



A **whole-life** approach to personalisation

Self-Directed Support for every child and young person

An In Control discussion paper by Nic Crosby and Simon Duffy



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Nic Crosby
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In Control

In Control is an independent network for social innovation. It develops, tests and shares ideas that can reform the welfare state and promote citizenship and community. It is a small organisation, but it supports an extensive network of organisations:

- ▶ 122 adult social services departments
- ▶ 24 children’s services
- ▶ 36 NHS Primary Care Trusts.

In Control is also a member of In Control International which has sister organisations in Australia, Northern Ireland, Scotland and Wales. Each organisation supports its own networks.

Introduction

In 2003, In Control published its model of Self-Directed Support, a new way of organising support that promotes citizenship for all.¹ Since 2003, In Control has developed and defined many of the key elements of Self-Directed Support, including the Individual or Personal Budget, Resource Allocation Systems, the Individual Service Fund, Support Planning and its functional analysis of brokerage.² In Control has also worked to connect these innovations to other relevant initiatives like Budget-Holding Lead Professionals and the development of Personal Health Budgets.

On the ground, progress towards Self-Directed Support has been significant. 9,000 people now use Personal Budgets. However, it will still take several years to transform the current care system – and there is still much to learn. Moreover, although Self-Directed Support began with children, it has often been perceived as only relevant to adults. This paper argues that this is an error and that Self-Directed Support offers a powerful and positive framework for all children and families.

We begin by setting out the emerging policy context for children's services with its increasing emphasis on the value of greater personalisation. We go on to argue that although personalisation is a valuable goal for services, it can only be achieved by a fundamental transformation in the power relationships between services and families.

Self-Directed Support and the use of Individual Budgets is one way of achieving this transformation and we go on to explore four of the essential elements of Self-Directed Support:

- 1. SAFEGUARDING** – keeping people safe from harm
- 2. RESOURCE ALLOCATION** – creating explicit rules for setting budgets
- 3. PLANNING TOGETHER** – enabling families to lead planning, with support
- 4. OUTCOMES FOCUS** – monitoring services in terms of what they actually achieve.

We will argue that this approach has the further benefit of moving us towards a model in which families can use an integrated budget – one which combines funding from health, social care and education. This Individual Budget can then be managed to deliver child-centred support in a way that:

- ▶ locates leadership in the most appropriate place
- ▶ involves all those who love and care for a child
- ▶ integrates support in a way that is personalised and child-centred
- ▶ maximises the efficient use of the limited resources available.

This approach treats the Individual Budget as just one part of the 'real wealth' that a child and family can draw on to get the support they need in a way which makes most sense to them. Support will not always consist of services that are paid for. Support can also come from networks, friends, extended families and community links. We define the sum total of these supports as the 'wealth' of support.

The paper concludes by exploring this notion of 'real wealth' and deficit. We will argue that Self-Directed Support is not a 'disability model' or a model linked to any particular group. Instead, Self-Directed Support is built on an understanding of social justice that is sensitive to the real experiences of people who need support. Many people require extra support because their situation demands it. But that support must make them more powerful, not weaker or more dependent. Good support will enable people to connect to family, friends and the wider community. People will be better able to live a good life.

The emerging policy context

Government policy and guidance has provided a positive space within which personalisation has flourished. Recent developments – particularly **The Children’s Plan** and earlier **Every Child Matters** policy – have provided further scope and have actively encouraged the personalisation agenda.

The next challenge is to ensure that the real-life practicalities of personalisation are properly understood and that real progress is made on the ground. Also, it will be helpful if policy-makers and practitioners develop a whole-life perspective on personalisation – a perspective that avoids the tendency to create approaches that do not connect across the range of human needs, and from birth to death.

Every Child Matters - holistic outcomes

Every Child Matters identifies five holistic outcomes:

- ▶ Stay safe
- ▶ Be healthy
- ▶ Make a positive contribution
- ▶ Achieve economic well-being
- ▶ Enjoy and achieve.

These five outcomes are not focused on services like education, health or social care services. Rather, they are genuinely universal outcomes – things each of us wants to achieve for ourselves and for those we love.

By specifying such outcomes, rather than setting targets for services, it becomes much clearer that nothing useful can be achieved without the combined efforts of the family, its community and professional services. Personalisation is essential because it is only by working **with** families that these outcomes can be achieved.

In fact, the logic of this approach is even stronger. For, not only must families be involved in producing these outcomes, it is only when the family itself can personalise the outcomes that they will make sense. As they stand, the five outcomes offer a framework. To be useful, though, they must be made relevant by the family – interpreted in the context of the family’s needs, goals and resources.

In the creation of personalised outcomes, a new context is established for their relationship with the multiplicity of service providers: schools, youth clubs, hospital, counsellors, social work team and so on. All services will need to work within one shared outcomes framework – while respecting the particular focus of each family.

The Children’s Plan

The primary vehicle for the delivery of policy towards children and families (alongside the **Children and Young People’s Bill**) is **The Children’s Plan (2008)**. This document makes very useful statements:

- ▶ Governments do not bring up children – parents do. So governments need to do more to back parents and families.
- ▶ All children have the potential to succeed and should go as far as their talents take them.
- ▶ Children and young people should enjoy their childhood as well as grow up prepared for adult life.
- ▶ Services should be shaped by, and be responsive to, children, young people and families, and should not be designed around professional boundaries.
- ▶ It is always better to prevent failure than tackle a crisis later.

These statements set a useful tone. It is impossible to provide children with the kind of support, guidance and love that is essential for children’s healthy development without working in partnership with families.

Families are the bedrock of community life and the modern welfare state must recognise that its ability to support children is completely dependent on its ability to support parents.

Other policy developments

Every Child Matters and the Children's Plan provide a strong starting point for future policy developments. We can also see that these shifts towards a more personalised response are mirrored by other policy developments:

- ▶ **Putting People First** (2007) is the cross-government concordat which made a commitment to substantial developments including the extension of Individual Budgets and Self-Directed Support to all those who need social care.
- ▶ **NHS Next Stage Review** (2008) is the report by Lord Darzi which has led to support for the piloting of Personal Health Budgets.
- ▶ **Aiming High for Disabled Children** (2007) outlines plans to launch pilots for Individual Budgets for Disabled Children, Young People and their families.
- ▶ **Budget Holding Lead Professional Pilots for Children in Care** (launched in April 2008) includes specific reference to Individual Budgets for young people in the care of local authorities.
- ▶ **Budget Holding Lead Professionals** (BHLP) provided an evidence base for personalised and self-directed use of funds to get support and access to mainstream services across a diverse group of children and young people: from those with high

support needs to those whose parents needed help with additional child care.

- ▶ **The National Service Framework for Children, Young People, Families and Maternity Services** supports the development of more child-centred care and support to families.

Furthermore, in July 2008 the Learning and Skills Council announced plans to personalise learning support funds. These plans describe the development of a simple way of allocating an Individual Learning Support Fund. This fund will be available to help a young person with additional learning support needs to get the support they need when they enter post-school learning.

All these reforms inform the long-term development of the **Every Child Matters** policy. Children's Centres will be developed in local communities. These will offer support to families and children of various ages and backgrounds. We can also expect further development of personalised approaches to learning within education policy.

In Control believes that the introduction of Self-Directed Support and Individual Budgets will be central to the success of the personalisation agenda. We know from the direct experience of families and people how successful Individual Budgets have been. We can also see how the current system continues to fail to meet the needs of an increasingly diverse population of 11 million children and young people.

Personalisation, citizenship and community

Making decisions about daily life for a family (for example, what time your children go to bed, the hours you can work to make sure you are home when they get back from school, where you go on holiday) is a day-to-day experience for most people. We make decisions that suit our individual life, that are functional and effective for us. This is self-direction in practice.

When a family member, perhaps a son or daughter, has need for additional support (due to an impairment, poor health or some other issue) then these decisions immediately become more complicated and more dependent on other factors: our resources, our families, where we live, our local school, transport links and so on. Increasingly our decisions depend on the availability, support, and decisions of 'outsiders'. Self-direction becomes more difficult and many people can come to feel that their life has become dominated by services.

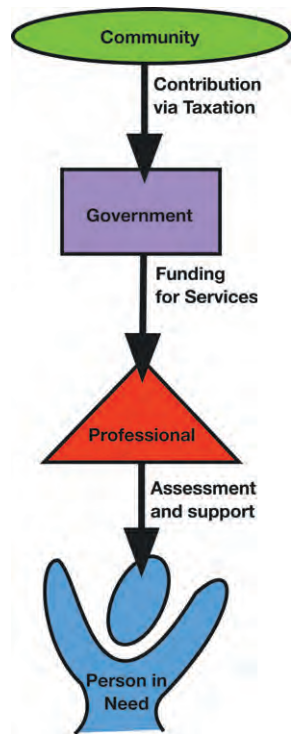
The level of interest in personalisation has grown to such an extent that many now argue that the next challenge for the welfare state is to embrace personalisation.³ This argument seems right to In Control. However, there is also a risk that the attractiveness of 'a personalised welfare state' can delude us into thinking that personalisation is something services can simply do **for** children and families: 'we just need to make our services more personal'.

In Control’s experience suggests that personalisation needs a more fundamental shift in the relationship between services and the person in need, which, in this context, often means the child and their family. This is a shift away from the ‘professional gift model’, in which services are merely delivered to the person, towards a ‘citizenship model’ in which support is seen as integral to a person’s life, and power must move closer to the individual.⁴ Practical technologies like Self-Directed Support and Individual Budgets are rooted in this deeper understanding of how personalisation must be achieved.

The Citizenship Model

It is a fundamental requirement of social justice that people should be treated as equals. But there are many obstacles to equal treatment when someone has extra support needs or faces other difficulties in playing their full part in society. In the past, the welfare state has often acted in ways that even exacerbate this injustice. While meeting a fundamental need it is easy to undermine the citizenship of the individual or family such that they:

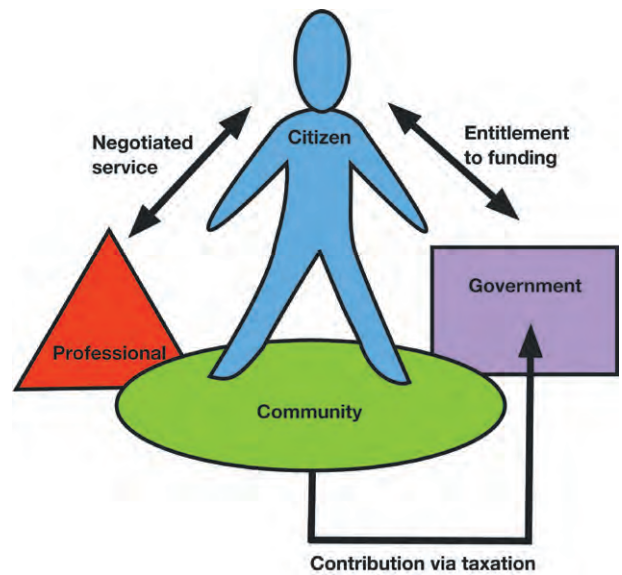
- ▶ are more dependent – less able to make their own decisions
- ▶ are trapped in poverty – there are disincentives to work or contribute in some other way
- ▶ are stigmatised – seen as different or less valuable
- ▶ are more cut off from family and friends.



THE PROFESSIONAL GIFT MODEL

This undermining of citizenship is not an unavoidable side-effect of helping people to meet their needs. But any welfare system runs the risk of being insensitive to its impact on citizenship and community. The challenge for the modern welfare state consists in ensuring it can meet the diverse support needs of the whole population while at the same time sustaining and promoting citizenship. **Self-Directed Support was designed to find a means of meeting diverse needs in a way that maximises citizenship. In practice this has meant:**

- ▶ focusing on people’s **entitlement** to additional support – acknowledging the support needs of the family when they have a child with additional support needs and treating these as a genuine entitlement which can be shaped by the family
- ▶ enabling families to **direct their own support** – mixing professional and unpaid support, integrating support into everyday life and ensuring the accountability of support providers to the family
- ▶ supporting people to make their own **decisions** – building capacity and competence in decision-making, working with the whole family around critical decisions, offering information and peer support.



THE CITIZENSHIP MODEL

In Control has developed a range of practical tools and technologies that make this paradigm shift in approach easier to achieve. We explore these in more detail below.

Early findings

In practice, the use of Self-Directed Support and Individual Budgets has led to greater satisfaction with services. It has also enabled people to make better use of the support available within their community.⁵ For instance, there have been significant improvements in people’s experience of ‘respite’ when people have the chance to design support solutions that make more sense to them:

- ▶ Now a young carer can take a break away from his home and be confident that his mother will be supported safely in their family home while he is away.

- ▶ Another family benefits by going on holiday together rather than have their daughter go into the overnight provision she always disliked.
- ▶ A family that does not use English as its first language has recruited two young adults from its own religious community (and agreed a rate of pay which exceeds that offered by agencies). Family members now have support from people who speak their own language and who respect the same religious tradition.
- ▶ A young man bought monthly gym membership to stay fit and reduce stress.
- ▶ A family has bought a caravan on the coast as a creative and flexible way of taking a break (or getting 'respite').
- ▶ Another family installed smooth wooden flooring and this enables a young man to more easily get around the house in his

wheelchair. This arrangement reduces strain on his mother's back.

All of these real examples are in sharp contrast to the very limited range of respite options currently available. Most families still do not get the chance to design their own way of having a break, are not able to design support around their own lifestyle, and are not able to ensure the specific support needs of their son or daughter are met. **Aiming High for Disabled Children** made clear how important it is for families to have breaks, but the current structure of 'respite services' does not work in a way that really supports families to thrive.

The experience of In Control suggests that only a commitment to Self-Directed Support and Individual Budgets will enable us to move from the rhetoric of personalisation to the reality of responsive supports, stronger families and better lives.

Four elements of personalisation

This paper focuses on four key elements from the widely disseminated **Seven Steps** approach to Self-Directed Support developed by In Control.⁶



A further discussion will be found in **The Seven Steps of Self-Directed Support** to be published in Autumn 2008 by the Department for Children, Schools and Families. This paper both sets out the steps and emphasises the central role of Self-Directed Support within the Department's drive to deliver outcomes-based commissioning.⁷

Self-Directed Support is an integral part of the Government's policy of introducing outcomes based commissioning; making explicit the relationship between outcomes achieved for an individual and those set out at the strategic level in commissioning strategies.

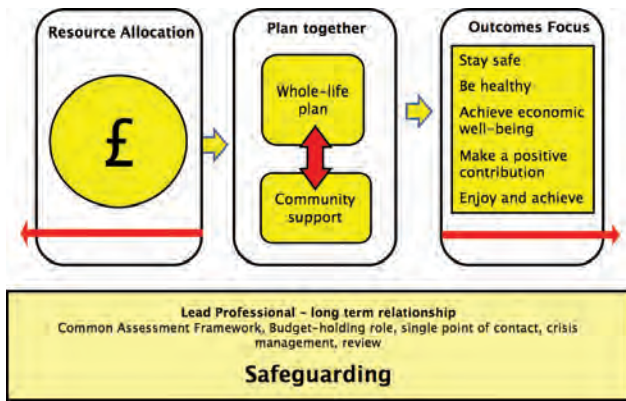
The four elements that we will explore in this paper are represented in the diagram below. They are:

- 1. SAFEGUARDING**
in particular the role of the Lead Professional

- 2. RESOURCE ALLOCATION**
understanding how resources can be used more effectively

- 3. PLANNING TOGETHER**
family-led planning, integrated with community support

- 4. OUTCOMES FOCUS**
the use of the **Every Child Matters** framework.



FOUR ELEMENTS OF PERSONALISATION

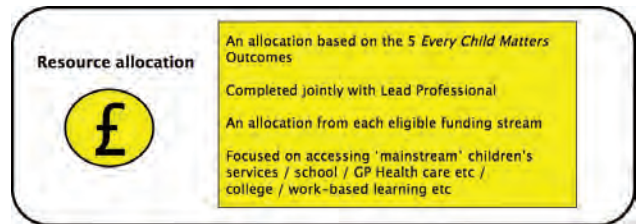
1. Safeguarding

Self-Directed Support enables public bodies to better fulfil their duty of care. In particular, Self-Directed Support offers a promising framework for improved safeguarding. It promotes transparency and improved decision-making in a number of areas:

- ▶ Self-Directed Support creates much greater clarity about the support that is being delivered, who is delivering it and how it is being monitored and managed.
- ▶ The flexibility of Self-Directed Support enables a more rational evaluation of the approaches which promote health and well-being and those that put people at risk – there is no in-built preference for institutional patterns of delivery (which typically demonstrate higher risk patterns).
- ▶ Self-Directed Support promotes effective decision-making on health and safety, limiting the damage done by inappropriately generalised rules that undermine positive outcomes.
- ▶ Self-Directed Support provides much clearer accountability: it is clear who has approved any plan. This approach positively encourages the shift towards the greater use of the Lead Professional model and away from unduly ambiguous modes of monitoring and supervision.
- ▶ Self-Directed Support provides flexibility around who, as a responsible adult, can take the role of Lead Professional. The ability to tailor that relationship to the child and family enables better quality support and greater focus and attention to detail.
- ▶ The facility to increase the involvement of both the child or young person and key adults from the family increases control and accountability and reduces the chance of risks going unreported.

So far, the experience in adult social care seems to support this analysis. Local authorities report improvements in the competency of support planning and the better management of risks.

2. Resource allocation



RESOURCE ALLOCATION: THE SECOND ELEMENT OF PERSONALISATION

Resource allocation is a simple transparent approach for allocating an indicative budget – what has become known as the ‘Individual Budget’.

In practice, it is a shared process, in which a family or child’s advocate and those closest to the child, complete a set of questions with the Lead Professional. The result is an indicative allocation of funding which is central to drawing up a child-centred support plan.

To date, the allocation of resources in children’s services has been based on an analysis of what it should take for someone to achieve the five **Every Child Matters** outcomes. In order to know how much money is needed, it is important to understand both the real needs of the child and their family’s situation.

One approach has been to develop a questionnaire that uses a set of positive statements, each linked to the Every Child Matters outcomes, for example:

- ▶ To stay safe with the people who I know and who know me well, I need no support.
- ▶ To stay safe with the people who I know and who know me well, I need some support.
- ▶ To stay safe with the people who I know and who know me well, I need substantial support.
- ▶ To stay safe with the people who I know and who know me well, I need an exceptional level of support.

Applying this approach has proved very useful in developing a quantifiable account of someone’s needs. Today, Taking Control sites are moving this work further forward and developing their own sets

of questions. However, the **Every Child Matters** remain the guiding reference.

A similar approach has been taken in those places where a resource allocation for an Individual Learning Support Fund is being developed. The questionnaire uses the five outcomes as a way of identifying the amount of learning support a young person needs to participate in learning activities.

The work with children’s health services, although in its very early stages, will similarly base the allocation of health funding on the five outcomes, thus building a simple and consistent approach to funding allocation and ensuring that the support delivers the five outcomes in a way that makes sense to the child or young person and those caring for them.

All these approaches to setting Individual Budgets are genuinely outcomes-based, setting resources according to the outcomes that need to be achieved, not by service type or process. Hence the process of using the Individual Budget can be tailored to the family and can focus on getting the best possible value from the limited resource.

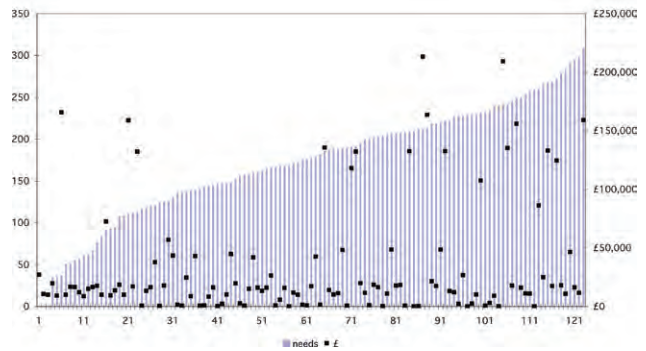
There are several reasons for making this shift to an outcomes-based, upfront resource allocation:

- ▶ It respects people as citizens who have an entitlement and who need to know that entitlement in order to control it.
- ▶ It is transparent and creates equity in a way that everyone involved can understand and communicate.
- ▶ It is more efficient and sensitive to need. It breaks away from the menu-driven approach to costing which does not reflect best value. Instead, resources are focused where they are needed most.

The development of systems for resource allocation reveals the vast inequities caused by the current system.

The following graph shows how allocations made by the current system in one local authority correlate to the assessed needs of 121 children and young people. The left side of the graph shows a scale of need as determined by a local assessment based on in Control’s self-assessment questionnaire. The right side shows a scale of cost. The graph itself indicates what is spent on each individual in the current system. It is clear that there is no correlation between need and expenditure.

Over £150,000 is spent on one individual who has very low support needs. On the other hand, a number of people with very high support needs receive an allocation of only a few thousand pounds. Many people across the needs spectrum receive nothing at all.



121 INDIVIDUALS IN ONE LOCAL AUTHORITY: NEED COMPARED TO CURRENT EXPENDITURE

The same dramatic level of inequity has been consistently found in adult social care services.⁸

Over the last two years, the Budget Holding Lead Professional pilots have supported this finding and provided further evidence of how a small budget, used in a family- or child-centred way, can meet the support needs of children efficiently and produce good outcomes.

One BHLPI pilot site recently reported to the Treasury that its experiences have led to the development of a Community Lead Professional role.⁹ The BHLPI site found that, for very small sums of money used flexibly, very good outcomes have been achieved – outcomes that might have been assumed to cost much more. Conversely, they also identified that the reliance of specialist services on a prescribed menu of services has had a high cost and cannot clearly be linked to successful outcomes for the individual child and those caring for them.

Not only does the current system fail to offer the right level of support, its lack of transparency can exacerbate a feeling of dependency. The system can encourage an attitude that actually undermines the ability of a family to find good solutions to its own problems.

The story on the next page comes from one of the first young people to get an Individual Budget from children’s services. This young man’s Individual Budget was substantially less than the cost of his previous support package – yet his life has improved considerably in the new system.

A musical and a curry

John is 16 and has needed 24-hour support from his family. He has epilepsy and learning difficulties. His family has used Direct Payments for a number of years but has found the regulations that go with Direct Payments gave them little flexibility and few breaks from the caring role.

John does not get to spend much time with other young people. In his support-planning circle, they have realised that John's cousin, Rob, is very important to him. Rob and John have agreed to do



things together: going into town shopping on a Saturday, going to the pictures, going for a meal (John loves curry).

John has a passion for musicals. He gets to a show each year and he is going to use some of his money to go to London to see **Dirty Dancing**. He can't wait.

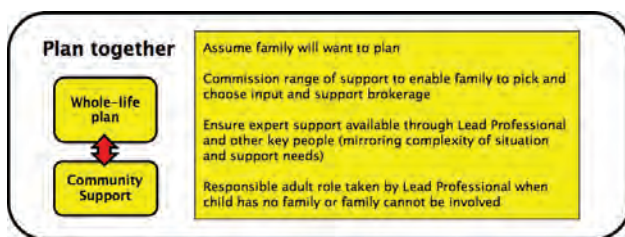
John and his family have written in his support plan that he will go to another show later in the year.

John's mother says, 'Why have you [the care manager] been sitting in my living room for the last 10 years? If you told us this 10 years ago we would have just got on with it. That's all we wanted'.

3. Planning together

The support plan sets out how a child will get the support they need to lead a healthy and active life. Some people need help to develop their support plan. Many others are more skilled than professionals may give them credit for.

When someone gets support to plan, that support needs to be appropriate and focused. The Lead Professional needs to have a clear role in ensuring people get the right help from the right people. The support plan becomes the initial means for funding bodies to determine how they will meet their duty of care. The final test is the extent to which positive outcomes are achieved.



PLANNING TOGETHER: THE THIRD ELEMENT OF PERSONALISATION

The default assumption within Self-Directed Support is that families will manage and control the use of the budget from the outset. That is to say that we should always begin by assuming the family is capable – that it has 'capacity'. However, another assumption within Self-Directed Support is that families can take the level of control they are comfortable with. Some parents may feel they cannot lead the process. Some may need a significant level of support to lead the process.

Other families may, of course, not be thought able to control the budget because of 'safeguarding concerns'. In such cases, a different system of decision-making is needed.

Issues of safety would be explored during the completion of the Common Assessment Framework. In some cases, the reason for referral to the children's service will determine the level of responsibility that can be taken by the family and also by the Lead Professional. For example, if a young child is taken into short-term care as a result of neglect or abusive relationships at home, it will be clear that the family is unlikely to be able to control the budget or manage the support. Self-Directed Support is about helping people to be safe and secure – a prerequisite for leading a good life. It is certainly not about giving control to anyone who will misuse that power such that a child will be put at risk of harm.

It is the role of the children's service to ensure that a variety of supports is available that enables the family or those advocating for a child to take the level of responsibility with which they feel comfortable. This approach differs greatly from most Direct Payments arrangements in which families often have to face a stark choice: to manage the whole process themselves or not be able to use Direct Payments at all. Self-Directed Support is about appropriately supporting and maximising self-determination. It must not be naively assumed that everyone is, at all times, ready to take the maximum level of control over their lives.

One of the most important ways of enabling Self-Directed Support is to offer people simple tools for

promoting autonomy and planning. In Control has a well-established collection of frameworks and approaches to person-centred support planning.

Taking Control has created a simple approach that is used in each of the participating sites. Key components of this approach include:

- ▶ identifying risk
- ▶ evidencing how **Every Child Matters** outcomes are being delivered
- ▶ ensuring the voice of the child or young person is heard
- ▶ making sure that the views of families and professionals are respected.

‘Support plan’ is not simply another name for ‘care plan’. A support plan starts by asking who the child is, who is most important to the child, what is important to know, what is and is not working. The support plan then goes on to set out how different sources of support (including from the wider family) will be used to provide the support the child or young person needs. If a disabled child has brothers, sisters and parents, support may include funding for breaks for young carers, for the child and for the parents. The outcome is likely to be a happier and healthier home life for the disabled child as envisaged in the five **Every Child Matters** outcomes.

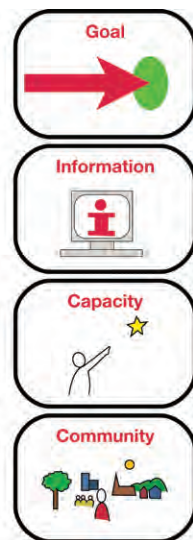
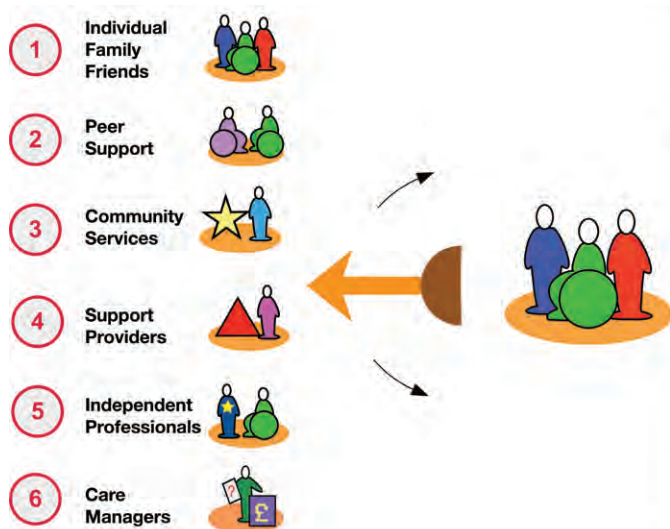
At all times, agreeing to fund a support plan means that the children’s service is confident the plan delivers the authority’s duty of care. When a plan draws on an integrated budget, it would include evidence about how the different funding streams will contribute to the support the child needs, and how this funding relates to **Every Child Matters** outcomes.

Children’s services will need to develop a range of options that children and families can call on for help in developing their plan and, later, co-ordinating and managing the support. In the graphic above, the left hand side of the image describes the six different kinds of support options that families may seek. The right hand side describes the factors that are likely to influence the decisions about what kind of support people will need. A broad understanding and application of the role of the Lead Professional may be helpful and could be used to integrate the Lead Professional into this support framework.

In the world of adult services, following the publication of **Putting People First**, there has been much discussion about the role of the independent broker. Often, there has been a tendency to exaggerate the value and necessity of this role and international evidence would suggest we should be cautious in investing too much in this approach.

In the children’s world, there have already been many developments that may circumvent the need for the establishment of this independent broker role on anything other than a small scale:

- ▶ The role of Lead Professional can be played by a wide variety of people, for example, family members, voluntary organisations, Personal Advisers, schools, GP’s, social workers, and nurses.
- ▶ The distinct role of Budget Holding Lead Professional can also be taken by a wide range of people.
- ▶ Children’s Centres are community buildings-based services offering a wide range of activity and information to all families within a community area.



However, the shift to Self-Directed Support does mean that support offered through Children’s Centres or Lead Professionals will need to include key services that may sometimes be overlooked:

- ▶ person-centred approaches to planning, participation and involvement
- ▶ money management – organisations should be able to offer payroll support (similar to Direct Payments support services now) and to open and manage bank accounts on behalf of a child and/or family

CHOICE OF BROKERAGE OPTIONS FOR CHILDREN, YOUNG PEOPLE AND FAMILIES

- ▶ information and guidance on options, support providers and activities that the child or young person can buy using their Individual Budget. If the budget is an integrated one, expertise in developing appropriate learning support, or accessing appropriate health care support and/or therapy services is needed
- ▶ agency-type arrangements to employ staff on behalf of a child, and advice on employment
- ▶ training for newly appointed support workers – training regularly delivered through the local authority and health trust as well as access to specialist and/or health and safety training from the voluntary and private sector.

The development and commissioning of these options will fall to the local integrated children’s service. Local authority adult services will also be exploring the availability of the same range of support brokerage services. Although Children’s Centres, for instance, may not feature in the plans of adult services, both children’s and adult’s services will create a similar pattern of services within Self-Directed Support. Greater collaboration between the two will lead to a more effective life-long support structure, one that is better integrated into mainstream services.

In fact, Self-Directed Support becomes an ideal tool for breaking down barriers between specialist and mainstream services. The Individual Budget will provide the funding that enables the child or young person to make best use of mainstream services alongside the additional support they need. This flexible support will:

- ▶ support the child to access mainstream services and community life
- ▶ provide highly skilled support around clinical and medical needs
- ▶ foster better links between school and home.

These shifts imply a radical change in the way that services are currently commissioned. Self-Directed Support shifts power from services towards families and those who are acting on behalf of the family (including professionals). Providers of support will need to offer options that families want to purchase. They will need to deliver a quality service if they want to retain the family as their customer, and they will no longer have the security of a long-term local authority contract. Early experience from the implementation of Self-Directed Support in adult services suggests

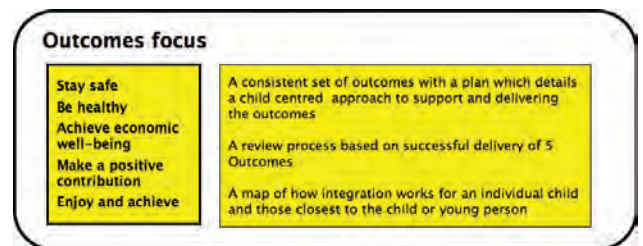
that this scenario is realistic and does not damage the service options available.

Furthermore, families could choose to employ their own support workers and can choose to pay an hourly rate that they think properly values the support their son or daughter requires. Providers would have to compete with these private arrangements and be able to justify the hourly rate paid to the support worker and the overall cost they charge the budget holder. This may help put pressure on the administration and management charges that, in many cases, seem high at present.

However, it will not be enough to simply challenge local providers to change the way they deliver services. A concerted partnership approach is needed to improve the market of available services. It should be said that early work suggests many support organisations have an appetite for change and are very willing to meet with families to explore new options.

4. Outcomes Focus

Self-Directed Support is an integral part of the Government’s policy of developing outcomes-based commissioning. This approach leads to an explicit relationship between the outcomes achieved for individuals through micro-commissioning and those set out at the strategic level in commissioning strategies.



OUTCOMES FOCUS: THE FOURTH ELEMENT OF PERSONALISATION

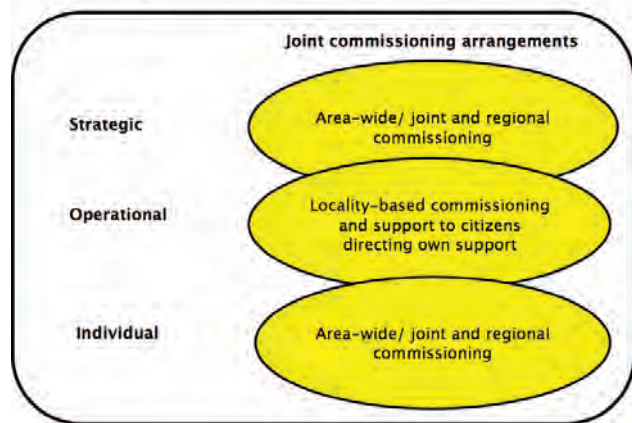
Using the **Every Child Matters** framework provides a way of identifying a common set of outcomes for all those supporting a child or young person and those closest to them. The five outcomes are also consistently used within the allocation system, the planning process and the review function.

Use of the framework improves understanding and communication. It sets out the rationale for supports and activities. The five outcomes link all activities for children and young people up to the age of 18 and for many to the age of 25. They bring together all agencies, professionals and sectors, and they provide a simple global way of explaining the purpose of

the support. Working out how these outcomes are interpreted, how the support works and what each outcome means personally to the child, young person or family is at the heart of personalisation.

The use of the **Every Child Matters** outcomes links all commissioning activity within the integrated

Levels of joint commissioning



COMMISSIONING FOR PERSONALISATION: A FRAMEWORK FOR LOCAL AUTHORITIES, DEPARTMENT OF HEALTH 2008 ¹¹

children’s service – all activity is focused on delivering these outcomes for a diverse local population. This strategy is detailed in the Office of Public Management paper, **Introducing Individual Budgets and Self-Directed Support for Disabled Children and their Families**, which explores ‘multi-level commissioning’.¹⁰ In summary, there are three levels of commissioning within any local area: strategic, operational and individual. Individual Budgets enable individual commissioning, while strategic and operational commissioning encompass wider agendas focused on the mainstream population and the needs of local and minority groups.

We continue to find that the use of one overarching framework for outcomes, one that does not focus on services, is powerful and productive. It provides a space in which children and families can develop their own approach to meeting their needs and setting their own goals. It provides a single, simple basis for the whole system, one which is open to any child or young person who requires and is eligible for one or more elements of funding to meet their support needs.

Towards integrated funding

As we move towards greater personalisation, we are discovering that its focus on the holistic needs of the individual offers a new means of overcoming the barriers between services. We can even begin to identify a new long-term vision for consistent and meaningful support across the age range and the increased use of integrated funding in Individual Budgets.

There are already many examples of Individual Budgets being offered to children and young people below the age of 18. There are also many examples of different funding streams being integrated into the Individual Budget: social care, learning funding, health funding, ILF (Independent Living Fund), Supporting People and DFG (Disabled Facilities Grant).

For children, there is a strong case for developing Individual Budgets which draw together the primary funding streams that support children: education, health and social care. A child’s life is not split into sectors or different systems. Support to a child should reflect the whole child’s life and their support needs. An integrated budget can be used to deliver a single support package for a child. It does not matter whether this is a young person recovering from a mental health problem and needing some health support alongside flexible learning support funding to help them get back in to the education system; or

a child with complex health support needs who has access to a social care and health budget.

The shift to integrated budgets is not as far away as it may at first appear:

- ▶ Social care funding in adult services is linked with various funding streams – Supporting People, Continuing Health Care and DFG – and is well established in some areas.
- ▶ The national Learning and Skills Council (LSC) has recently committed itself to developing a simple mechanism to allocate an Individual Learning Support Fund. In Control has led work on developing an initial Resource Allocation System for LSC funding.
- ▶ A number of members of Taking Control, along with their health partners, have committed to developing Personal Health Budgets in line with recent pronouncements

in the Darzi report outlining the Government's intention to pilot this approach.

- ▶ Finally, the work of the Budget Holding Lead Professional pilots has drawn health, social care and education funding together to deliver small Individual Budgets to children and young people that they can use flexibly to address immediate and presenting support needs: for example, new school uniforms, bereavement counselling, out-of-school learning support and access to individualised work-based learning.

There are clearly legislative boundaries to how money is managed: education money sits within the school and health funding is currently managed within the health sector. However, even while these boundaries exist there are no legitimate reasons for not treating the money as a single pot that can deliver holistic and meaningful support to a child or young person. The following two stories illustrate the value of combining social care, health and learning funding (LSC) to deliver holistic support.

Joined-up Support

Jonathan is a disabled teenager. His quality of life has been transformed since he left school in July 2008 with an Individual Budget. Now he and his Mum decide what he should do, when he should do it and who should support him.

Jonathan's complex health condition means he receives funding through Continuing Health Care. And he was fortunate to be part of a pilot run by the Learning and Skills Council giving individual learning support funds. Putting the different funds together has enabled Jonathan to employ one full time personal assistant (PA) and two part time PAs for activities in the evenings and weekends.

Jonathan's Mum reports an 'amazing improvement in his quality of life. ...It has given him so much more freedom to explore life. Without this Individual Budget he would not have been able to do anything like the things he can do now. I would have had difficulty taking him to these things.

It is encouraging Jonathan to have a bit of an independent life style. And with Jonathan having his PAs, I have more time to spend with my other two sons who both have learning difficulties. And Jonathan can't stop smiling!

In addition to enjoyment and happiness, Jonathan's learning needs are fully taken care of. His week – tailor-made for him – allows many opportunities for developing his independent life skills, his special interest in computers and multi-media, and individual tuition.

Learning on the Job

Daniel is a sociable 18 year-old with a great sense of humour. A Sheffield United fan, Daniel loves going to the pub with family and friends and enjoys working on his family's allotment. With an Individual Budget made up of money from adult social care and the Learning and Skills Council, Daniel's life is exciting and full of activities that he chooses. He has used some of his Individual Budget to rent his own allotment – close to the family one. He and his PA now spend happy hours there digging and tending to vegetables. The new skills Daniel is developing from his time at the allotment are recognised by the Learning and Skills Council as valid learning outcomes.

One of Daniel's worries about leaving school was losing touch with his friends. His Individual Budget allows him to have new adventures. With the support of a PA, Daniel and two friends meet up regularly and go away for weekends together.

Daniel has bought a season ticket for his beloved Sheffield United, and is supported by his brother who gets a pint in the pub afterwards for his hard labour! Daniel, his parents and his brother and sisters are delighted with the opportunities that have opened up for all of them: 'This is one of the best things. We get to tell people what we need, and then go out and get it. It is wonderful!'

Work is already underway which brings the reality of integrated budgets much closer:

- ▶ Taking Control's pilot activity in 24 children's services with approximately 100 children and young people across all ages and support needs (health, education, social care)
- ▶ Taking Control is supporting the development of Resource Allocation Systems for social care, health and learning. Each follows the same structure and allocates a budget closely allied with the 5 Outcomes of Every Child Matters
- ▶ the development of single support plans: for example in the Mencap Living and Learning Now projects in Essex and Sheffield. These

plans are based on LSC funding alongside social care Individual Budgets – and in one case Continuing Health Care funding

- ▶ the development of capacity within the wider local workforce through pilot projects in 24 children’s services to support families and children in putting together their own support plan
- ▶ the involvement of family representatives from the outset in steering the project locally. Consultations are held with a diverse group of children and young people across the 24 sites
- ▶ the development of partnerships with, and forums for, local providers and services –

involving them in the wider and longer term work to offer support that children, young people and families want and will purchase

- ▶ developing a first version of a whole-system pathway that underwrites the introduction of Individual Budgets across children’s services.

Delivering a framework for integrated Individual Budgets gives children and those closest to them the chance to develop their skills in deciding how they want to be supported. It builds a positive and interdependent relationship between the child, their family or carers and those involved in supporting them to take charge of their life.

Lessons for social justice

The welfare state is rightly shaped by assumptions about how to achieve greater social justice. However, it is not uncommon for policy-makers and political theorists to make assumptions based on misunderstandings of the reality of service delivery and the factors that shape the achievement of a good life.

Common assumptions include:

- ▶ more money will lead to better outcomes
- ▶ services and supports are always good things
- ▶ people with needs are naturally dependent on others and always require guidance.

These assumptions may be rooted in the paternalistic nature of early welfare provision. However, there are good reasons to be suspicious of them. As we have suggested earlier in this paper:

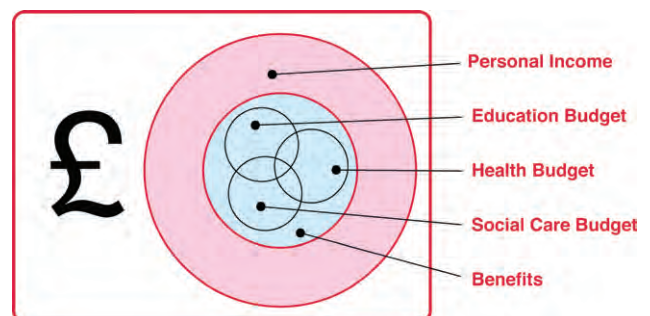
- ▶ more money does not often correlate with good outcomes
- ▶ people can become so dependent on services that they lose opportunities
- ▶ many people have capacities for creativity and productivity which just need to be unleashed.

At In Control, we are interested in how these lessons might inform a deeper understanding of the factors which really determine how people have a good life and what society should do to support its members and promote greater social justice.

Real family wealth

Real family wealth consists of more than just money. We go on to mention the different components of real wealth below. But, to begin with, it is obviously important to consider money as one essential ingredient of real wealth.

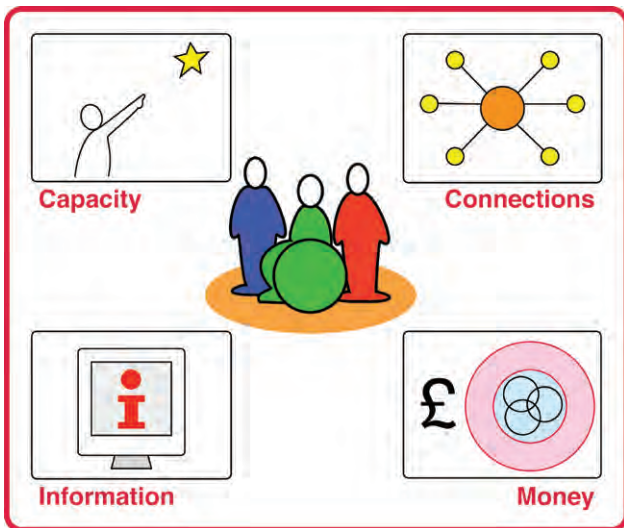
The integrated Individual Budget must be seen in the context of the individual’s benefits and personal income. The budget can be made up of money from a variety of sources – including personal income. There is currently insufficient attention paid to the diverse disincentives for individuals and families to improve their income and savings.



FAMILY WEALTH: THE MONEY PART

While money is an important element of wealth, it is not the only one. We are learning that what it actually takes for people to achieve a good life is dependent on a number of factors, each of which is logically independent:

- ▶ **Capacity** – abilities, skills, health, communication abilities
- ▶ **Connection** – family, extended family, friends, work colleagues, peers, organisations, clubs, groups, networks
- ▶ **Information** – knowledge of possibilities, best value and community resources
- ▶ **Money** – income, benefits, tax credits, capital assets and, where eligible, an Individual Budget.



THE ELEMENTS THAT CONTRIBUTE TO REAL FAMILY WEALTH

Richer communities

Of course, wealth, even ‘real family wealth’ is, in itself, not the only factor determining the outcomes we can achieve.

It is the way in which we use our wealth in the context of our wider community that will shape those outcomes:

- ▶ the quality of family life in the community
- ▶ the associations, clubs, circles available
- ▶ social enterprises, charities, faith organisations
- ▶ business, commerce and economic environment
- ▶ public services, hospitals, schools and emergency services
- ▶ law, regulations, democratic and judicial structures.

If this analysis is correct, it suggests that the modern welfare state will need to become more sensitive to the value and tension between three broad strategies:

- ▶ developing richer communities
- ▶ increasing family wealth
- ▶ offering effective support.

See the diagram on the facing page.

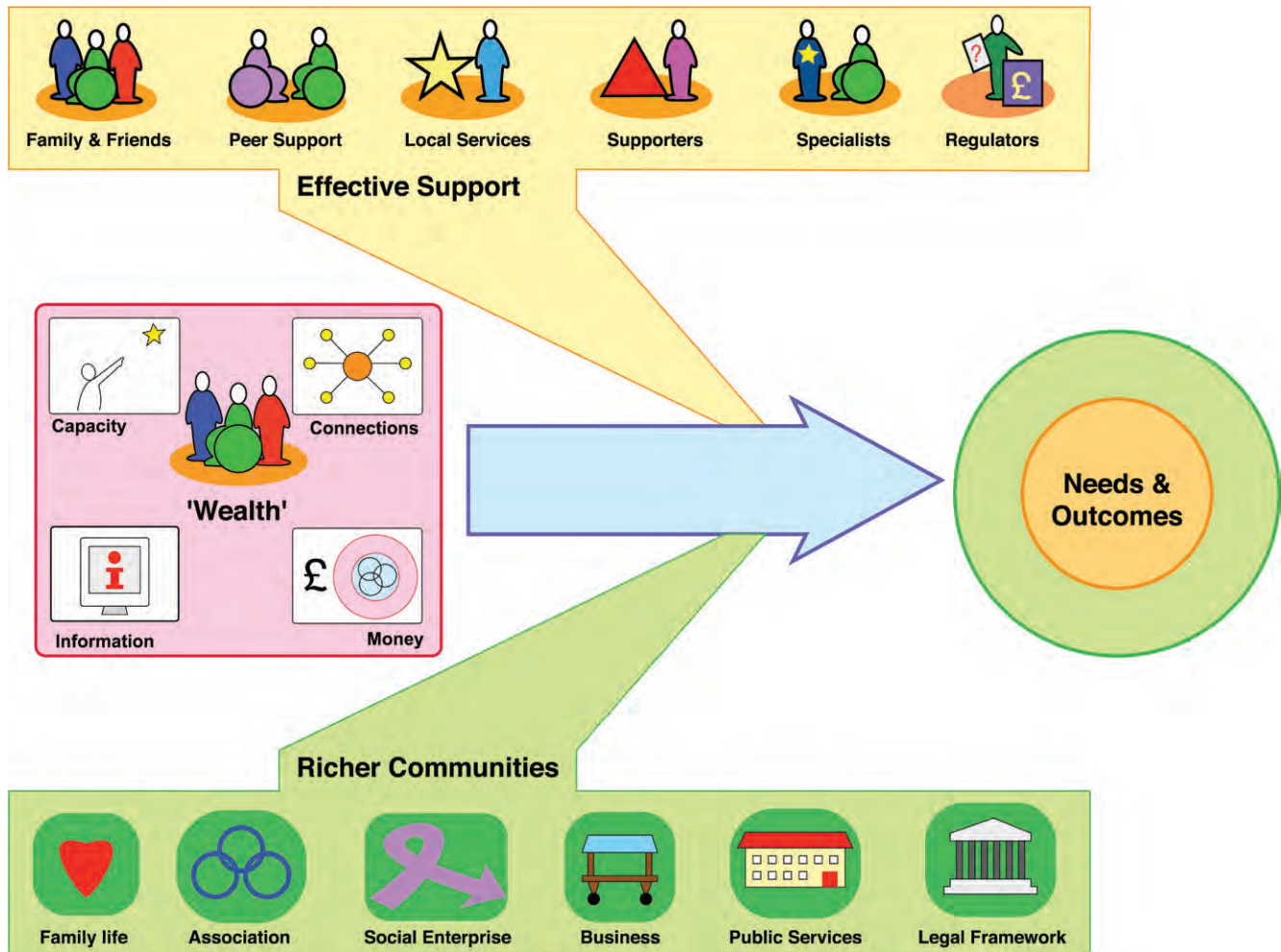
This framework helps us to see that, if our primary responsibility is to help people have good lives, then we must learn to establish the conditions for success.

This means we have to go beyond a simplistic view that good supports lead to good outcomes. We even have to go beyond the idea that family wealth is a critical and powerful contributor to success. These two factors will only be able to play their part in the achievement of good outcomes if we recognise a third factor – the role of community. Rich and diverse communities that welcome the involvement of all their members are perhaps more than an essential ingredient for success. They are the soil in which the seeds of good support and family wealth can produce fruit. We need to see how best to invest in our own society to ensure that we genuinely support success.

It is important to see that this is a whole-system model. A change in one part of the model will require changes at other points:

- ▶ Increased money in public services necessarily reduces the money that can be invested in family wealth.
- ▶ Increasing the investment in appropriate support reduces the money that can be invested in family wealth.
- ▶ It is important to invest in the most effective support – and this may not be how resources are currently invested.
- ▶ It is important to invest in those aspects of community that will be most productive – and this may not be how resources are currently invested.

In Control does not claim to know how best to support families to achieve good outcomes. There is still much to learn about how to enhance social justice – but this framework may offer the means of exploring more deeply how to achieve good outcomes. It could be the basis of a genuinely empirical approach for promoting greater justice and better lives for everyone – however complex their needs.



A COMPREHENSIVE FRAMEWORK FOR ACHIEVING GOOD OUTCOMES FOR PEOPLE WHO NEED SUPPORT

Conclusion

The support that a child needs – whether health, education or social care support – impacts on all parts of that child’s life. Likewise, the family’s ability to offer the support their child needs will depend, on the whole, on their ‘real wealth’ – their capacity, resources, connections and the information they control. Furthermore, the effectiveness of this wealth will depend critically on the richness of their community.

An integrated Individual Budget is based on the acknowledgement that a child’s support need is integral to the whole life of the child and the fact that, when support needs are identified, greater demands will be made on the wealth of the family, child and those who care for the child. An integrated Individual Budget is an entitlement that can be used to meet additional support needs. Without help, the family or those caring for the child are unable to thrive – whether in the classroom, at home or in the wider community.

We believe that Self-Directed Support and the use of Individual Budgets offers a powerful tool for promoting social justice and citizenship for all. It is an approach that is sensitive to the complexity of human life and the need for both self-determination and richer communities. It offers a framework for the reform of the whole welfare state and greater respect for human dignity.

Nic Crosby and Simon Duffy

Evidence and bibliography

The paper draws on early learning from a number of important development programmes: **New Partnerships (2003-06)**, **Dynamite (2005-08)**, **Budget-Holding Lead Professional Programme (2005-2007 and 2007-2008)** and the wider work of **In Control (2003 onwards)**. Currently, In Control's work with children and families is concentrated in the **Taking Control** programme which was launched in 2007. Together these development programmes provide a rich source of early evidence.

In Control developed many of the key concepts of Self-Directed Support, including the term Individual Budget. In Control has published its learning since 2003 on www.in-control.org.uk. We have also used a number of unpublished papers relating to the pilots for Budget Holding Lead Professionals (DCSF and OPM). Other sources we have drawn on include

- » **A Report on In Control's First Phase 2003-2005** – Poll et al.
- » **A Report on In Control's Second Phase 2005-2007** – Poll and Duffy (eds.)
- » **The Economics of Self-Directed Support** – In Control
- » **Dynamite: The First Two Years 2005-2007** – Paradigm
- » **Multi-level Commissioning** – Office of Public Management
- » **Keys to Citizenship** – Duffy

- » **The Seven Steps of Self-Directed Support** – Bennion, Crosby, and DCSF Commissioning Team, September 2008, www.everychildmatters.gov.uk
- » **Introducing Individual Budgets for Disabled Children and Families** – Crosby, N. Miller, C. The Office for Public Management, October 2007, www.opm.co.uk
- » **The Children's Plan Department for Children, Schools and Families, 2007**
- » **The National Framework for Children, Young People and Maternity Services** – Department for Health, September 2005
- » **Aiming High for Disabled Children and Young People** – HM Treasury, May 2007
- » **Individual Budgets and Self-Directed Support for Children and Young People; Examples of Workforce Development and Budgetary Management** – Cathles, Crosby, (Unpublished)

Endnotes

- 1 See **In Control's Statement of Ethical Principles** and the full range of resources available through www.in-control.org.uk
- 2 There has been some confusion about the use of the term Individual Budget. The idea, initially defined as an 'indicative resource allocation' was renamed 'Individual Budget' by In Control in 2004. Subsequently, the Government's own enthusiasm for the idea led to In Control being requested to use an alternative term. Hence, from 2006, In Control used the term 'Personal Budget.' However, in **Putting People First** the term 'Personal Budget' is preferred to 'Individual Budget'. As defined by In Control all three terms are identical in meaning.
- 3 See **Making it Personal** from Demos.
- 4 See **Keys to Citizenship** from Paradigm.
- 5 See **A Report on In Control's First Phase 2003-2005** and **A Report on In Control's Second Phase 2005-2007**.
- 6 See **A Report on In Control's First Phase 2003-2005** and a whole range of materials available at www.in-control.org.uk
- 7 See **Personalisation: Seven Steps of Self-Directed Support** by Bennion, Crosby and the Commissioning Team, DCSF (September 2008, awaiting publication).
- 8 See **The Economics of Self-Directed Support** from In Control.
- 9 **Individual Budgets and Self-directed Support for Children and Young people, Examples of Workforce Development and Budgetary Management**; Cathles and Crosby, June 2008 (unpublished).
- 10 **Introducing Individual Budgets and Self-Directed Support for Disabled Children and their Families**, Crosby, Miller, Office of Public Management, 2007.
- 11 Based on **Commissioning Change for Children – Understanding how the Budget Holding Lead professional Role can transform services**, Miller and Smythe, Office of Public Management, 2006.





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