deputy attends every child or young person’s review. Judith says she would like to see holistic person-centred planning starting in Year 7. She says:

“The Plan should be owned by the young person and can be added to at each review.”

Person-centred reviews are set to become the norm at Talbot, not just for students in transition. And the balance of what is presented and discussed in transition reviews is changing, with a greater emphasis on the young person’s aspirations and what they plan to do when they leave school. Any discussions about learning are in the context of the student’s whole life.

Judith reports that the mindset ‘gathered its own pace’ as colleagues in other agencies were equally dissatisfied with transition and keen to improve the outcomes for school leavers by working together.

Being involved in the Sheffield Transition Group also gave a voice to Talbot at a city-wide strategic level. Enthusiasm for the person-centred approach to transitions increased as students began to achieve improved outcomes. Much of the success came through a work experience project run in school.

Josh’s dream

Josh has long since dreamed of working with the police:

“Fast cars. Walkie talkies. Stopping crime. Helping people. The Bill!”

Josh’s mum and dad told school that Josh had talked about being a police officer since he was a little boy. Dad said:

“I can’t imagine him being a police officer, but I can see he could have a role in the police. Josh is very good at helping people.”

Josh started working at the Hammerton Road Police Station every Friday, under the watchful eye of Kay the administrator who made sure that he experienced different aspects of police work. His tasks included: washing police cars; sorting the mail; delivering messages; shadowing Police Officers in their various duties; watching officers deal with crime reports as they came in; visiting the horses in the mounted police section and spending time in a patrol car.

Josh’s superb people skills and enthusiasm quickly led him to become a valued member of the team. He has been asked to stay on as a volunteer for one day a week during his last year at school. Staff at the station are keen for Josh to continue working with them when he leaves school.

“Josh is an asset to the police station. Everyone knows him and he is part of the team here. We would like to find a way for Josh to be here long term.”

ADMINISTRATOR, HAMMERTON ROAD POLICE STATION

“It has been wonderful and beyond all our expectations. He is just exhausted when he leaves and often falls asleep in the car on the way home.”

JOSH’S MUM

“It is just fantastic! When he is at school it is all he will talk about! It has really helped him to be more responsible.”

TEACHING ASSISTANT SUPPORTING JOSH

Seeing more inclusive solutions meant young people, parents and staff started

to see the prospect of new, exciting possibilities.

Top Tips: Curriculum for Citizenship

- Develop person-centred approaches throughout school.
- Communication, alongside giving opportunities for choice and control, lies at the heart of the curriculum.
- Give young people the opportunity to try out new activities.
- Person centred reviews are essential for all students ensuring that any health issues are included.
- Engage staff throughout school in the process of change.
- Give young people the opportunity to influence their learning throughout school.

Part 3 - Individual Budgets

Having an individual budget means that young people and their families are told how much they have to spend from the relevant funding agencies – health, social care and education – and can then plan how to spend that money.

Working out an individual budget for each young person demanded a massive piece of work for senior managers in the three funding agencies involved in the Sheffield work – social services, health and the Learning and Skills Council. The complexity of signing off funding from these three agencies took a lot of ‘behind the scenes’ work and was only achieved with managers in each agency working together, championing the concept of self-directed support and being determined to find a new way to make positive transitions happen.

At the point at which we initiated personalised transitions at Talbot, preparations for self-directed support in social services were

already underway. This meant that personal budgets for school leavers could become an early part of their work across the city. The support of the personalisation lead in Sheffield social services was fundamental to the success of the new way of working.

Similarly without support from the Continuing Health Care lead, and the Learning and Skills Council, self-directed support would not have been possible for some young people. They found ways to enable young people to hold individual health and learning budgets at a time when these concepts were in their infancy. Their ‘can do’ approach came from a desire to make things work positively for young people and families.

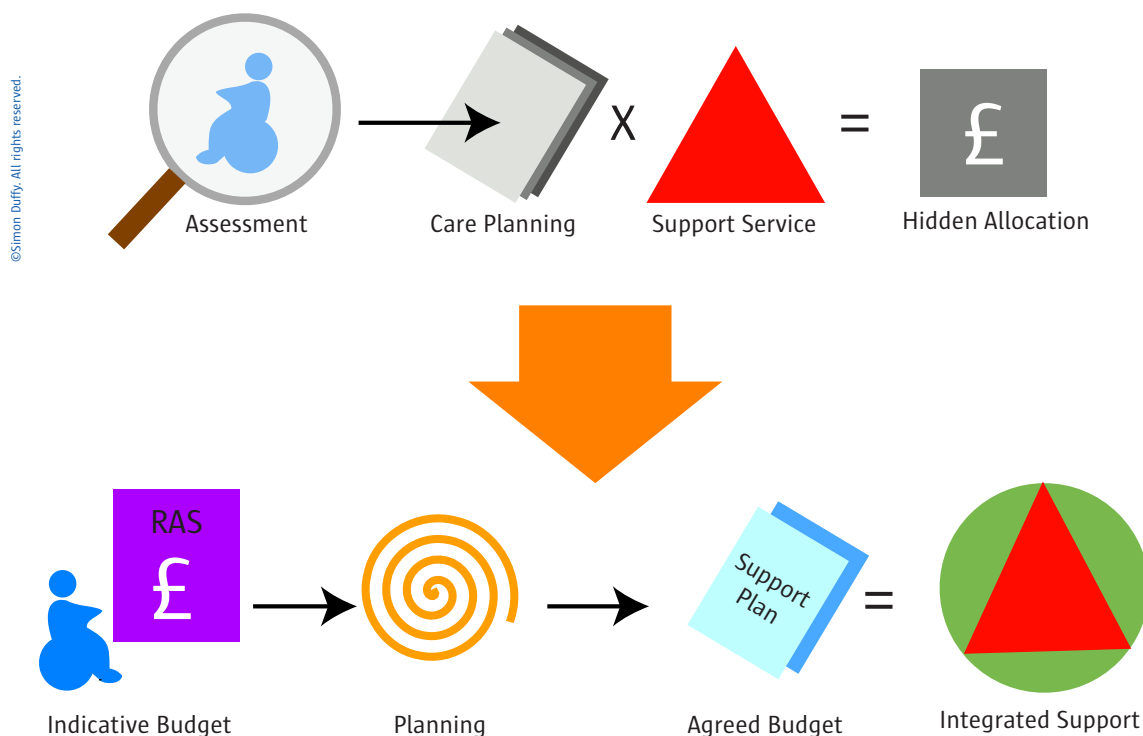


Figure 5 - Shift to Individual Budgets

Transparent Entitlements

If people are entitled to support, funding or access to particular services then these entitlements must be clear and transparent in order that people can evaluate what is available and how best to use any resources they can control. Without an individual budget self-directed transition planning simply cannot work. Young people and families need to know how much they have to spend, and what they can spend it on, before they start to plan (see Figure 5).

Social Care

To work out a young person's individual budget they and their family must fill in a 'supported self-assessment'. This is usually done with the support of a care manager from the social services Transitions Team. The questionnaire is then tested out against Fair Access to Care (FACS). There is no separate community care assessment. Evidence from the supported self-assessment questionnaire and the support plan must meet the statutory requirements for sign off.

Health

Continuing Care funding forms an important part of the individual budget for some young people. The application process is complicated, with strict criteria and no indicative budget. As transition liaison nurse, Carolyn Western's role is to make the process work

smoothly for families. Adult Continuing Care funding is only payable from age 18 but Community Learning Disability Nurses agreed to carry out the assessments at 16 to ensure things were in place when the young people left school. Carolyn told us:

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

Protocols are in place for young people with the most complex health needs to be referred into the Adult Community Learning Disability Team at the age of 17. The nurses then provide health co-ordination formulating links into Adult Health Services. These nurses also carry out the initial assessment via referrals from the Transition Social Workers to identify any health funding.

Further education

Learning and Skills Council (LSC) development funding over the last two years was allocated originally through the Learning and Living Now Project. Similar to the social care assessment, the LSC devised a supported self-assessment questionnaire to evaluate the appropriate level of funding for each student. The idea of individual budgets for learning was new and this was a way to test out creative ways of defining learning. As a result, one young man has spent three days at college and employs a PA to support him to research setting up a micro-enterprise for the other days.

Top Tips: Individual budgets and integrated funding

- Transparent entitlements make sense to everyone - but demand new and better systems.
- Professional integrity and hard work behind the scenes are essential to make things happen.
- There can be no progress without a positive, can-do, attitude.
- There is no reason why we can't have self-directed support from birth to death.
- Clear eligibility and resource allocation systems for different systems enable integration at the level of the individual.
- The earlier you know your budget the more useful it is so provide people with information as early as possible.

With the closure of the Learning and Skills Council in March 2010 it is not yet clear how learning will be funded for young disabled people from that date. Some LSC funding will be used regionally, and some will be administered through local authorities. At the time of writing, details of this funding are not known. However in Sheffield the

funding will be 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.

Part 4 - Co-ordinated Expert Support

Transition planning is now school-based and person-centred - focusing on the young person rather than on a bureaucratic process. Professionals from social care, health and Sheffield College come together with school to plan and co-ordinate support to young people and their families. The aim is to have a key professional working with the young person and their family to maximise empowerment and minimise interference and complexity. Both families whose young people have left school in the last two years and allied professionals have endorsed this approach.

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Self-directed support for young people at Talbot School has only been possible because professionals were willing to work together. The extent and complexity of the work means that no one person or agency continually took the lead. Rather there was effective leadership within the agencies from senior managers to make their agency's role work. Different people have taken the lead or solved different problems at different times and there has been consistent commitment from all agencies to learn how to work together to help young disabled people and their families to build better lives for themselves.

Whilst there has been passion for change in many places, there has also been anxiety about what self-directed support might mean for different professionals. Managing these anxieties at a time of many uncertainties continues to be a challenge for senior managers.

Communication between agencies about progress has been crucial. Positive regard for each other's roles and responsibilities is only possible when professionals know clearly what their colleagues in other agencies do, including their statutory responsibilities. Colleagues attendance at each others' meetings has improved communication.

The move to personalised transition has been a shared journey for all those involved. The transition strategy has worked best when agencies have put young people and their families at the centre of their working; listened to each other with mutual respect; and acknowledged each other's roles and embraced each other's issues – in other words, worked in a person centred way with each other. This means the young person is in charge of their own move to adulthood and that any transition pathway guides, but does not rule, this move.

Further work to rationalise the different transition meetings and agendas across the city is ongoing. Talbot School is represented within these forums at a senior level.

School at the centre

Whilst school is the place where transition planning happens, the school needs to work effectively with the many partners involved in supporting the young person. It would be impossible for school to work in isolation, especially given the different funding streams and the statutory responsibilities of social services, education and health agencies. But it does mean that school can ensure that

the young person and their family remain firmly at the centre of any plans or decision making.

Jeanette Thompson, Personalisation Lead, Sheffield City Council said:

“This way we are no longer planning just around social care. We are planning around someone’s life.”

The school community is the natural place for students to plan their future. It’s where the young person themselves is the focus; most will have been in school for many years, know staff well and families will have built up trust and relationships with teachers and other staff who know their son or daughter well. In turn, staff know them and their families well and it’s important that their knowledge helps inform students’ planning. Young people and families have the opportunity of learning from each other by coming together to plan. And school staff can also learn from families who are already exploring opportunities for their sons and daughters. Work experience opportunities are already managed from school.

This doesn’t mean, of course, that school does all the work around transition but it does serve as a focal point for young people’s planning - welcoming into school other professionals, from other agencies who also have a role to support young people at this time, and coordinating their input.

Collaboration with health

As 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 is an important link person with both a strategic and operational remit. This means she is well placed to ensure that the needs of young people with complex health needs are voiced in forums and agencies ranging from the Transitions Strategy Group and the Dental Care Project Group to the Ryegate Centre and the Sheffield Learning Disabilities Partnership Board.

“Without good health, students can’t enjoy learning or living. For some young people, health is critical. Empowering young people and their families to be independent in terms of their health needs once they leave school is key to a successful transition.”

The transition from children’s to adult health care can be a ‘minefield’ and Carolyn’s post was originally created to support those students with the most complex physical health needs, most of whom attended Talbot School. It provided a much needed opportunity to work more closely with colleagues in the social services Transition Team, and other specialist health colleagues including school nurses, and to set up protocols where necessary between the different agencies involved. Carolyn was also a member of the Talbot Transition Strategy Group. She says:

“A lot of my role is around linking people and forward planning – making sure people’s health is supported as they leave school.”

Collaboration with social care

Person-centred approaches have been developed since 2004 within Sheffield City Council. Niki Marshall, a champion of person-centred planning, is currently part of the Transitions Team where an important part of her role is to undertake statutory Pathway Planning with disabled young people who use the short breaks service. It is an OFSTED requirement that a plan is in place when young disabled people leave short break provision. Pathway plans have fed into support planning within Talbot School.

Over the past few years Niki has worked with social workers, residential workers, health professionals and schools to develop person-centred approaches. Niki has worked for some time within Talbot School, along with ibk initiatives, to raise the voices of disabled teenagers, including making school reviews person centred. Her work as person-centred planning coordinator has laid the foundations for support planning at Talbot School.

As she develops support planning for all ages across the city, Niki advises school staff on the essential components of a support plan and works with individual families to develop their plans. Niki also works closely alongside Carolyn Western to ensure Health Action Plans are included where necessary. Niki believes that empowering young people and families to be ready for a different, self-directed future is particularly important. She says:

"I hope that in the future parents, relatives and friends of the young person will write (their own) plans. Social services will be the coordinating agency that assesses and agrees the plan. We should not do any more than that unless we are invited to be involved."

Developing new ways of working

Talbot School is now on a journey which involves taking a wider perspective than just being concerned with what goes on within the school. It recognises all the work that has to be done to negotiate funding, services, learning opportunities and so on, communicating with everyone else involved, listening to others' genuine concerns and facilitating ways round these, always ensuring that the young person's voice is heard. In this way, the statutory requirements of transition should happen effortlessly around the young person, their family and the school. Not only must the school lead the way in improving the transition process but it must continue to listen to the voices of young people and families and to change and improve the process over time.

Learning from the last two years has informed the current year's transition programme (2009/10). An assistant head, Tricia Bennett, has been appointed to lead the transition work. With 22 leavers this year, the school is taking the lead in organising information and support planning meetings for school leavers and their families. Planning, review and information meetings are starting much earlier, two years before young people

leave school, to allow for preparation, support planning and implementation of the plan. Parents of younger children at Talbot are also invited to these initial meetings on the basis that it's never too early to think about the future.

Support planning this year will involve workshop days where professionals who know the young people well will help them and their families to fill in assessments. Families will be asked at annual reviews who they would like to help them with the support planning. The *All about Me* booklets will be an important part of support planning.

This way of supporting transitions represents a major shift in the way young people's futures are planned. Some families naturally plan with their son or daughter but for others the shift towards them being regarded as the 'experts' can be daunting initially. Families may need encouragement to think creatively with their son or daughter about what they will do when they leave school. For those who do, self-directed support can be a life changing experience. Having a PA can provide one to one support to enable the young person to live the life they choose. Yet others see self-directed support as a way of freeing up their thinking to create unique person-centred transitions for their young people.

A word of caution

It is absolutely right to celebrate the potential and life-changing experiences of self-directed support for many disabled people including school leavers. But it's also important to recognise that achieving a fulfilling life is no easy task and may come at significant and hidden costs to families. As John O'Brien and Connie Lyle O'Brien (1997) say:

"(We must) be careful never to compromise the human dignity of people with disabilities and be cautious not to betray hope with inflated stories of easy success or perfect relationships".

Alongside the positive stories we were also told about disappointments, isolation and

on-going struggle. Several parents told us how they are still waiting for support plans, agreed in the early summer of 2009, to be implemented. And some parents told us of the attraction of placements offering activities over five days a week (as opposed to the three day courses offered by Sheffield College) and the attraction of a social care organisation offering carers (as opposed to personal assistants). Only two families so far have chosen to hold their individual budget themselves because of the additional responsibilities this brings. Very few families have chosen to recruit their own personal assistants because of a lack of confidence around employment issues.

As we reflected on the experiences of young people and families we were struck by the fact that some young people and their families had greater support than others.

Young 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 informed, well motivated professional

can be very powerful. It can make the difference between an exciting, fulfilling life and a 'good enough' one. Without this mix, tensions are likely to arise and there is a danger of the young person slipping from the centre of the planning.

Over the last two years transition team social workers have been key to transforming young people's plans into actions once support plans have been agreed by the funders. With a much higher number of school leavers and expansion of self-directed support in other special schools in Sheffield social work support from the transitions team will be less available. Some young people may be helped by Connexions PAs but their resources too are limited. With so many professionals involved, each with different systems and policies, Talbot school is currently considering the possibility of employing their own coordinator to pull together all the arrangements from their leavers' support plans.

Multiagency working at senior management and operational levels will continue to be crucial to successful transitions. The school is keen that support available from all agencies and the roles they play is clearly spelt out. Individual champions within each agency

Top Tips: Working together

- Have a clear transition pathway and be clear about roles and responsibilities and how to streamline the different transition forums.
- Find a champion for self-directed transition in every agency.
- Establish effective, open and honest partnerships and dialogues between agencies – health, social services, education - with the people who have power to change things.
- Agencies will include – in no particular order – Children's and Adult Services, the Transition Team, Transition Liaison Nurse, Specialist School Nursing, Paediatrician, Dental, Seeability, Teaching Staff, Connexions, Community Learning Disability Teams, and so on.
- Accept that change and on-going learning are necessary and inevitable in the fast-moving policy environments of health, social care and education.
- Make sure you are truly transforming lives – not replacing one lot of services with another.
- Understand the workload and pressures on colleagues in other agencies who may be working to very different systems and procedures.
- Make sure there is effective communication between all agencies.

help to keep self-directed support at transition on the agenda.

The new model of transition is beginning to influence the whole school and person-centredness is becoming the way of working. Empowering students to make their voices heard and make informed choices are now key skills and form part of the school curriculum from Year 7.

Developing new opportunities

In the mean time students' real choice is limited in terms of learning providers. As one parent put it:

"There is an illusion of choice - in fact things are just the same as ever unless parents choose to set things up themselves."

However the fact that individual young people now have their own budget has meant that the quality within existing services has improved. In practice it is likely that real choices will only become available over time.

It is still early days for personalised transition but it is likely that the grit and determination that has enabled the Talbot School Transition Strategy to get this far will enable it to continue to develop. And as more positive stories are told, individual budgets will become the norm.

As one parent told us:

"Having choice and control has been a positive, life changing experience for all the family, especially my son".

Achievements



Achievements

BY ALISON COWEN, SIMON DUFFY & PIPPA MURRAY

The immediate benefits of personalised transition have primarily been found in the improved outcomes for 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 on-going need to overcome tendencies to bureaucratised or control decision-making). Financially the improvements have been broadly cost-neutral, but with 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.

Outcomes

Overall the primary outcomes of the implementation of personalised transition are:

- Young people and families with better and more active lives.
- 23 young people were given individual budgets in the first two years and were able to shape and determine, with family support, their post-school package of support and education. This is now the default system for all disabled people in Sheffield.
- Real individualisation and integration of health, education and social funding under control of the young person - the first time, to our knowledge, all of this has ever been achieved in England.
- Good quality planning, carried out well in advance of the end of the school year, is now the norm - with some students and families taking much more control of the planning process.
- Some young people are using their budgets more flexibly and creatively - including innovations in the delivery of educational outcomes.
- Individual Service Funds (individual budgets managed by service providers) have been successfully used by the City to facilitate the shift to self-directed support.
- There have been significant reductions in the use of institutional services, with no one leaving the City or attending residential colleges.
- The voice of the young person is stronger both inside and outside the school.
- The school has demonstrated its willingness to lead and to host the transition process and work effectively with expert professional groups.
- The school has integrated personalised transition into its whole ethos and way of working, supporting an increase in person-centred practice, an increased focus on citizenship and an increased reputation for excellence - now recognised as an outstanding school by OFSTED.
- Personalised transition is a model which can be replicated and adapted regionally and nationally.

It seems that people are now leading lives that are more positive and individualised. And the outcomes go far beyond the achievements of young people. Parents now talk of self-directed support leading to positive outcomes for all the family, not just the young person. They speak of increased self-esteem, improvements in health and their son or daughter's happiness.

In her introduction to the evaluation of *Just Look at Us Now!* (Murray, 2009), Pippa highlights some qualitative success indicators:

"The smiles, laughter and giggling of the young people; the relief and joy of parents; the ever increasing maturity and independence of the young people; the loosening of parental control; the positive learning curve described by parents, supporting professionals and providers; and the call for more of the same."

Parents are very positive about having self-directed support:

"(There has been) an amazing improvement in his quality of life. It has given him so much freedom to explore life... With Tony having his own PAs now I have more time to spend with my other sons."

"...it has made a big difference to Reuben's life... and it has made me more happy knowing that he is doing what he is wanting to do... It has been brilliant as far as our Reuben is concerned."

The report goes on to say:

"Providers and parents acknowledge social skills development in all areas, young people showing huge delight, excitement and pride about the lives they are now leading."

"For the first time ever I don't have to encourage him to get up in the morning and leave the house. He is waiting for his carer, and as soon as he sees his car he will go out of the house..."

And there have been unexpected developments for some young people and families. The ease with which one of the young men has adapted to his new life, and the maturity he has gained over the past few months has enabled his family

to think about independent living.

Other parents too reported that self-directed support has given them the opportunity of contemplating 'letting go' - seeing their sons' and daughters' capabilities and growing sense of self-worth.

This self-directed way of living meant that families began to identify the lack of choice around purposeful activities as limiting their sons' and daughters' lifestyles.

A major aim of personalised transition is to facilitate learning across a range of environments and situations. Families are choosing to spend some learning funding in less traditional learning settings. For example, one young man goes to the gym regularly; another spends time on his allotment; and another pays a PA to come and teach him computer skills in the evening. Young people and families reported the 'huge benefits' of this flexible approach to learning.

"Because a big thing for Pete is that we have been able to create a learning programme for him but not have him coming into a college building. And not having to send him to a residential college..."

The flexibility of funding allows young people to take part in a range of activities which are meaningful to them. A more traditional view might place some of these activities under the category of 'leisure'. However the young people are showing that purposeful activity in any setting allows for learning to take place.

The impressive achievements are not restricted to the outcomes for young people but also the working together of committed professionals within many agencies. Whilst recognising the sheer hard work, difficulties and barriers to achieving success, it's even more important to acknowledge the determination to make things work and the shared commitment to creating exciting, well planned, person-centred transitions for each young person. Importantly that commitment has come from both senior managers and operational professionals across all agencies.

The resolve for personalised transition grew once everyone could see the great lives some

young people were starting to achieve – such as the young man offered a job with the police following a successful work placement and the young woman who was able to buy a laptop to learn computer skills from a family friend – having an individual education budget meant that her learning needs could be met in this different and supportive way.

The school itself could take pride in ex-Talbot students doing ordinary things they wanted to do, having a job, moving to their own place and so on. They are providing role models for younger students who are now starting to push for change and new opportunities themselves.

Limits

We are aware that we are at the beginning of a powerful process that has the potential to transform the experience of disabled young people and their families. But there are many limits still to be overcome and it is important to recognise these as we move forward.

- A few families found that it took some months after school for services to be set up by their chosen service provider.
- Most families and young people still use relatively standard support solutions to meet their needs, innovation is by a minority.
- Some professionals are still struggling to come to terms with the new flexibility of self-directed support and some restrictions on how people can spend their budgets have been put in place which seem hard to justify.
- Market development is still limited, and most families are using one of a limited supply of support services to manage their budget.
- Family confidence seems surprisingly low, with only two families managing their budget directly (this compares with 50% of individual budget holders using some form of direct payment in other national studies).
- There is no framework for peer support for young people and their families after

school and this can leave families without any easy way of comparing notes on their services or offering help to each other.

- Although Learning and Skills funding is now shifting to local control there is still uncertainty at the local and national levels as to whether these successful innovations will continue to be supported in the future.

The lack of individual budgets for children and families in the City means that expectations of family control are low and families only come to think about the possibility of greater control at a relatively late stage. (In fact families are often having to take greater control at the very point that they would – at least for non-disabled children – be thinking about giving away greater control to the young person. It would be more appropriate to make family control the default option for children with disabilities in future.)

Costs

A common misconception about personalisation is that it is inherently more expensive than traditional forms of support despite all the evidence to the contrary, see the recent report from the University of Birmingham (Glasby, 2010). However this misconception exists for at least three reasons:

1. When traditional services individualise their own services they always create more expensive versions of their own services – they tend to replicate the same forms of support but at a different scale.
2. Individual budgets and the use of resource allocation systems tends to cap costs at the outset and ensure that the budget is controlled.
3. Self-directed support and the kinds of person-centred planning processes used in personalised transition should help people make better use of fixed resources – enabling a synergy of public resources and the resources of the individual and their community – not just money, but rather the talents, interests and social capital.

In other words personalisation may be more effective because it treats money as just one input into the production of greater social value and not as the price of that increased social value. This approach is called 'pull economics' (see Figure 6). This makes a simplistic account of the economics of personalisation untenable. It is not a question of whether personalisation is more or less expensive than the older system; rather it is a question of how can personalisation be designed so that it helps create greater social value. A fuller discussion of these questions can be found elsewhere (see Hagel and Seely Brown, 2005).

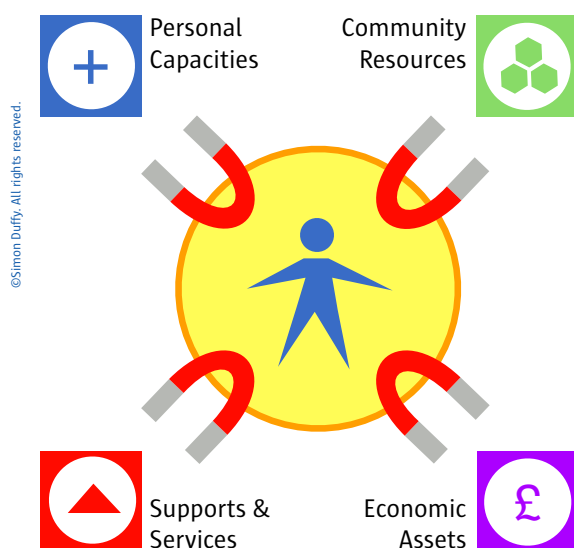


Figure 6 - Pull Economics

A simpler question, and one that can be tested empirically, is to ask whether the significant improvements in outcomes that have been reported can simply be explained by an increase in funding. We have therefore examined all the available data on costs below.

Overall 25 young people went through personalised transition in 2008 and 2009. 23 were deemed eligible for support by local services and one family opted out of the process and used the older system. In the previous two years (2006 and 2007) 24 young people went through the old transition process and of these 20 were eligible for local services. 21 are currently going through in 2010 but they have

been excluded from this analysis as they have not reached the end of the process.

To get the widest and most balanced figures possible we have distinguished these two groups:

- **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 for 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%
LSC	10798	18870	+ 75%
ILF	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%.

One further uncertainty in this data is 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. Generally students who attend Talbot Specialist School tend to have some of the highest levels of need in the city, but the differences in needs between students can be very large and much larger than the differences in need between people with lower needs.

There have also been other important changes in funding, in particular the application since 2008 of a new policy for funding 'Continued Health Care' attempted 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.

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, and would often bear the full cost of these residential packages. In 2008 the LSC in Sheffield began to use a tool for allocating resources as part of the Learning and Living Now Project which was applied in Sheffield. There were also additional 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 some combination of the two factors).

When we look at the detailed analysis there are some further interesting changes that are worth examining:

- In the 'after' group there were 15 packages based on mixed funding. In the 'before' group there were only 2 packages of mixed funding. This seems to reflect the effectiveness of resource allocation systems at developing a more balanced approach to defining entitlements and the support such systems provide to joint working.
- In the 'before' group there were 8 residential placements - schools or care homes - in the 'after' group there were none. This seems to suggest that giving people clear entitlements and time to plan is helpful in discouraging people from seeking more institutional forms of support.
- It is also interesting to note that the resource allocation system developed by the local authority was developed as part of its commitment to a universal system of personalisation. So, from the perspective of the authority it must be encouraging that budget levels are being set at what must be relatively more sustainable levels.

Finally it is worth noting that no effort has been made to explore the process costs of managing the implementation of personalised transition. Transition is expensive and process intensive, many professional groups are involved and many pre-existing initiatives were woven into the process of personalised transition. Overall the school has tried to normalise its own pastoral and supportive role, but has certainly spent more of its own resources on transition than it used to.

However, 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.

Control

When comparing the 'before' and 'after' outcomes, limits and costs it is possible to forget the most important change of all - the shift of control to the young person and their family.

This shift is important for four reasons, each of which has the potential to bring on-going benefits which far outweigh the immediate advantages or disadvantages of the short-term impact of personalised transition:

- **Dignity** - Individuals and families feel that 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; this creates on-going opportunities for increased efficiency and effectiveness.
- **Quality** - Being in control lets you change what is not working more quickly - as one parent said: "its all about control - we've changed the service four times already - if we don't like something we change it".

The real test of the success of personalised transition, and the systems of self-directed support to which it is linked, will come about over time as more people manage and improve their support - learning both from others and from their own experiences.

Policy Implications



Policy Implications

BY SIMON DUFFY & PIPPA MURRAY

The implications of personalised transition go much further than simply offering an important systemic solution to a long-standing public policy problem - the 'transition problem'.

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 on-going difficulty of integrating different and competing public 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.

In the following sections we will explore the advantages of the possible reforms and offer some suggestions as to how we might begin to take these new technologies forward in practice.

Reforming Transition

The most obvious and pressing lesson from this work is the need to apply these ideas to help solve the problem of transition locally, regionally and nationally. Personalised transition offers a coherent and replicable model that could be applied and improved:

- Giving families and young people clear rights to control and direct their support and education.
- Making person-centred principles central to the planning and development of

support and education - within and outside the school.

- Supporting schools to develop their role with other professionals as the hub of peer support for families.
- Rethinking the organisation of professional input into the transition process, creating a more flexible and person-centred framework of professional support.
- Setting individual budgets in advance before young people leave school.
- Extending the model across both special and mainstream schools to include all children who need extra support or who are leaving care and are at risk of exclusion.

All of these steps should become priorities for leaders involved in the transition process. As we have found in Sheffield, the benefits of this innovation will quickly spread beyond the confines of transition - increasingly people will come to see that elements of this approach could be extended into many other aspects of public service.

Deepening Reforms in Adult Social Care

The key to the success of personalised transition has been the willingness of the adult social care team to innovate and test out the first individual budgets in Sheffield with the young people and families at Talbot. Without this leadership all the other subsequent innovations would not have taken place and it is important to acknowledge the hard work and courage of key staff such as Jeanette Thompson, Josie Bennett and Cath Roff. It is this willingness

to innovate that has given other partners the courage to move forward with them.

It is still early days for personalisation in adult social care in England and Sheffield is one of the leading authorities. It is currently in the process of ensuring that all those eligible for support in the City will have an individual budget. This will hopefully bring about much deeper changes in culture and in the lives of the people that are supported directly or indirectly by the City.

Some of the issues for the future that the local authority will need to think about is how to ensure that the genuine innovation and achievements of a few spread to the many. This will require:

- **Flexibility** - clarity about people's right to use their individual budgets flexibly. Any unwillingness to give away control which is endemic to all public services will need to be carefully managed and challenged in the coming years. If it is not citizens will find their individual budgets becoming a burden rather than a tool for liberation - having to guess what will or will not be allowed or hiding what they are doing for fear of falling foul of unclear rights. An entitlements-based approach would help avoid this risk.
- **Control** - The fact that none of the Talbot families have chosen to manage their individual budget as a direct payment tells us that both professionals and families feel the burden of managing a direct payment is too great. However in other local authorities the rate of use of an individual budget as a direct payment is around 50%. It would be useful to explore why so few families are taking up this option.
- **Peer Support** - The system of peer support and planning which Sheffield City and Talbot Specialist School have put in place has clearly made a big difference to people's ability to plan for the future with confidence. Unfortunately there are no structures in place to reinforce and support peer support after school years have ended. Such systems could be very inexpensive to

create and foster. This would be an avenue worth exploring.

- **Provider Development** – A strength of Sheffield's work has been the use of service providers to manage individual budgets through individual service funds. However it would be good to see more innovation and individual accountability within the wider market for services in Sheffield. This may arise if more people take direct payments - but if it does not, it would be worth exploring with young people and families how the role of service providers might develop in the future and the kinds of support that would be most valued.

Sheffield City is to be congratulated on its role in leading one of the most exciting innovations in recent times and it demonstrates the power of local pride and potential for genuine civic renewal. Leaders who are introducing personalisation may also need to remember that these ideas were not developed nationally but came out of local innovations - their power lies in their ability to unlock talent, creativity and energy from within communities. If local systems are not sensitive to the power of personalisation they will find that the reforms will not fulfil their potential.

Supporting personalisation in health care

Sheffield's use of individual budgets in health care came long before the government's own thinking on personalisation began to change. There is increasing awareness that many forms of health care could be delivered in more personal ways and that having an individual budget (or what has now rather confusingly been named a 'personal health budget') is one mechanism to help achieve this change.

The examples from Sheffield typify the advantages of personalisation:

- When resources are portable, flexible and individual they can be used to support the design of more appropriate services.

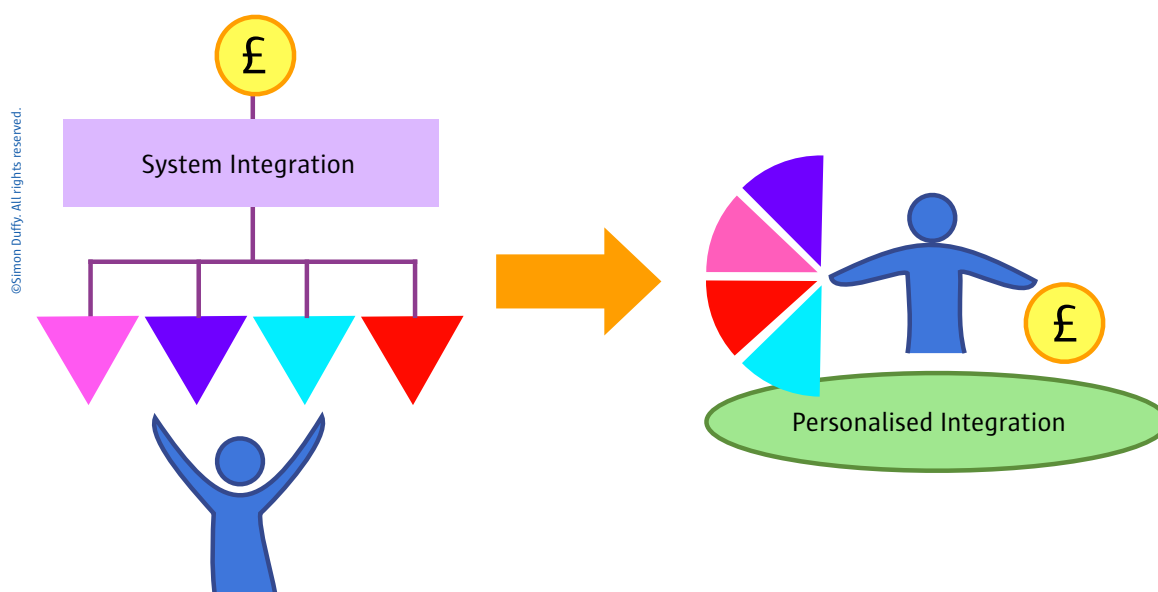


Figure 7 - Shift to Personalised Integration

- People can use their funding for support or technology that moves with them and fits into their life instead of being locked into residential or hospital-type support.
- Instead of having to receive care from people who don't know or who may not even like you, you are able to choose who supports you, when and how.
- People can examine the resources available and make the best use of them, and they can also innovate and use resources more effectively than any standardised system makes possible.
- Personalising support and planning ensures that health care is provided by the right person, with the appropriate skills, in the best environment.
- Individual budgets from different statutory organisations can be integrated at the level of the individual (see Figure 7).

It is a fallacy to believe that personalisation will be a threat to high quality health care and some of the greatest health gains are likely to come by engaging citizens and families more fully in the process of thinking through, designing and delivering good quality health care solutions.

In practice it would be quite possible to extend the good practice in Sheffield in a

number of ways and these approaches could be developed by any member of the NHS:

- Extend the process of setting individual budgets to all people needing Continuing Health Care.
- Develop a resource allocation system that can simplify the process of setting individual budgets in a similar way to the system used in adult social care.
- Collaborate with the local authority on a joint contracting and monitoring arrangement (rather than running two systems in parallel).
- Create partnerships with non-statutory services to oversee and manage individual budgets where any legal restrictions make direct payments impossible.

It is still very early days for personalisation in health care. The key for NHS organisations will be to identify leaders who can begin thinking through its implications, and building an internal community of champions and innovators. Sheffield is very lucky that it has had officers such as Julia Thompson and Leah Chilengwe who were able to support and protect these early innovations. Support for leaders such as these will determine the extent of further progress.

Exploring personalisation in education

One of the most remarkable successes of the work in Sheffield was the opportunity to test out the thesis that educational funding could and should be individualised. This has been despite significant scepticism as to the benefits of personalisation in education. In some respects the resistance to personalisation in education is surprising:

- Education requires a high degree of sensitivity to the learning styles, needs and interests of the individual - people can rarely be forced to learn.
- Good teaching has always been innovative, sensitive to the needs and gifts of the learner and keen to innovate and find better ways of sharing learning.
- High educational standards demand the necessary flexibility and motivational power of personalisation.
- There are many educational resources, within families and communities and outside the formal boundaries of educational institutions, that could be better used.

However education is also one of the most highly politicised domains of the welfare state and there have also been powerful counter-vailing tendencies:

- The desire to determine what people should learn and when - through the national curriculum and similar initiatives.
- The desire to determine how people teach - through standardised teaching procedures.
- The closer correlation of teaching and standardised measures of success which, if it does not erode educational standards, certainly defines the standard in terms which are more likely to achieve success - at least in superficial political, if not educational - terms.

The work in Sheffield (together with some parallel work in Essex) shows that, despite

these pressures, change is possible and this change could - with the right leadership - help revitalise education and learning across England. However this will require a new level of thoughtfulness and systemic creativity. In particular it will be important to ensure that, in this new way of thinking, we do not slip into the habit of seeing schools or educators as 'mere providers'. The success of personalisation in social care has not been about market economics - it has been about the ability of individuals and professionals to redesign and rethink supports and interventions so that they are more effective.

Hopefully Sheffield will continue the good work of those innovators within the Learning and Skills Council who enabled these local innovations to take place. If they do, then they will need to work closely with schools and colleges to help them see the inherent opportunities of such an approach. In fact funding for the educational system is already largely individualised - the opportunity of personalisation is to bring the citizen into the conversation about defining the right education for them in the light of their entitlements.

Rethinking the role of the school

The attitude of society to school is strangely double-edged - perhaps reflecting the powerful impact school can have on us as individuals. On the one hand there is a strong sense of the powerful and positive role that schools can, and sometimes do, have in our society. On the other hand, there is a tendency for society to try to dictate how schools should be as if they were just simple instruments of the state or society.

This double-edged attitude of extreme respect and acute paternalism of society towards the school is matched by how it feels to be within the school. On the one hand schools feel very much as 'little worlds' subject to their own rules, powers and cultures. On the other hand schools feel powerless in relation to systems of funding, policy,

curriculum and exam development which treats them as passive objects simply to be managed by the system.

Our view is that we need to begin to rethink the role of the school. We need to be more realistic about what schools can and should do, to recognise that they exist as only one part of the world of the student and they cannot by themselves - on behalf of society - impose all the necessary values, learning and discipline that students need to prepare themselves for citizenship.

On the other hand we need to develop a more positive and respectful attitude towards the role of schools. Schools are an important part of our civil society; they can offer so much to the whole community, especially through building respectful partnerships with their families and children.

It is this vision for schools that has been dominant in our thinking and we believe that it is time to try and shift policy-making in this area:

- Schools could be supporting education, not just class-based learning, and could manage individual education budgets for this purpose.
- Schools could focus on the family, as the natural source of authority and support to young people, helping the whole family.
- Schools should be able to shape their own identity and role within the whole framework of the local community.
- Schools should be able to act as guardians of education and citizenship throughout the whole of civil society.

These are wide and ambitious goals. But the work of Talbot in supporting and developing personalised transition demonstrates they are not unrealistic. There is still a long way to go for the school, but it may be time for policy-makers to have a fresh think about schools and to examine the current systems of funding, regulation and control which do not seem to support these kinds of innovative developments.

Extending personalisation into services for children and families

A further challenge for Sheffield, and other local authorities, is to extend the scope of personalisation into the design of systems for young people and families. Perhaps the most important challenge is created by the complex relationship between safeguarding and personalisation.

The issue of safeguarding children has become so dominant within children's services that personalisation may be seen as at best an irrelevant luxury, or at worst a threat to the duty to safeguard children. However there may be ways of beginning to rethink personalisation so that it can become a helpful technology to children's services.

Many parents of disabled children feel reluctant to ask their local authority for help as eligibility for support is linked (through legislation) to child protection and children in need processes. In the majority of cases, however, parents simply want an extra pair of hands to help out at particular times of the day. Sadly, such a straightforward solution is rarely available under our present system. Families seeking help are subjected to lengthy assessment processes and then, if they are deemed eligible for services, offered limited support that often adds to their stress. Pulling families, who simply want to take the best possible care of their children, into systems focussed on managing the risk of abuse creates unnecessary, time consuming and expensive processes that often have little benefit for those seeking support.

Although we take the view that supporting disabled children and their families is an equalities, as opposed to a safeguarding issue, we also argue that safeguarding would be better managed using personalisation technologies. The obstacle to seeing this possibility is often the belief that personalisation is simply another word for a direct payment (i.e. a family controlling cash given to them by the state).

In fact personalisation is not the same as direct payments - a direct payment is a useful tool for some people, in some situations - but it is not always the preferred option. Other useful technologies include:

- **Individual Budgets** - making budgets transparent can help people solve problems in better ways because they can begin to identify more flexible and appropriate systems of support.
- **Small Sparks** - small grants which must be spent on community-building efforts, these can help people connect and build better local relationships.
- **Budget-Holding Lead Professionals** - giving professionals more flexible use of resources, without making these budgets transparent, is also very helpful in building smarter responses to need.
- **Individual Service Funds** - service providers managing someone's budget for them.
- **Family Centred Plans** - planning in ways that engage the needs and aspirations of all family members can help people move away from damaging patterns of behaviour.
- **Community Connecting** - planning with whole communities to strengthen the whole social fabric and solve problems together.

None of this erodes the responsibility of the local authority for determining whether a child is at undue risk of abuse and acting appropriately. However these tools do give local authorities a wider array of tools for better supporting families and reducing the overall level of risk. Hopefully Sheffield's children's services and others across the region will begin to see personalisation as an opportunity for transforming the lives of all children and young people.

The final policy implication of this work is for local agencies to begin the process of finding one coherent model for this work embracing all agencies and all needs. The biggest challenge and opportunity for local leaders is to develop an integrated approach

to individual budgets stretching from birth to death.

Linking personalisation and Total Place

There is a need for reflection on the role of personalisation within the strategic development of local governance and the commissioning of all public services. This is not because personalisation is the answer to all the challenges of public policy, but because it offers a coherent methodology that could be extended to many areas of public policy from which it is currently excluded. Personalisation needs to be tested alongside other critical strategies (see Figure 8).

In our view local partners would benefit from exploring ways of developing a model of Total Place commissioning which will enable commissioners to develop distinct strategies for:

- Personalisation - or micro-commissioning through and with citizens and families.
- Community development - support locally led solutions from within and through new and old forms of civil society.
- Service commissioning - identifying where the direct provision of public service still adds significant value and cannot be carried out through individual or community action.

Finding the right balance between these approaches is the central task for commissioners and will involve the following steps:

1. **Locally Agreed Outcomes** - The identification of an overarching local vision, which identifies desired outcomes and the needs that must be met to achieve those outcomes.
2. **Co-production** - The strategy must recognise that the positive outcomes cannot be achieved without the leadership and involvement of citizens and communities. Professionals and services can only co-produce improved outcomes.

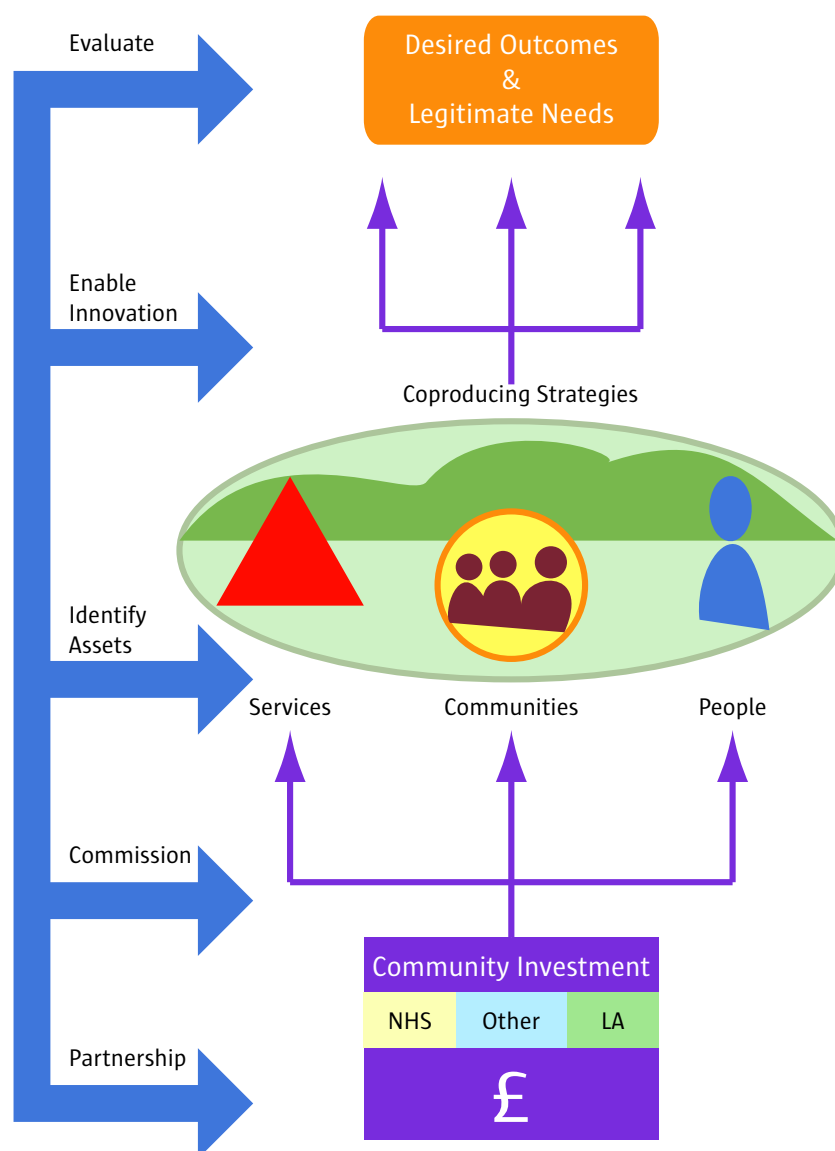


Figure 8 - Total Place Commissioning

3. **Community Assets** - Strategies to achieve these outcomes must be based on the identification and support of all community assets, this includes public services, but goes much further to include citizens, families and the full range of community resources.
 4. **Smart Investments** - Local commissioning and investment decisions must be based upon real evidence of effectiveness and the use of all forms of investment, this includes prevention and enablement, the use of individual budgets, and support for community infrastructure.
 5. **Real Partnership** - Local partners making investment decisions together in the light of the different obligations and constraints placed upon them by central government.
 6. **Innovation and Evaluation** - The whole process of Total Place commissioning must be underpinned by competence in encouraging innovation and examining what practices are genuinely working.
- Personalised transition is one part of a new solution for public services. Total Place commissioning might be the framework within which personalised transition can maximise its impact.

Information

Keystage 3



Information

Research

This report is based on interviews with parents and professionals. The views of disabled young people have been included through information gathered in workshops and the support planning process. We have also included learning from regular evaluation workshops over the past three years, and related evaluations e.g. *Just Look at Us Now!* (Murray, 2008).

Costings

Most data has been provided at 2009 prices, however some data may be older and this will dampen the costs within the 'before data'. In-house day services have been priced at £12,500 per year.

There were two services where there are discussions about possible NHS funding but no agreement and so we have applied NHS costs as zero in these cases.

Over the whole period the LSC continued to block fund Sheffield colleges and the costs for these services, which were determined independently of this initiative, have not been included in this analysis.

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Useful Resources

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www.in-control.org.uk
www.transitionsupportprogramme.org.uk
www.valuingpeople.gov.uk

Glossary

We have used some language throughout this report which may not be familiar to readers. This glossary sets out some of the key terms and how we have defined them.

Direct Payment - The system, begun in 1996, which enables some people to directly control their own budget. This concept is often confused with the concept of an individual budget but they are categorically distinct. In particular it is possible to have an individual budget without a direct payment, instead another control mechanism can be used [for example an individual service fund or asking a local authority to manage the budget on your behalf.]

Individual Budget - The money to which a citizen or family is entitled and which can be used to purchase necessary support to achieve valued social outcomes conditional upon the agreement and oversight of public services. [To avoid confusion we are avoiding using only this term, the original name for the concept, although its central meaning is identical with the plethora of other terms now being used - such as personal budgets, personalised budgets, personal health budgets etc.]

Individual Service Fund - This is a way of managing an individual budget through a service provider where the budget is held by the provider but restricted in its use to the benefit of the person whose budget it is.

Personalised Transition - A model by which young people, with the support of their families take control of their journey from school into adult life and which is supported by a school that prepares people for citizenship, clear entitlements that people can plan around and expert, but coordinated, support.

Person-Centred Plan - This is a plan which is controlled by the person and which can be developed and amended under their authority. For people who need help to plan it may require support from people who know the person well and who care about them.

Resource Allocation System - This a set of rules which enable assessed needs to be turned into a suitable level of funding. It is this system which enables individual budgets to be identified before people begin planning.

Self-Directed Support - This is a system for organising support to people who need extra help in their lives and which enables them to remain in control of the design and delivery of that support. It is a flexible system which can be applied in social care, health care and education and it allows many different levels of control to suit the individual.

Contributors

The author and editors would like to say a big thank you to the Talbot school leavers in 2008 and 2009 and their families, for sharing with us their experiences of a personalised transition. We would like to thank all the professionals from Talbot Specialist School, Sheffield; Sheffield City Council; NHS Sheffield; the Learning and Skills Council and Sheffield College who generously gave their time and shared their views about the Talbot School transition strategy. Thank you to:

Adele Ainsworth, Learning and Skills Council
 Katarina Bajin-Stone, Manager, Transitions Team, Sheffield
 Josie Bennett, Head of Joint Learning Disabilities Service, Sheffield
 Tricia Bennett, Assistant Head teacher, Talbot School
 Alison Butlin, Speech and Language Therapist, NHS Sheffield
 Jenny Cooke, Lecturer, Sheffield College
 Leah Chilengwe, NHS Sheffield
 Katrina Ellershaw, Parent Governor, Talbot School
 Claire Hemingway, Learning and Skills Council
 Denise Jones, Transitions Lead, Sheffield College
 Jayne Ludlam, Head of Children's Services, Sheffield
 Keith McKinstrie, Service Manager for Social Care, Joint Learning Disabilities Service, Sheffield
 Niki Marshall, Person-centred Planner, Transitions Team, Sheffield
 Kit Moran, Service Manager, Transitions Team, Sheffield
 Ricardo Moreira, NHS Sheffield
 Phil Morgan, Parent Governor, Talbot School
 Cath Roff, Director of Adult Services, Sheffield
 Roger Simmons, Manager, Connexions
 Judith Smith, Head teacher, Talbot School
 Carolyn Sutcliffe, Deputy Head teacher, Talbot School
 Julia Thompson, Yorkshire and Humber Joint Improvement Partnership
 Jeanette Thompson, Personalisation Lead, Sheffield
 Jill Tomlinson, Connexions PA
 Ann Wain, Senior Business Support Officer, Sheffield
 Carolyn Western, Transition Liaison Nurse, Sheffield Health and Social Care Trust

Special thanks also to the Yorkshire and Humber Improvement Partnership for funding the primary research used within this report and thanks to Yorkshire and Humber Joint Improvement Partnership for the funding, additional writing, editing and publication of the report.

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The Centre for Welfare Reform is an independent research and development network. Its aim is to transform the current welfare state so that it supports citizenship, family and community. It works by developing and sharing social innovations and influencing government and society to achieve necessary reforms.

ibk initiatives

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ibk initiatives is a research, consultancy, training and development agency whose aims are to promote the inclusion of disabled children, disabled young people and their families in their local communities, and to challenge a disabling world that denies their right to an ordinary existence.





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WWW.CENTREFORWELFAREREFORM.ORG

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