

A Fair Start

A Personalised Pathway for disabled children and their families

Pippa Murray

Editors: Simon Duffy, Jon Glasby and Catherine Needham



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About this series

Joint policy document series

In the summer of 2010 The University of Birmingham's Health Service Management Centre hosted a two day think-tank to explore whether recent innovations in health and social care might be the key to a more radical redesign of the whole welfare state.

As part of the think tank papers were produced which proposed significant policy developments. These papers were then subject to debate and criticism. The papers were then further developed for publication.

Each paper in the series has been produced by a leading practitioner and social innovator. The papers combine evidence and ideas for policy reform which are rooted in the real experience of bringing about change from the 'bottom-up'.

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Contents

About this series	2
Acknowledgements	2
Contents	3
Preface	5
Summary	8
Introduction	9
An unfair start	12
Eligibility and safeguarding	14
Complex systems	16
Social and economic impact	19
What families need	21
Real wealth	25
A relational approach	29
Personalisation	33
Personalisation in education	35
Personalisation in employment	39
Personalisation in health	41
Personalisation in transport	43
Personalisation in housing	45
Beyond individual budgets	46
Personalised Pathway	49
Bibliography	55
Contributors	57
Author	57
Editors	58
Publishing information	59
Small print	59

Preface

In the early twenty-first century, elements of the welfare state are in the middle of a ‘transformation’ process based on the concepts of personalisation and self-directed support. Beginning in adult social care, these approaches seek to recast users of state welfare away from being passive recipients of pre-purchased services towards a situation where they are active citizens with a right to control and shape their own support. Various described as a form of ‘co-production’ or in terms of individuals becoming the ‘micro-commissioners’ of their own support, this has been seen as a shift away from a ‘professional gift model’ towards a citizenship-based approach, arguably more in keeping with other aspects of our lives (Figure 1).

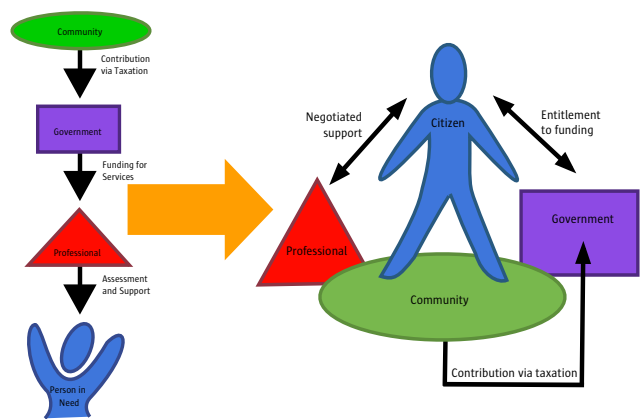


Figure 1. From Professional Gift to Citizenship Model

Central to this agenda to date has been the concept of direct payments (pioneered by disabled people's organisations and developing in the UK from the mid-1980s onwards) and individual budgets (developed from 2003 onwards by In Control). Beginning with 60 people in six local authority pilots in late 2003, there are now possibly 100,000 people receiving an individual budget and the government has stated that all adult social care will be delivered by this mechanism in future.

Although starting in adult social care, this approach is now being piloted in children's services and in health care, with several leading think tanks and commentators interested in its possible extension to other areas of state welfare (such as the tax and benefits system, housing, education, rehabilitation for ex-offenders, substance misuse services and support for young people not in education, employment or training). If privatisation was the key focus of the 1980s, it has been claimed, then personalisation could be the key focus of the early twenty-first century. Hardly surprisingly, such issues have acquired even greater relevance in the current financial and political context, with debates about reduced state expenditure and potential government shrinkage.

Despite recent progress, much more remains to be done, including:

- Fully embedding personalisation in the training of social workers and other public service practitioners and managers.
- Exploring the implications of self-directed support for broader areas of state welfare.
- Understanding key levers for embedding change in policy and practice.
- Understanding more fully the implications for cost-effective use of scarce resources in a challenging economic climate.
- Developing more explicit theoretical and conceptual frameworks around citizenship, ethics and social justice.

Against this background, this series of papers was first presented and discussed at a national ‘think tank’ funded by the University of Birmingham’s Advanced Social Sciences Collaborative (ASSC).

We invited real experts to explore the changes they think could bring about positive change in:

- Local government and civil society
- Services for children and families
- Our health and social care systems
- The criminal justice system
- The tax-benefit system

In turn these ideas were challenged and reviewed by an audience of leading policy makers, managers, practitioners, policy analysts and researchers. We are publishing these papers in their revised form.

Underpinning many current policy debates is a sense that the ethos, law and structures that underpin the current welfare state is dominated by 1940s thinking and assumptions – and that some of the concepts inherent in debates about personalisation and self-directed support could help to shape future welfare reform. The Beveridge Report is widely credited with establishing the thinking behind the post-war welfare state. It is time to engage in the same depth of thinking about the relationship between the state and the individual in the twenty-first century. We hope that these papers contribute some fresh thinking.

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Summary

This policy paper proposes that local and national leaders work with families and communities to create a Personalised Pathway for the care, support and education of disabled children and their families, that will enable children with the most significant disadvantages to get a fair start in life.

An Unfair Start

If we examine the current systems of welfare for disabled children we see the good intentions of all thwarted by the incoherence, opacity, rigidity and complexity of the current system.

What Families Need

If we examine what people really need then we see that this help must be personalised. This is not just about financial control, it is more about respecting the very fabric of family life - their strengths, relationships and communities - building on the family's Real Wealth. Families do not want to do everything for themselves - but they want real relationships which are based on trust and enable the best solutions for their particular needs.

Personalisation

Scattered across the country are a range of exciting and positive reforms all of which promote personalisation in care, education, health, transport and other services. But progress is slow, and patchy and has become unduly tied to different departmental priorities and perspectives. There is a danger of personalisation driving up bureaucracy and complexity.

Personalised Pathway

What families really need is a unified and coherent pathway to personalisation and the key elements of this pathway are:

- Family leadership
- Curriculum for citizenship
- Co-ordinated expert support
- Integrated individual budgets

Introduction

Disabled children and their families pose a particular challenge to those charged with developing a sustainable welfare system as their support needs are unlikely to reduce. Indeed, increased support is often needed as young people approach adulthood so that they can reduce their dependency on their parents and fulfil their potential as independent citizens.

Since the inception of the welfare state, efforts to support disabled children and their families have been rooted within a paternalistic culture encouraging dependency. When a chronic illness or impairment is first identified, families are told there will be professionals and services to support them. In the main those services take children out of their local communities and place control with professionals. Parents are given the message that the demands of impairment are so difficult, and so tragic, that their child needs specialist help that only exists in particular places (Mason, 2008). This works against helping families to cope with daily life and the development of economically viable solutions.

In spite of the plethora of policy and legislation attempting to improve the life chances of disabled children and adults over the past decade or so, and the many different models of support available, families continue to report poverty, exclusion *and* having to struggle for the education and support they need (DCSF, 2009). And disabled teenagers report an over reliance on their parents as they depend on them for their basic support needs as they grow into adulthood (Murray, 2002).

It is very encouraging that policy-makers have begun to focus on the benefits of personalisation for disabled children and families, but there needs to be a much greater understanding of

the potential that personalisation offers to transform family life, provide greater equity, and allow scarce resources to go further.

This paper explores ways through which personalisation can deliver its potential for the transformation of education and support.

1. Personalisation is focused on strengthening citizenship and gives families the autonomy to take control over their own lives.
2. Personalisation improves the current system of supporting families by the use of Self-Directed Support which provides them with the flexibility to shape the support they need and respond to the fluctuating demands of illness, impairment and family life.
3. Personalisation provides a framework for taking support for disabled families out of expensive safeguarding processes at the same time as providing comprehensive risk management.
4. Personalisation enables families to feel better about themselves and develop greater resilience and emotional well-being.
5. Personalisation offers children and young people the opportunity to make friends, try things out, follow their interests, develop self-confidence and self-esteem.
6. Finally, personalisation provides sustainable solutions by using existing resources more effectively, at the same time as creating opportunities for children and families to participate in their local communities.

In contrast to the rapid growth of personalisation in adult social care, progress with children and families has been slow (Crosby, 2010). Moreover the main public service for children - education - has largely been treated as outside the bounds of this particular policy innovation. And there are only a small number of personal health budgets for children as PCTs and strategic health authorities continue to explore ways of releasing money from block contracts and giving direct payments directly to families (DH, 2010).

Yet much more radical and positive change is possible. The recently published model of Personalised Transition describes a real, radical and systemic innovation - developed in Sheffield - where health, care and education budgets are put under the direction of the young person and their family (Cowen, 2010). This has led to improved outcomes and increased efficiency. This paper, written by one of the innovators behind the Personalised Transition model, extends the logic of Personalised Transition to ensure that disabled children and their families are in control of their care, support and education from birth into adulthood. This new model is called the Personalised Pathway.

An unfair start

The welfare state exists to ensure that those in most need get essential help. But in reality those who need the most help often seem to get the roughest treatment. Families whose children are born with significant impairments find that critical help is missing or organised in ways which are baffling and frustrating.

The problems families face are numerous. Although it is often health related issues that place the greatest strain on family life, for example frequent admissions to hospital, disturbed sleep patterns or unpredictable behaviour, these needs are diagnosed by health professionals and then handed over to social care professionals for assessment of the impact they have on families' lives.

Subsequent support is then linked, through legislation, to child protection and children in need processes. Social care is expected to deliver on the broader issues of family support through an opaque and subjective assessment system, where resources are only available when parents demonstrate that they are struggling and heading towards family breakdown.

Special education is mired in a long-running and irresolvable ideological conflict which does little to help young people grow into active citizens or to help families flourish. Families are told by professionals what is best for their child - despite any significant evidence base (Abbott, Morris and Ward, 2001). Some professionals say a special school is best; others say children should be in mainstream education - but families get no real choice.

In addition to this, the current system regularly fails to offer any meaningful education to disabled children. Sadly, it struggles to provide personalised education, or to respect the right of a family to guide their child's education. Some parents fight to have their children placed in specialist residential schools (often miles from home and with costs that are many, many times

higher than local resources); some families feel they have to make a choice between segregated or mainstream education (often with neither leading to the outcomes they desire); and some families feel forced to take their children out of formal education all together.

The outcomes of the present education system are undeniably poor for the majority of disabled children as so few leave school to go on to further education, into the workforce or to lead meaningful lives (Harris, 2008; CSCI, 2006; DH, 2009 a). Although parents in the last century fought long and hard for the right to have their disabled child educated, parents in this century are left asking the question, ‘What are we educating our children for?’

The problems in the current systems are many, but two problems stand out and demand particular attention:

- Complexity - how help is organised
- Eligibility - how people get help

Eligibility and safeguarding

For families who have a disabled child the most striking problem within the current system of children's services is that in order to get support they must enter systems whose primary focus has become 'safeguarding' children from abuse. In other words, when seeking help, parents can often find themselves treated more as potential child-abusers instead of loving parents needing a little extra help.

Moreover, it turns out that only those families who are deemed to be at the greatest risk of family breakdown are eligible for any support from social care. These strict criteria are all the more necessary because the predominant type of support on offer – residential respite care – is expensive and therefore has to be tightly rationed.

The impact of this present system puts families in the demoralising position of having to put the worst case scenario across in order to get a minimal amount of support – and even then there is no guarantee they will get the help they need:

We shouldn't have to be interrogated. I felt like I was begging for things. Our social worker told us we couldn't get services unless he was severely disabled. I wondered what could be worse than being blind, brain damaged, paralysed and going to die? We actually didn't get agreement for the support we had asked for until after his death.

Parent, 2009

This extreme example highlights the pressure the current system places on all families (Murray and Penman, 1996). Pulling families who simply want to take the best possible care of their children into systems focused on managing the risk of abuse creates unnecessary, time consuming and expensive processes that often have little benefit for those seeking support.

An argument often put against the development of personalisation in children's services is that professionals need to maintain a

degree of control over families in order to fulfil their safeguarding duties. Some professionals go so far as to argue that personalisation is at odds with safeguarding (Community Care, 2010).

The real risk for disabled families is that of parents buckling under the demands of daily life which include prolonged sleep deprivation, the unpredictable health of their child, demands on their time in meeting the needs of their child with an impairment, physically managing 2 or 3 young children including a disabled child, and the higher costs associated with bringing up a disabled child. The majority of families love their disabled child in the same way that they love their non-disabled child, they just need a bit more help to manage family life:

All we want is someone to take our son for a walk or to the park every now and then. It doesn't have to be far, it can be only round the corner but that'd give me a bit of time just to catch my breath and have a coffee. ...and an extra pair of hands around the house during the week but especially during school holidays so that we can all go out together.

Parent, 2009

Removing support for disabled children from the larger safeguarding agenda allows us to take a more pragmatic approach to meeting the needs of the families of disabled children. As families have differing needs and circumstances that are subject to constant change, personalisation is the key to providing them with the support they need.

Besides this, personalisation offers the opportunity to explore a fresh approach to risk management: an entitlement model gives families the opportunity to co-produce support that increases well-being and reduces risk factors in their lives; strengthening connections within local communities lessens isolation and loneliness; and finally, knowing the exact amount of their budget and deciding how the money should be spent encourages careful spending. Developments in this area will provide a direction of travel for the broader safeguarding agenda throughout children's services.

Complex systems

Paradoxically, while the care system is very tightly rationed there is in fact a plethora of disconnected, confused and confusing supports and systems for disabled children and their families - scattered across the welfare state. If you are lucky you may end up getting help from one or parts of this complex system, but many families are not that lucky.

There are at least six distinct systems that impact on the lives of disabled children and their families:

1. **Health Care** - provided by the NHS and subject to the Department of Health (DH)
2. **Benefits** - provided by the nationalised benefit system and subject to the Department for Work and Pensions (DWP)
3. **Tax and Tax Credits** - organised through the Inland Revenue and subject to the Treasury
4. **Education & Schooling** - organised through the local authority's education system, but subject to the Department for Education (DfE)
5. **Children's Social Care** - organised through the local authority's social care system for children, but subject to the Department for Education (DfE)
6. **Adult's Social Care** - organised through the local authority's social care system for adults, but subject to the Department of Health (DH)

This array of systems (see Figure 2) means that most families are confused about what they are entitled to and professionals struggle to keep abreast with accurate, timely and integrated information to aid effective support.



Figure 2. Complex Service Array for Disabled Children and Families

Few people in the entire system actually understand what people are entitled to and can ensure they get what they need. Instead families must move through the dark:

Fighting to manage their pride – having to ask for help, often from systems which seem to seek to stigmatise and treat ‘clients’ in an undignified way.

Trying to stay strong – not wanting to be exhausted by the constant battle to seek assessments, make claims, appeal or reclaim.

Trying to keep the faith – not wanting to give up on themselves or their child, trying to see the positive when the system demands they focus on the negative just to get modest levels of help.

If we were measuring the commitment of society to support disabled children and their families in terms of the range and complexity of the social provision that is potentially available, then we would conclude that disabled children were

highly valued. But our social commitment is vitiated and undermined by the organisation of this system:

There is no flexibility – services must be accepted as they are offered, they can seldom be tailored to better suit the needs of the child or the whole family.

There is no coherence – multiple systems offer different piecemeal supports, using different rationales and regulations.

There is no control – all the respect and dignity that families expect as they attempt to bring up their children as active citizens is undermined by the paternalism and suspicion that is written into the DNA of the current systems.

There is no meaningful legal or constitutional guarantee to support – although policy documents relating to disabled children and young people support citizenship, current systems disempower by encouraging dependency.

There is no transparency about cost – parents have no idea how much services cost and what gives best value.

Many families manage anyway, despite the complexity and lack of help. Many do not, and this is reflected in high-profile incidents like a parent killing themselves and their child or low profile phenomena, such as the high divorce rate for families with disabled children (Glen, 2007).

Social and economic impact

The social and economic cost of the current system is high. Taking children away from their families and out of their local communities leads to fractured relationships and isolation.

Disabled children are given the message that they are a burden to their families. They are not easily accepted as the individuals they are but rather given labels and categories that can make it difficult for them to be accepted, and can prevent them from easily belonging. They have to struggle hard to enjoy ordinariness and parents have to work hard to protect the bits of belonging that do happen. Brothers and sisters are given the message their disabled sibling is different from them and that they too are unfortunate.

Parents feel that making a decision about the support on offer places them between a rock and a hard place – giving them a night's sleep at the expense of not knowing exactly who is looking after their child or worrying about the emotional impact a night away is having on their child. In addition to this, residential respite care does not necessarily help with the daily demands of family life. And on top of this damage to families, communities are impoverished by the loss of their children.

Residential education and care are expensive financially as well as socially. Based on the number of children with a statement of Special Educational Needs and in receipt of Disability Living Allowance, there are estimated to be between 288,000 and 513,000 children with complex impairments and high support needs in England (Mooney, Owen and Statham, 2008). It has been estimated that it would cost £150 million for the families of the 100,000 most severely disabled children to have 20 nights' break a year (Bennett, 2007). This level of spending means that only 1 in 24 families of disabled children receive help through current systems.

Disabled children and their families should be at the heart of any decent system of welfare. Most people would think that the test for the very effectiveness of the welfare state would be how

these families are treated. Yet the reality is that families do not get a fair start, and things only seem to get worse with time.

Personalisation begins to provide an answer to these systemic problems. Personalisation means helping people to take control, build on their strengths and build lives of integrity and meaning. It challenges the tendency to provide fixed, narrow or damaging solutions; instead it proposes that solutions to need must be based on a family's strengths and capacities.

A fair start, for families with complex needs, is not a standardised solution. A fair start means a personalised solution - one that strengthens family life and enables active citizenship.

What families need

Since the inception of the *Quality Protects* programme at the end of the last century government has encouraged consultation with disabled children, young people and their families in order to develop support in line with their needs, interests and aspirations (Franklin and Sloper, 2009). Every major consultation with children and young people has come up with findings expressing their desire to have the opportunity to do the same things their non-disabled peers take for granted (The Children's Society, 2003).

The findings around the wishes of parents are more complex. Often families express a wish for traditional, segregated or high-cost solutions which may seem very different to the personalised supports that have proved most effective. This is perhaps inevitable as parents come from a variety of backgrounds, have a range of understandings around impairment and disablement and have different aspirations for their own lives and for their children. These differences lead parents to express different opinions about the type and amount of support they need in their lives, with the most significant debate being around the need for building-based services versus support to enable participation in universal services and community life.

At the point of their child's initial diagnosis parents are told they are not on their own as there are services to help them. They are not generally told they will have to meet restrictive and opaque eligibility criteria to access those services. Nor are they asked what *they* think might be helpful. Rather they are given the impression, at a point at which they are particularly vulnerable, that help is at

hand. As time goes on, parents find themselves facing the daily challenges of living with impairment in a disabling world: isolation, discrimination, complicated systems, insufficient information and a differential experience of family life. It can be hard for parents to negotiate their way through each day and any offer of support feels like a lifeline. Of course many continue to ask for traditional services – it is the only help they have been offered. And when the demands of family life become too much again, they feel they need more of the same because that is all they have known.

The perceived need for specialist services is reinforced by the difficulties disabled children have in accessing mainstream clubs and activities. In addition to this, even if children can physically access a setting, support around relational aspects of bringing disabled and non-disabled children together is often completely missing (Douch, 2006). It seems like the only thing that could ever work is a service designed exclusively for disabled children – even if that denies the relational needs of children.

When we delve a bit deeper however, and ask parents to look beyond what is on offer, most say they need flexible, high quality support that gives their child a positive experience, makes them happy, and supports family life:

I wouldn't want Jacob to be away for great periods of time, and I wouldn't want great blocks of care time allocated to us. What I'd really like is just a few hours every day, especially during summer holidays, where someone could take Jacob out, even if it's only to the park round the corner. This regular time off would give me the space to get on with other things in the house, to have some time for myself or maybe to relax for a bit. If I knew they were regular, I would really look forward to them. It would be really good sometimes to have an extra pair of hands around the house during the week but especially during school holidays so that we can all go out together. If I have all three children on my own it gets a bit too much for one person.

Parent, 2009

Parents frequently tell of the difficulties they face as the result of support that focuses only on the needs of their disabled child and

ignores the needs of their non-disabled children. Indeed, parents with more than one disabled child describe how this individual approach leaves them with support that causes them logistical problems as each child is looked at separately rather than within the context of the family as a whole (Beresford, Rabiee and Sloper, 2007).

The underlying reason for the requests for building-based services is then a result of the lack of understanding, resourcing and quality support shaped to meet the individual needs of families within their communities. Something is better than nothing:

Both children had one weekend a month at the respite centre. Anthony would go one weekend but they couldn't take Emily. She would go the next weekend. We had asked for respite so that we could have an evening together and a good night's sleep every now and again. But the way it worked out we never got that and the children missed each other. It is a catch 22 situation. We would prefer not to use respite, but we need it as a family.

Parent, 2009

Personalisation provides an opportunity for coming up with creative solutions to such long entrenched problems (Cowen, 2010). Families benefitting from a personalised approach tell us they are delighted with outcomes giving them (Murray, 2009):

- choice and flexibility for the whole family
- a voice
- a sense of being valued
- a positive view of their disabled child
- opportunities to make connections within their communities
- opportunities for children and young people to make friends
- simple solutions
- adult time with their partner

- opportunities to carry on or return to work
- ability to respond to the fluctuating needs of illness and impairment
- transparency and greater understanding of what services and support costs
- time with their other children
- opportunities for children to develop self-confidence and self-esteem
- opportunities to try things out to see what works best
- control over how the money allocated to them is spent

In other words, what families need can only be properly understood and defined by each individual family. Families do not need pre-defined solutions imposed upon them. However we can already see two important themes arising from the kinds of solutions families generate for themselves:

- Real Wealth - families build solutions around their own strengths and other assets in order to sustain their own resilience.
- Relationships - families want to connect to others, to other families and to professionals, in order to get the strength and value that comes through different connections and experiences.

Real wealth

Supporting children, young people and their families to feel better about themselves, and therefore stronger, is key to the development of a model that genuinely empowers individuals and ultimately builds communities.

In the following diagram (Figure 3) we identify five broad categories, each of which is essential to our ability to lead a life that holds meaning and allows us to be productive. Paying attention to each of these elements focuses energy and attention on all aspects of family life, and therefore helps families develop their own strategies for coping (Duffy, 2010).



Figure 3. Real Wealth Model

Relationships

Families can only thrive if they are connected to, valued by and have a sense of belonging within their local communities. The ability to bond and connect with others starts at the basic level of a loving relationship between parents and their child.

At present the messages parents receive at the point of their child's diagnosis and in subsequent dealings with professionals threatens that natural loving bond (Mason, 2008). We need to find ways to help parents trust their instinctive love for their child and build confidence in their parenting ability. When parents feel good about their child and their role as a parent they are more likely to make positive connections within their communities.

Access

In order to make connections and develop relationships, children and families need to be able to feel they belong in their communities. They need to be able to access community activities and buildings; they need information that is welcoming and inclusive. Agencies have to understand the different aspects to access, for example physical, sensory, social and psychological, in order to appreciate the need for flexibility created by individual access needs. And it is not just about access to buildings, but more importantly access to relationships, opportunities and a wide human experience.

Unfortunately, it is still commonplace for disabled children to experience difficulties in accessing activities and experiences their non-disabled peers take for granted (Murray, 2004). This has a knock on effect on their opportunities to make friends and develop natural support systems. The isolation they experience has a negative effect on their self-esteem and emotional well-being.

Strengths

In order to make the most of our lives we need opportunities to develop our natural strengths, interests and talents. As we support connections and develop greater opportunities for taking part, we will help people who have not had the opportunity to get to know disabled children realise how much these children have to offer. Our culture places such an emphasis on the value of 'doing' that we often lose sight of the benefits we bring to each other through our very existence – our 'being'. Our existence gives us a presence, and the value of that presence does not vary

according to whether or not we have an impairment. We are all of equal value.

Sadly, it is still too often assumed that disabled children have little to offer. Consequently, they are denied opportunities to develop interests. Often their natural interests and passions are misunderstood or unrecognised. We have to develop a wider understanding of the universal truth that impairment does not make us 'less than' and we all have much to offer each other.

Control

When we are denied the possibility of shaping our own lives, we lose opportunities to develop our autonomy. This makes us vulnerable and puts us at risk of being abused by others. Personalisation challenges us to find ways to trust each other enough so that we allow those we are in relationship with to find their own way through life, make their own decisions and learn about the consequences. We need to value the bodily expressions of children with the most complex impairments, in the same way that we value speech and language, so that we give them opportunities to shape their lives according to their likes and dislikes. Without this basic control, they cannot learn about or exercise their inherent citizenship.

We continue to live in a world that gives parents the message that experts know best and fails to appreciate the communication of children who do not use speech or language to express themselves. Parents struggle to get communication aids for their children, and children's natural modes of expressing preference go largely unacknowledged as a valid system for building autonomy and giving control.

Resilience

Our experience of these four elements affecting our outer lives impacts on our inner strength and natural resilience. The events that happen to us, and the way others treat us plays a part in weakening or strengthening our inner spirit. And it is this inner spirit that ultimately shapes our ability to take responsibility for the way we respond to life. When we give care and attention to this inner dimension – our own and other people's – we create

an environment conducive to our personal and collective positive growth. Cultivating this environment, which we all contribute to and take from, allows us to claim the right of citizenship and embrace the accompanying responsibilities.

This Real Wealth model, developed by the author together with Nic Crosby and Simon Duffy, is included here as a reminder that in order to build a fairer society we must attend to the real factors that underpin the quality of people's lives. Money helps strengthen our capacity for control, but we must develop a broader picture of how support effects each aspect of our Real Wealth. This will help us move towards sustainable solutions and helps us understand the appropriate context for a Personalised Pathway for disabled children and their families.

A relational approach

It is a universal truth that we are more open, receptive and trusting when others value and appreciate us. This is the same whether we are relating to family, friends, colleagues or acquaintances. It is all too easy for this simple fact to be forgotten, and it seems particularly difficult to maintain within larger organisations with complex systems. The success of personalisation depends on professionals from all agencies finding new ways of relating to those they are being paid to help.

Early learning from local authorities offering individual budgets is that the new process shines a light upon the high degree of complexity, duplication and lack of transparency within current processes, systems and services (Murray, 2008). Early evidence from families indicates a high level of satisfaction with the outcomes afforded by an individual budget, but a low level of satisfaction with the process:

...this is meant to be about choice and control. And yet all along the way the process has been full of contradiction. They keep telling me different things, they don't keep their promises, they don't turn up on time, they don't believe me when I tell them what my son is like and the kind of help we need, they tell me what I can and cannot spend the money on. We will keep going because the end result will be positive – it is the only way for our family, but I can't help thinking the process should have a different quality to it.

Parent, 2009

Disabled children and their families report that effective support depends not so much on the model being offered, but rather on the quality of the support relationship (Murray and Penman, 1996). The lack of trust experienced by the above parent points to a central issue in the development of a Personalisation Pathway: the need to build a new type of relationship between families and professionals. This relationship has to embody the

ethos and principles of personalisation: an appreciation of equality of being that gives rise to a code of ethics that is manifested in the way we treat each other.

Experience to date shows the positive effect that a focus on building relationships has to the success of a personalised approach. Budget-Holding Lead Professionals (BHLP) have stressed that the success of their role lies in the positive relationship they develop with children and families (Office of Public Management, 2008). Placing the support offered – money, access to universal and specialist services, developing community networks etc – in the context of a relational model is therefore a pre-requisite for the development of a Personalisation Pathway.

The quality of relationship within a relational model is characterised by the understanding that we are all of equal value. As soon as we recognise others as being of equal value to ourselves we enter into relationships of respect and empathy that are able to transcend differences such as gender, impairment, ethnicity, background and age. And this allows for a very different relationship to emerge between professionals and families:

The truth is we do need you, not to be 'experts' or managers of our lives, but to be friends, enablers and receivers of our 'gifts' to you. We need you to admit cheerfully that you don't know, without shame; to ask us what we need before providing it, to lend us your physical strength when appropriate, to allow us to teach you necessary skills; to champion our rights, to remove barriers previously set in place, to return to us any power you may have had over our lives. We may also need you to remind us of our importance to the world, and to each other, at times of tiredness and discouragement. We can live without patronage, pity and sentimentality, but we cannot live without closeness, respect and co-operation from other people. Above all we need you to refuse to accept any 'segregation' of one group of humans from another as anything else but an unacceptable loss for all concerned.

Micheline Mason, Disability Activist & Academic (Mason and Reiser, 1990)

Research into different therapeutic processes show that a relational model is what makes things work (Holmes, Paul and Pelham, 1996). A relational perspective understands that the relationship, as opposed to any task or system, is central to the work. A relational model can underpin any theory or way of working. There is no room within a relational model for one person to do something to another, as that would be a deviation from the central principle that the relationship is co-created. This co-created relationship then becomes the driver for any solutions or actions (Haugh and Paul, 2008).

The recently published Occupational Standards of the UK Council for Psychotherapy place relationship at the centre of the therapeutic process, and emphasise the need for therapists to develop competencies in establishing and maintaining relationship:

Psychotherapeutic counselling has an emphasis on the co-creation of an in-depth therapeutic relationship where human beings are viewed holistically – body, mind and soul – and in the context of a concrete life situation and developmental stage. ...The development of competencies in establishing and maintaining the psychotherapeutic counselling relationship is the central factor in the work.

(UK Council for Psychotherapy, 2010)

The impact of difficult life experiences – such as living with impairment in a disabling world – can be very distressing. The diversity involved in terms of families' health and social care needs, their personal and social circumstances and their perceptions of what might feel helpful in response to their practical challenges and emotional distress is extremely varied. In addition to this, the cultural diversity of families demands an openness to working with issues of difference in relation to clients' lived experience, systems of meaning and beliefs and values.

Social care for children and their families is about establishing a truly personal relationship between worker and family. It requires each worker to sit down with each family without any preconceptions about 'families in their circumstances' or 'very good services' for children with a particular diagnosis. The worker needs to see him or herself as a contributor on equal terms, a co-producer with knowledge and skills to share.

Commissioning Project Manager and Aiming High Lead Gloucestershire County Council (Crosby, 2010)

When professionals and families co-create support, families are more likely to make considered choices and consequently experience a more resilient, integrated sense of self. A relational model therefore, offers an alternative way of working that results in families empowering themselves and breaking the current cycle of dependency. As we show in Figure 4 below, when a relational model is used to underpin personalisation families are supported to take the lead, make decisions and co-produce the support best suited to their particular circumstances.

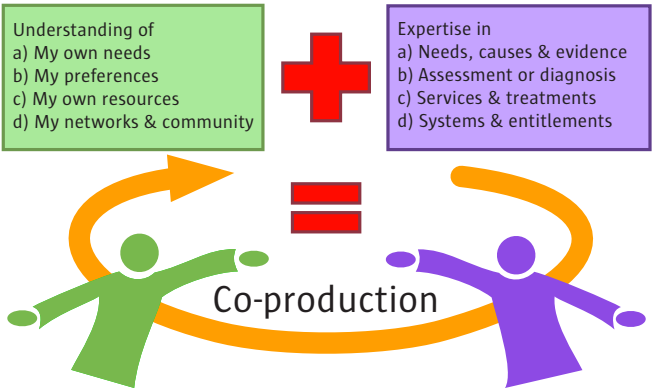


Figure 4. Co-production

Personalisation

Personalisation of family support is still in its infancy, but individual budgets are fast becoming popular. There are currently over 500 children and young people (aged 3 to 17) with an individual budgets from children's social care departments and these figures increase if we add the number of those using individual budgets when they leave school and those families whose funds are managed by a budget-holding lead professional (In Control, 2010).

Some families use their individual budget to buy services provided by the local authority alongside privately arranged services or activities in their local community; others opt for employing an extra pair of hands to help out within the family or a personal assistant for their child. Embracing the control offered through an individual budget allows families to flourish:

Having an individual budget has affected the whole family. We have had a summer like no other - we are a lot less stressed out and we have a much healthier relationship with each other. All our children are happy. They are allowed to be just kids who are having fun together.

Parent (Murray, 2009)

A growing body of evidence from young people and families indicates that individual budgets have the potential to dramatically transform the relationship between families and the state (Crosby, 2010). Rather than families having little choice or control of the support on offer, individual budgets provide an important technology for giving young people and families greater control of, and responsibility for their lives. As the number of families

benefitting from an individual budget increases it is becoming evident that they hold the potential to meet a basic demand of social justice - they allow children and young people to have the same opportunities that are available to their non-disabled peers.

However many of the targeted services on which children and their families draw, for example health, education, housing, transport, employment and leisure, are provided outside of children's social care services and therefore lie outside of the present funding for individual budgets. Personalisation may be happening to some degree in some of these areas but is currently limited by rules and processes that are system-centred rather than person-centred. In the next section we look at ways in which a Personalisation Pathway could be developed through the introduction of individual budgets in education, health, transport and housing.

Personalisation in education

The development of personalisation in education has, in the main, developed separately from the notion of self-directed support in social care and health. Broadly speaking, personalisation in education is understood to mean that students should have curriculum choice and a choice of specialism; and the school day and lessons should be organised to enable this. However at the same time there is a contradictory focus on assessment for learning and target-setting; and those targets are determined nationally.

Having an individual budget through education funding is not an entirely new concept. In 2006 a pilot project in Essex and South Yorkshire, developed by Mencap and the Learning and Skills Council, trialled a small number of individual budgets using Learning and Skills Council funding for young people who would previously have left school and gone onto a residential college.

The initial pilot was so successful that the work has continued in both Essex and Sheffield and is transforming outcomes for young people as they leave school:

The immediate benefits of Personalised Transition have primarily been found in the improved outcomes for young people and their families and better systems of communication and planning with and between professionals.

...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 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, ‘It’s all about control – if we don’t like something we change it’.

(Cowan, 2010)

Discussions within pilot sites funded by the Department for Education revealed a will to include particular forms of education funding as an individual budget. These included the Extended Schools, Sure Start and Children’s Centre budgets, which could all be used to meet the current demand from families with disabled children for intensive childcare support (SQW, 2008).

In addition to this a special school in Devon has embarked on a system of vouchers for therapies for children and families in Key Stages 3 and 4, as well as giving each Year 14 student a modest sum of money in their final year to use as they choose to enable them to make a successful transition from school to adult life:

It has been a natural extension of our work to include an aspect of resource allocation at some point in a young person’s school life. The resource allocation is linked to decision making in Key Stages 3 and 4 where students are asked to make direct choices about their timetable. In preparation for a real understanding of choice and empowerment, students can opt to try new things or participate in favourite activities. From 2011 every young person in their final year of school will have a modest budget of £1000 to support their transition action plan. This will allow them to purchase the sort of opportunities that will help them realise their aspirations for adulthood.

Headteacher, 2010 (Murray and Warne, forthcoming)

The biggest challenge, but also the biggest policy opportunity, would be to give families with disabled children a budget for their educational needs from the earliest age possible. There seems to be no reason in principle why a 'Statement of Special Educational Need (SEN)' could not be linked directly to a fair and reasonable budget.

One of the many benefits of this approach is to end the ideological warfare over the status of special and mainstream education and, instead, to bring families themselves into the centre of developing genuinely personalised education solutions - solutions that will often include elements of specialist input and mainstream access. Like all individual budgets, such budgets would remain subject to public rules and agreement with the state. Such a model would drive both personalisation and innovation by enabling educational resources to be used in much more flexible and imaginative ways (see Figure 5).

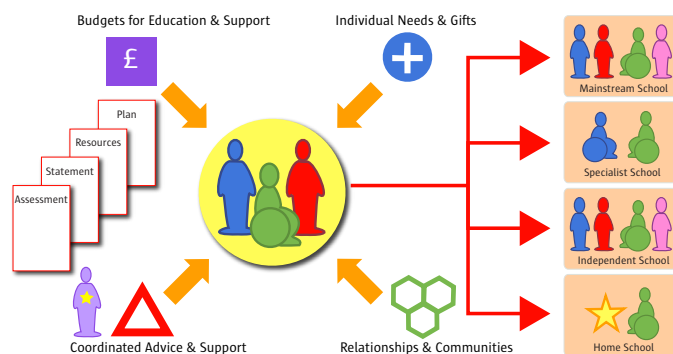


Figure 5. Individual Education Budget

Furthermore this will demand that professionals focus on the child and family in the context of the rest of their whole life. For a Statement of SEN provides entitlements not just to education but to health therapies such as physiotherapy and speech and language therapy; and to transport to and from school. Individual budgets attached to a statement therefore, bring with it the need to explore individual budgets for health and transport.

Pulling education into the centre of systems supporting disabled families is central to the development of the Personalised

Pathway we outline later in this paper. Teaching children they are of value and have a place in society, giving them the skills and confidence they need to direct their lives, control their support and become tomorrow's leaders is clearly a key educational objective. As we show in Figure 5, education needs to be at the centre of family support if we are to make the best use of resources available, empower children to fulfil their potential and take responsibility for their lives.

Personalisation in employment

A common preoccupation of childhood, encouraged by parents and schools alike, is supporting children to think about what they will do when they grow up. Conversations about wanting to be a spaceman, an explorer, a princess or a gardener, the starting point of any career pathway, are simply unlikely to take place between adults and disabled children:

People just don't know what to say when Elsa (my daughter who has a learning disability) tells them she wants to be a nurse and work with poorly children.

Parent, 2010 (www.aspirationsforlife.org)

At present few disabled young people move from school or college to paid employment, and opportunities for voluntary work that might provide a stepping stone from education to employment are limited (DH, 2009 b).

The notion of an adult life that includes employment, if it comes at all, is introduced in the early teenage years in formal settings such as transition reviews, by which time disabled young people and their families have assimilated the message that work, employment or a career is highly unlikely. This works against the notion of citizenship and actively forces young people into a relationship of dependency on the state.

Such low expectations are reinforced by our special education system which does not provide opportunities for students with learning difficulties to take exams or gain qualifications other than ASDAN. Other young disabled people, particularly those with communication impairments, also find their life chances limited by the education system (Biklen et al, 2005).

In addition to such negative attitudes, the benefits system acts as a barrier to disabled young people taking up work: anyone working over 16 hours a week is automatically disqualified from

core benefits including income support, incapacity benefit, housing benefit and council tax benefit.

There is a need for schools to take a lead role in raising aspirations and educating disabled children to take their place in the workforce. An individual budget, available to young people aged 16 and over, helps them to gain practical experience in real work environments. Some schools are breaking new ground in this area. Exciting innovations include:

- giving all Year 14 students a modest individual budget to use to support learning and work experience
- personalising work experience placements to fit the interests and aspirations of individual young people
- working with local employers (including local authorities) to provide work opportunities for their students

The Living and Learning for Work Framework developed by the recently formed Young People's Learning Agency provides a tool to bring together a variety of funding streams contributing towards an individual budget to support work related activities. An exploration of monies available as an individual budget through Access to Work, Job Centre Plus etc would further support disabled young people take their place in the workforce.

Developing this work opens up the possibility of providing young disabled people an alternative to an adult life where they have no option but to be dependent on benefits. Not only is this a positive move financially, it also provides the opportunity for young disabled people to take up an aspect of citizenship so often denied to them to develop their interests, discover new talents, meet new people, strengthen their presence in local communities and feel better about themselves.

Personalisation in health

There are now several examples where NHS funding is being managed flexibly, through an individual budget, to deliver improved and personalised health outcomes. However the cultural and systemic obstacles to personalisation in health care remain formidable. Improved progress in this area would allow families to buy support they identify as helpful with respect to health and therapy needs, and specialist equipment.

Indeed, a small number of individual budgets using health funding have recently been implemented in one local authority and a small number of Primary Care Trusts are testing personal health budgets for children with complex health conditions (DCSF, 2010).

Making individual budgets available to families to meet health needs at an early stage in their child's life would go a long way towards moving away from a dependency culture. The first point of contact with professionals related to their child's impairment is often a children's development centre attached to the local hospital. Although the initial medical assessment is multi-disciplinary it is dominated by a medical perspective that can place more focus on the impairment, and related medical conditions, instead of its wider social impact and the practical and emotional help that families need. Parents commonly report that this experience gives them the sensation of losing the essence of their child to a diagnosis and prognosis. That experience will inevitably be coloured by the attitude of those leading the assessment.

Introducing the notion of an individual budget at the point of initial assessment could give families a much greater sense of autonomy and the opportunity, from the beginning, of shaping support to meet their needs and lifestyle. It would also help parents hold onto the distinct identity of their son or daughter and make them less likely to absorb the negativity associated with generic labels used to describe particular conditions.

For example, Hull City Council have worked with seven families (children aged 3 – 17) to deliver an individual budget

through health funding. All families are delighted with the outcomes they have achieved as a result, because they are finding the support they purchase is giving them some room to breathe.

Parents tell us that the simplest solutions are proving to be the most effective:

We pay someone £25 a fortnight to do all our ironing. I can't tell you what a difference that makes. We use the rest of our budget for childcare, but I think it is that ironing money that has the greatest impact on our life. Now we can go out together as a family at the weekend. We go on bike rides and we laugh and play together. It is the best thing!

Parent, 2010

The difficulties encountered with engaging health colleagues in the delivery of individual budgets has led some local authority workers to use their own funding to achieve health-related outcomes. For example, one family has two children under five. The eldest child had a tracheostomy fitted as a baby and needed additional support to attend the same nursery as his little sister. A modest individual budget allowed this to happen. As the boy grew his health improved and his tracheostomy was removed. Recently social care have given the family a reduced individual budget to cover his present needs and it looks likely that the little boy will not need additional funding in the future.

The individual budget meant that, throughout this traumatic period in the family's life, the little boy has remained connected to his sister and his local community. The family have been supported by their children's nursery and other parents in their neighbourhood. And staff at the nursery learned they can include and support a child with complex health needs. This success story is giving professionals in the local authority a lever to explore the idea of health budgets with their colleagues in the NHS.

Personalisation in transport

The majority of children going to special schools receive free transport to and from school. This is usually organised centrally, it is organisationally highly complex and involves long bus journeys. Families are often unhappy about the length of time their child spends travelling to and from school and report frustration about the lack of flexibility in the system. For example, if a child wants to go from a special school to an after-school club or a sporting activity in their local community this is impossible to arrange through the centralised system. This lack of flexibility has a major impact on the lives of families – disabled children are more isolated, and parents have to be at home for whenever the taxi drops their child off:

It is difficult to express in words the impact inflexible transport places on our family. It's not just my ability to work, or my disabled son's ability to do things after school, but it also impacts on my daughter's life. I have to find people to take her to her after school activities because I have to be at home at a certain time for Joseph. She is always telling me that she wants me to take her places, but I just can't. And it is the same in the morning – by the time Joseph's bus comes it is too late for me to get Amber to school. She can't be late every day, so I have to ask my friend to take her. It makes me sad that I can't take her into her classroom and settle her in. She is only five.

Parent, 2010

And children as young as three are expected to go on special transport without introduction to the driver or escort. As many of these children have communication impairments this arrangement puts them at risk. In short, current transport arrangements present significant barriers to a child's emotional and physical well-being.

Moreover, the rigidity in current systems can make for gross inefficiencies. For example, a young woman was recently given an individual budget to allow her to shape her life as she moves

into adulthood. Her family were told that £18,000 of her budget must be spent on the authority's own transport solution. This seemed a very high amount to her parents who investigated alternatives. They found they could address all their daughter's transport needs for half the amount. The local authority were reluctant to allow the changes to happen in spite of the cost savings and the fact that the young woman would be safer, as she would be travelling with one of her own personal assistants as opposed to an escort she doesn't know. Negotiations between the family and the local authority are still underway.

In 2004 the Department for Education and CAPITA investigated SEN transport costs in a representative 20% sample of local authorities in England (DFES and CAPITA, 2004). Few of the local authorities held detailed information about costs and no relationship between statements and overall costs could be identified. The report states that the local authorities which delegated resources, and therefore created the possibility of greater flexibility, did not spend more than those that did not. In addition to this the report concluded savings could be made by assisting many young people to travel more independently.

There is a clear need for local authorities to take a detailed look at transport costs, systems and outcomes. Individual travel budgets would go a long way to supporting independence, choice and well-being at the same time as reducing costs.

Personalisation in housing

As with transport, giving families control over the spending of a Disabled Facilities Grant (DFG) offers the potential for major improvements in their lives. Although grants are awarded in consultation with families, plans are frequently made that do not allow for the needs of the whole family.

For example, a family were recently awarded the maximum of £30,000 to make adaptations to their home. Unfortunately their terraced house was not easy to adapt and, after many consultations with occupational therapists and architects, the recommended solution was for them to adapt the front room into a bedroom and bathroom for their disabled child.

This would have left the family without a front room and the disabled child sleeping on a different level to her family:

I wasn't happy with the practicalities of living without a front room. But perhaps we could have coped with that. However the final straw was their response when I told them I had to be on the same level as my daughter as her seizures are so frequent and life threatening. They told me I could sleep on the floor in her bedroom!

Parent, 2008

The family investigated alternatives and discovered they could move to a bungalow with the number of rooms they required. The difference between the cost of the bungalow and their terraced house was £30,000. However, restrictions on the spending of the DFG meant they were unable to use their allocation for this purpose.

The rigidity of the system means a great deal of stress for the families concerned. In the example above, the family offered a reasonable solution that would have cost no more than the preferred option of the local authority. Freeing the money up for use as an individual budget would have facilitated a straightforward solution.

Beyond individual budgets

Personalisation is not just about agencies giving money to families. This is an important aspect of personalisation, but a broader approach can lead to further improvements in outcomes and greater sustainability.

The Budget-Holding Lead Professional (BHLP) pilots for children with additional needs, supported by the Office of Public Management (OPM), ran from June 2006 – March 2008. The BHLPs worked with children who had additional needs. They were required to work with the individual children and their families to identify their needs against the five outcomes of Every Child Matters, develop and agree an action plan and then secure the services that the children and families identified as most likely to help them meet their needs. As part of the support process BHLPs were provided with budgets of up to £3,000 per child to be used to buy personalised support that was not available through the currently provided or contracted services. In 2007 the BHLP approach was extended to work with children and young people who were looked after or on the ‘edge of care’ (OPM, 2008).

Gloucestershire County Council has moved from this starting point to develop the role of a budget-holding community lead professional to support disabled families. The lead professionals work with families to complete a Common Assessment Framework (CAF) and to signpost to suitable activities within local communities. Holding a small budget for each family to use if needed, allows them to offer an immediate, flexible response. Families report great satisfaction with this way of working and senior managers acknowledge the approach provides a more sustainable way of working as fewer families are referred to social services, leaving social workers to provide more intensive support for those who need it.

Gloucestershire County Council has developed an innovative new programme of short break provision to run alongside this work. ‘Of course we can!’ is based on the ideas of disabled adults and young people and offers opportunities for *all* children and

young people to come together to try out new activities and learn new skills. The overwhelming success of the initial pilot has inspired senior managers to continue to develop the programme in ways which support the mainstream voluntary sector to develop confidence and expertise in working with disabled children and their families.

As reported in the initial evaluation report and accompanying DVD, the result is a win-win situation for young people, parents, siblings, providers, and professionals in the statutory and voluntary sector (Of course we can, 2010). With respect to individual budgets both parents and professionals report that, with the increase of providers in the market, there is more to spend individual budgets on and therefore outcomes of having an individual budget have been dramatically improved.

In addition to an individual health budget, the Health Act 1999 Partnership Arrangements allow for health services to release monies for:

- Lead commissioning
- Integrated provision
- Pooled budgets

Pooled budgets and integrated funding provides flexibility for funds to flow where they are most needed, in order to provide a personalised service. There is already evidence to show that this flexibility can lead to a shift away from high intensity specialist care to lower level, preventative services (DH, 2005, p.49). A key criterion is that any payment is likely to secure a more effective use of public funds than the deployment of an equivalent amount on the provision of the grant giving partner's services (DH, 2006).

However this flexibility has not been fully exploited by local authorities. In a scoping report for the Departement for Education SQW looked specifically at the integration or alignment of health budgets within individual budgets and concluded that little progress appears to have been made in this area (SQW, 2008).

All these examples give a glimmer of the opportunity personalisation offers: to provide the means to develop links between family and community, recognise the contribution disabled children can make to their communities and develop opportunities for learning new skills. When those aspects are addressed personalisation becomes a means of fostering inner strength and emotional well-being. As we develop inner strength we find greater confidence to come up with our own solutions to the difficulties we face.

Yet the goal of achieving personalisation for disabled children and families seems to be a very long way off. In particular the development of personalisation seems to reflect, rather than resolve, the very complexity and incoherence that bedevils services for children and families. Many families are finding that they are having to grapple with complexities and bureaucratic barriers that are simply side-effects of the departmentalised nature of public services. It is time for a more sensible approach; we do not just need personalised solutions we need a Personalised Pathway - supporting families and young people to be in control at every step along that path.

Personalised Pathway

Real progress on personalisation for children and families will only come if the whole system is radically redesigned to promote personalisation from birth. It is time to end the confused departmentalisation of need and service and instead to offer people a Personalised Pathway with the following 4 key elements:

1. Family leadership - the systems need to respect and support the leadership of families at every stage.
2. Curriculum for citizenship - people do need support and additional expertise, but this support should be focused on helping the young person achieve active citizenship.
3. Co-ordinated expert support - people do need a partnership with the state and this is usually best managed through one clearly identified individual working within an appropriate organisation.
4. Integrated individual budgets - most additional support and funding could be integrated in one individual budget that can be managed by the family or a trusted professional or representative.

As we show in Figure 6 below, no one organisation is currently providing a full Personalised Pathway, but it is possible to extrapolate from the successful model from Sheffield described in *Personalised Transition* (Cowen, 2010) in order to identify the key ingredients to this approach.

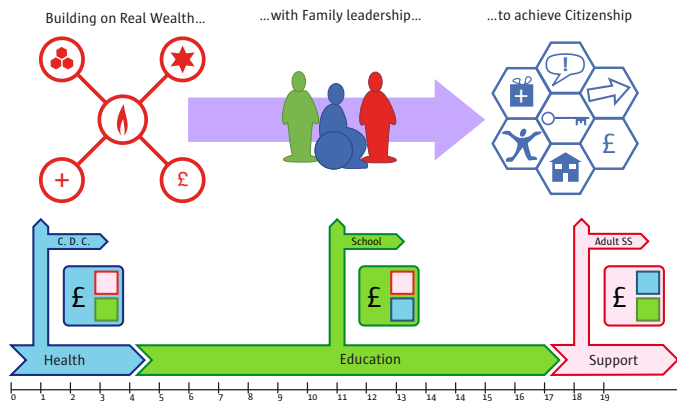


Figure 6. Personalised Pathway

1. Family leadership

All families should have the authority to plan and lead their own support and shape the way things work locally.

This capacity should be assumed and supported. At the initial point of contact parents will be:

- Put in touch with other families – all parents bringing their child to the Development Centre will have opportunities to meet other parents prior to their initial appointment.
- Given information about systems and the range of available support and services. Once parents have enough information to understand the world they are entering into they can influence, demand and offer constructive criticism with confidence. They will be empowered to put their own views forward, regardless of the availability of activities, support or services. Those views will be taken into account as plans are made for their child.

2. Curriculum for citizenship

When children reach school age the school should become the natural hub for providing support and education to the child and their family. The school will takeover from the Development

Centre the role of co-ordinating any additional external expertise. Developing a curriculum for citizenship helps schools realize their role as a valuable resource to support the student's preparation for life as a citizen.

In addition, personalised learning programmes in schools should:

- Enable *all* children and young people to communicate what is important to them. This fulfils the fundamental human right of having a voice, and allows staff to focus on the voice of each student, whatever their means of communication. This careful listening provides *the* starting point for developing a wide, creative curriculum with a focus on communication and skills.
- Develop person centred approaches throughout the school and this will include person centred reviews for all students (ensuring health issues are included), home school agreements, communication charts.
- Provide a skills based curriculum giving students opportunities to make choices and (where appropriate) decisions. All students with a Statement of Educational Need should have an identified budget with which to buy the education and resources that best suits their needs.

3. Co-ordinated expert support

Families should get the right support, at the right time, with professional leadership and co-ordination provided by one lead agency at any time - Children's Development Centres and Schools will become vital points of focus for professional support.

The initial multi-agency assessment will act as a critical point for:

- Informing parents about their entitlements - working out any individual budget through health; and preparing the way for an individual budget connected to the child's eventual Statement of Educational Needs.

- Completing the Common Assessment Framework – this will be linked to a modest budget held by community lead professionals or key workers. Families will be signposted, as appropriate, to specialist services *and* resources in their local communities.
- Giving parents information about community resources and relevant voluntary agencies.

4. Integrated individual budgets

All families should have a clear entitlement to an individual budget which combines funding for support, education and the management of long-term health conditions.

The Pathway should ensure that:

- Entitlements are transparent with clear eligibility and resource allocation systems for the different funding streams (eventually these systems will marry, with families having one assessment form that covers health, education and support).
- Families are informed of their budget at an early stage in the process so that they can take time and care with planning.
- Professionals supporting individual families will take the lead on streamlining particular areas of support needed from other agencies – e.g. housing, transport.

If we extend these principles we have a Personalised Pathway from birth to death. Our policy proposal is that the 223,600 disabled children with complex health needs and those currently entitled to a Statement of Special Educational Need (DCSF, 2008) will be supported on this Pathway.

With these four elements in place, the Pathway can lead to:

Improved outcomes for children and families – Families will be able to shape the particular help they need to give their child the care and support most appropriate to

their individual needs and their family life. Personalised education, assisted by a Portable Education Budget, will equip children for effective citizenship in adult life.

A stronger voice for parents – Families will be enabled to organize the additional support they need to help their family flourish. Children and families will be at the heart of planning for their support and developing the Pathway in their local area.

A greater focus on children's needs – Timely, accurate, positive assessments and regular reviews linked to personal budgets will lead directly to desired outcomes.

Systems will become simpler, more efficient and more accountable – Entitlements and administrative systems can be streamlined and simplified, and professional expertise better focused. Entitlements, expressed as individual budgets in health, education and support, will be transparent.

The development of a more strategic local approach – Health, education and social care agencies will work closely together taking account of each other's role and responsibilities in the light of the entitlements, needs and requirements of children and families, and in the context of plans for all children and families.

Moreover this policy can be put into practice now, because it is:

- **Effective** - increased personalisation of education, support and health care will drive up standards and better enable families to get the right support for their disabled child. Children and families will be able to get the support they need, at the time they need it.
- **Feasible** - education, health and social care are already funded in ways which allow for individual funding and portability and only minor technical changes in local policy are required to operationalise this system and much of the necessary changes have already been piloted. Local agencies, such as Children's Development Centres, Children's Centres and schools will realize their roles as

valuable resources to support all aspects of family life.

- **Affordable** - it will cost the system no more, it will make better use of existing resources and it may even reduce some costs (particularly the demand for expensive residential schools).

However to drive this policy forward we will need to see local and national leaders move on from narrow, departmental perspectives. We will need to see leaders emerge who are willing to champion the family and the young person and understand that the needs of the family come before the needs of the system.

Conclusion

The inability of current services – health, education and support - to make a sustained difference to the lives of disabled children and their families results in distress and inequality. Parents are looking for straightforward solutions to the difficulties and pressures they face: an extra pair of hands, a night's sleep, and flexibility to use support when they need it most. Disabled children want opportunities for friendship and fun; their brothers and sisters want to hang out with their friends and have quality family time. The Personalised Pathway outlined in this paper provides the opportunity for all these things to happen in a simple, straightforward way that has the scope to transform family life, provide greater equity, and allow scarce resources go further.

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Dr Pippa Murray

Pippa is a nationally respected parent, social innovator and writer who is working to transform the current special education system and the support available for disabled children and their families so that they can live happy and fulfilling lives.

Pippa is best known for promoting the voice of disabled children, young people and their families. She supports practitioners and policy makers to listen to these voices to influence developments in education and support. She is the author of several books documenting the lives of disabled families and highlighting the need for reform of the current system of support. These publications include *Let Our Children Be: a collection of stories* and *Hello! Are you listening?*

The experience of parenting a disabled and a non-disabled child gave Pippa an understanding of the family experience and inspired her to found several parent-led organisations in the 80s and 90s. Following the death of her son Kim in 1998 Pippa completed a doctorate further exploring support for disabled families. In 2005 she set up ibk initiatives, a development agency promoting citizenship, to put her ideas into practice.

Pippa has played a leading part in developing personalised approaches to support and education and is an internationally recognised expert in transition. She was one of the leading practioners behind the radical model of Personalised Transition developed in Sheffield.

She is currently leading the development of a range of practical and ground-breaking approaches to help families with young children and she continues to find new ways to support young disabled adults to lead meaningful lives when they leave school and further education.



Pippa lives in Sheffield and is discovering the delights of being a grandparent. She loves swimming in the sea and listening to the wind whistling through the trees.

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Publishing information

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The Centre for Welfare Reform was established in 2009 to develop and help redesign the welfare state in order to promote citizenship, support families, strengthen communities and increase social justice. The Centre's fellowship includes a wide-range of social innovators and local leaders.

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