

A strategy for change



Making personalisation a reality for children, young people and their families

Nic Crosby

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Acknowledgements

As a final report setting out four years of work, acknowledgements need to be made to everyone who has supported and participated. There are too many people to name all, but a big thank you to everyone from children’s services who have taken part, to all the families who took a step into the unknown with their children, to everyone at In Control who supported this work and to our growing group of partners who have got involved and started to think what this all means for them and their organisation.

Nic Crosby

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Foreword

I am really delighted to present this report of the learning to date from In Control's Children's programme and the strategy for change that flows from this work. Most importantly, four years of effort and experience, with 40 children's services has led to many real improvements to the lives of children and their families – that's what we are here for.

Very excitingly, the work has also pointed the way forward, revealing the steps that children's services can take to make these improvements happen for all. Crucially, we are building approaches which start from children and family's own assets and resources and in the context of their whole lives and communities. This allows us to avoid limiting people to the goals and resources provided by specialist services. The important contribution of services is via self-directed support, with the massive opportunities this presents for flexibility and joint contribution.

We are in challenging times but this is also a moment of opportunity, similar to the 1980s which was both a period of severe pressure on public resources but also the time when de-institutionalisation for disabled people really started to gather pace. Personalisation is here to stay in government policy and there is political consensus behind it. We will see both the spirit and culture of personalisation and the mechanism of self-directed support and individualised funding driving policy, including in children's services. This is an opportunity to be seized both by families and children wanting full lives and by those working across the children's sector frustrated by the limitations of our current service models.

This report makes a contribution, by offering approaches, mechanisms and concrete examples for the application of self-directed support to change children's services. We look forward to further developing these approaches in practice with partners over the coming years. Most of the work to date has been focused on supporting disabled children and their families; however, from the very early stages links have been built with emerging practice around budget holding and individual commissioning. These links and the ongoing sharing have informed our understanding of how personalisation can work for children and young people. All our work is focused on a single and simple way of supporting all children, young people and their families to self-direct their lives. We do not believe it would be a useful exercise to set out a pathway for disabled children and another for children and young people who are being supported for other reasons.



Julie Stansfield, Chief Executive, In Control

In Control

In Control is a small charity and our mission is to create a fairer society where everyone needing additional support has the right, responsibility and freedom to control that support.

We operate as an extensive community network that is working for change and to provide people with the knowledge, power and tools to control their support.

This community for change includes:

- individuals who need support as a result of age, disability or social disadvantage, together with their families
- user-led organisations
- government and civil servants
- local authorities, elected members and paid staff
- commercial companies
- charitable and not-for-profit organisations
- general members of the public.

Through this community for change, In Control:

- works directly with people who need support, and with their families, to seek ways in which they can learn from and work together to provide mutual support
- develops and tests new and innovative ways for people to be in control of their lives
- develops simple, effective ways of measuring the impact on people's everyday lives
- gives advice and information through fact sheets, events, DVDs, books, leaflets, workshops, forums, events and by linking people with the right people who can help

- holds a national overview of best practice and shares this with our members
- is developing ground-breaking new technology – shop4support - that helps people take charge of their support so they can live the life they want.

The history of In Control

We began our work in 2003, when a small group came together in Wigan, Lancashire, to try and change things for some local families with disabled members. The group found inspiration in the independent living movement that created direct payments and in the inclusion movement that works to help people with disabilities to live and work at home, in their own communities.

This small group was responsible for pioneering the concept of self-directed support – based on the concepts of self-assessment, transparent resource allocation, support planning and review. This self-directed support model was successfully piloted in six areas across England showing hugely positive outcomes for people with no increase in costs.

In 2007, this work influenced Government policy and resulted in the Putting People First concordat. In Control then went on to develop as an independent social enterprise with charitable status. We are now actively working to promote self-direction for people at all stages of life, children and young people and for users of health services, as well as focusing on what it is that communities need to promote choice and control for all.

Introduction

In Control has taken a leading role in driving forwards the use of personal budgets, self-directed support and the wider personalisation agenda since its beginnings in 2003. Over the past four years, we have built from scratch a programme of work with children’s services, solely funded by annual subscriptions.

We are now working with 40 children’s services across the country, across sectors (health, education and social care) and with all partners including families, children, voluntary sector organisations such as Barnardos, Action for Children and KIDS, development groups such as OPM and the Local Government Development Agency and Government departments.

Our response is built upon four years of work with children’s services, developing our understanding of how self-directed support works, what personalisation means for children, families and the services working with them and our wider work across adult social care, health services and local government.

Over the past four years, we have worked with the following local authority children’s services:

Northumberland	Dudley
North Lincolnshire	Hartlepool
Essex	Gloucestershire
Newcastle	Hull
Lincolnshire	Devon
Cambridgeshire	Leeds
North Tyneside	Wokingham
Oldham	Bradford
Gateshead	Southwark
South Tyneside	Kirklees
Halton	Newham
Wirral	Calderdale
Gateshead	Islington
Manchester	Sheffield
West Sussex	Redbridge
Middlesbrough	Doncaster
Stoke-on-Trent	Barnet
Medway	North East Lincolnshire
Barnsley	Enfield
Redcar & Cleveland	Northamptonshire

Introduction - our vision

- **Founded upon our work with 40 children's services over the past four years.**
- **Informed through work with families and children which has seen the take-up of over 500 individual budgets, across all ages and support needs.**

This paper sets out a Strategy for Change for children's services and their partners including the voluntary sector and children and families. This Strategy for Change draws heavily on work detailed in three briefings published this year by In Control covering practice, discussion and evaluation. In turn, this work brings together four years of work with children, families and children's services who are part of the In Control Children's programme.

The Children's programme is part of In Control's vision of a whole life approach to individual budgets, self-directed support and personalisation. Our vision, as set out in our Vision 2020 document¹, focuses on three key ideas:

- **Real wealth** – the individual's resources which may or may not include an individual budget
- **Whole life** – sees the individual in their whole context; across support needs and ages
- **Community** – the place we live, the place we meet

In the next year we will be setting out in much greater detail what this means in practice. Simply put, the individual makes use of their 'real wealth' to live their 'whole' life in their local community and wider society. We see personalisation as bringing together investment in an individual's real wealth with investment and support to the local community, thus enabling people to be active with the support they need, to be healthy, safe, to play, learn, socialise, participate and contribute.

This work is already underway in some local authorities, we are working with a small number of members to develop our and their understanding of 'whole life', we are also beginning work with a similar group of local authorities mapping out 'life-long disability services' and we are continuing to bring together learning about successful community development work from across our membership. For the children's world, where there is yet to be any clear formal policy statement made by the current Government, much of this is only at its very earliest stages; this Strategy for Change sets out what needs to happen to make individual budgets, self-directed support and personalisation a reality for children and families across the country.

In Control sees the soon-to-be published Green Paper for SEN and Disability as a once-in-a-lifetime opportunity to make a lasting transformation to disabled children, young people and their families experiences of support from education, health and social care. We see this as the opportunity to take forward support which centres on the whole child not on distinct parts of their lives; we see this as the opportunity to set out a single, simple approach to meeting the support needs of a child and their family and in so doing giving families the control over how their child grows up, how they live as a family and how they look to the future with confidence. This is how most families lead their lives. In Control sees this Green Paper as the chance to make this a reality for all families, whatever support they or their child need.

Summary

This Strategy for Change sets out the actions needing to be taken by the Government, children's services, their partners, and children and families, which if completed will ensure that children, young people and their families will be able to take control of their support and their lives.

The outcome

All disabled children and young people are able to participate in the life of their local community, are able to learn, aspire and achieve; and with the support of their family are able to self-direct their lives and the support they need.

A life-long approach to supporting the needs of disabled children, young people, adults and older people, across all ages and support needs; a whole life approach to personalisation².

The process

Self-directed support is the single approach to meeting the support needs of any child or young person and those of their family whether learning, personal or health related.

A personal budget is allocated where the child or young person needs additional support above that which can be offered in mainstream and universal settings.

Delivering self-directed support and individual budgets

The Government will set out its expectation of a whole life / life-long approach to meeting the support needs of any disabled child, young person, adult or older person and those caring for the individual.

The Government will identify the funding in health, social care and education which it expects to see as part of a child or young person's individual budget.

The Government will act to remove regulatory barriers set around the management of funding streams which restricts their flexible use as part of a child's individual budget.

Children's services will work closely with parents and families; ensuring that family representatives are involved and have a say in how self-directed support is introduced and how all disabled children and those caring for them are involved in a real and meaningful way.

Children's services will ensure that all families know how to get help when they need it, either when their child is very young or when there are changes in health, family circumstances or a crisis which affects the child.

Children's services will ensure that there is an open door in local communities for families to seek information, advice and guidance on local opportunities, support networks and activities which their child can participate in.

Children's services will make every effort to include the child in local activities, services and education and where this cannot be clearly achieved without additional individual support an individual budget is allocated to that child.

Children's services will provide all families and children, from the outset, with clear information about their responsibilities, the responsibilities of the children's services, the self-directed support process and any agreements regarding money management, contingency, risk management, crisis management, review/audit. That children's services ensure that families are given the support they need to understand this information.

Children's services will allocate an individual budget; each children's service will adopt an approach to resource allocation which enables them to tell families what financial resource is available to contribute to the meeting of the support needs of the disabled child or young person.

Children's services will ensure there is a choice of support which focuses on helping families making best use of all their own 'real wealth' and local resources and which may include an individual budget. That this choice of support will centre on commissioned support in the voluntary and community sector from organisations rooted in the life of local communities.

Children's services will, in agreeing to fund a support plan, base that agreement on the ability of the support plan to deliver three simple outcomes or variations based on Every Child Matters.

- Having a safe and healthy life at home, school and in the local community.
- Being able to learn, aspire and achieve.
- Being able to participate in family, community and school life.

Children's services will support children and families to explore child-centred, flexible and creative ways of getting the support needed. Children's services, through their commissioning activities and partnerships with community, voluntary and private partners, will ensure the provision of good-quality support options. That families have easy access to this local offer of support and can use this information in the development of their child's support plan.

Children's services will continue to commission/ provide a 'sufficiency' of support enabling them to respond to crisis, periods of ill health or changes in family circumstances. It is the duty of every children's service to ensure that they are able to meet the support needs of any child assessed as a child in need. For disabled children, the vehicle for meeting these support needs will be an individual budget whether managed by a lead professional, a voluntary organisation or a family member. The children's service will always need to be able to respond to crisis, changes in health or in family circumstances or if a support package should break down.

Thinking more widely

Children's services will, in embracing the whole personalisation agenda, recognise the need for skilled commissioning, the need to invest and support the real wealth and social capital in local communities and embed self-directed support as the single and simple approach to helping children and young people who need support.

The outcome

All disabled children and young people are able to participate in the life of their local community, are able to learn, aspire and achieve; and with the support of their family are able to self-direct their lives and the support they need.

A life-long approach to supporting the needs of disabled children, young people, adults and older people, across all ages and support needs; a whole life approach to personalisation³.

The process

A single approach to meeting the support needs of any child or young person with Special Educational Needs and/or disabilities.

The Seven Steps of Self-Directed Support



Figure 1 – Seven steps of self-directed support, 2010

1. Self-directed support⁴ will be the single approach to identifying support needs (whether learning, personal or health related), making best use of all resources and developing a child-centred plan which addresses the support needs of the child in the family context.
2. Where it is not possible to meet the support needs of a disabled child within mainstream services, the child and family will be given an indicative allocation of financial resource which they can use alongside all other resources available to meet their support needs and provide the child with a healthy, stimulating and safe home life.

3. Where a child requires support across different public services (health, education and social care) that the child and family are provided with an indicative allocation of financial resource from each public service which will be used as a virtual individual budget to develop a single support plan aimed at meeting the support needs of the child and family 'in the round'.

This approach will ensure that all children and young people are given the support they need which will enable them to be active members of their local community and the wider society. This approach, aligned with work in adults' services and with health services, sets out a single approach supporting all, and their participation in an inclusive and diverse 'big society'.

Explaining self-directed support

In Control first set out the seven steps to self-directed support in 2003. We understood that from the start how we explained self-directed support and individual budgets would change as we worked with a wider group of people, families and services. We have learnt through our work in the last few years, including that with children and families and in health that people take control of their lives and their support in a wide variety of ways. Money is always important in this, but it is always a means to an end; and it is not always an ‘individual budget’ in the narrow way we understood it in 2003. We have always been clear that money alone will be insufficient. Information, support to explore how to make the best use of all resources the person, child or family bring to the process, access to expertise as and when needed, and different ways to ‘hold’ any money are also necessary.

We see our seven steps of self-directed support as a best-practice model of supporting any child, young person, family, adult or older person when they need some additional support to enable them to stay safe, be healthy, and be able to make a contribution to the life of their local community and the wider society.

We are confident about saying that self-directed support is ‘best practice’ because, through following its seven steps, the individual, the child and their family take control of the decisions about how their support needs are to be met .

‘Real wealth’: at the heart of self-directed support.



Figure 2: Step 2 – The seven steps of self-directed support



Figure 3: Real Wealth

Figure 3 sets out all the resources that the child, their family or the individual bring. We describe these resources as the ‘real wealth’ of the family or individual.

- **Connections** – the important people in a person’s life, people who love, respect and care for the child or adult
- **Access** – being able to get out and about, use cars and public transport, being able to access information and knowledge
- **Capacities** – skills, abilities, knowledge, learning and work within the family or the person’s own capacities
- **Control** – the assets under the control of the person/family, including capital goods such as a house and maybe including an individual or personal budget
- **Resilience** – at the heart of our real wealth; physical and mental health, emotional well being, inner strength, faith or belief system of the person and/or family

The state may then add to these resources through the allocation of an individual budget. This is an additional resource offered in specified circumstances where it is determined that the person or family needs it to achieve specific outcomes. In order to maximise the opportunity for choice and control, In Control always prefers the direct allocation of an individual budget to the use of pre-commissioned specialist services. Sometimes people will choose to buy such services with their budget, sometimes they will buy ‘universal services’ that everyone in the community uses.

Whether or not the child, family or person are allocated an individual budget, the real wealth remains theirs, and hence how it is used is under their control. The skilled support from a social worker, lead professional, care manager, education or health professional will help families explore how this wealth can be used to enable them to find their own solutions to the challenges they face. If we are to change the relationship between the child or adult with the state then it is essential to value and recognise the individual’s real wealth and their entitlement to control how they make best use of it.

Self-directed support is an approach which values the ‘real wealth’ of the person or the family. It welcomes, when necessary, expert professional advice on the best treatment or support options which are known, to inform the solutions on offer. It makes it clear that solutions to the issues faced by the person or the family are to be found largely in their own hands, with the help of those closest to them, and relevant expertise and specialist knowledge. In some circumstances, an individual budget is needed to boost their ability to achieve this.

Why self-directed support and individual budgets?

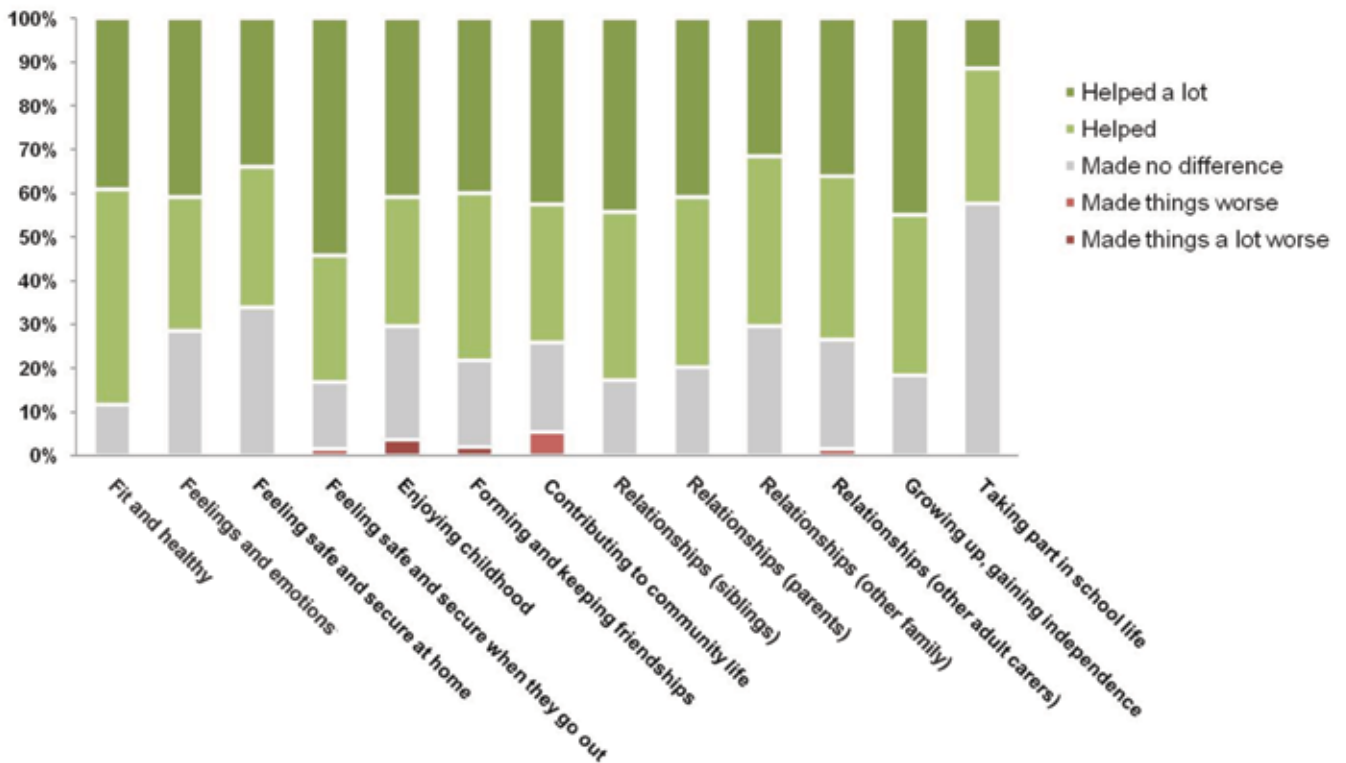
In Control pioneered the development of the seven steps to self-directed support and individual budgets. There are clear reasons why this approach should underpin a new approach to supporting disabled children, young people and families. We see this process being common across social care, education and health, and working from the first time additional support needs are identified.

Self-directed support and individual budgets have a positive impact on outcomes for disabled children, young people and their families.

The following two graphs have been compiled from the first tranche of responses from families who have completed our Evaluation and Outcomes Questionnaire. They record the outcome of moving from a current support package to a support package based on an individual budget using self-directed support for 67 children and families.

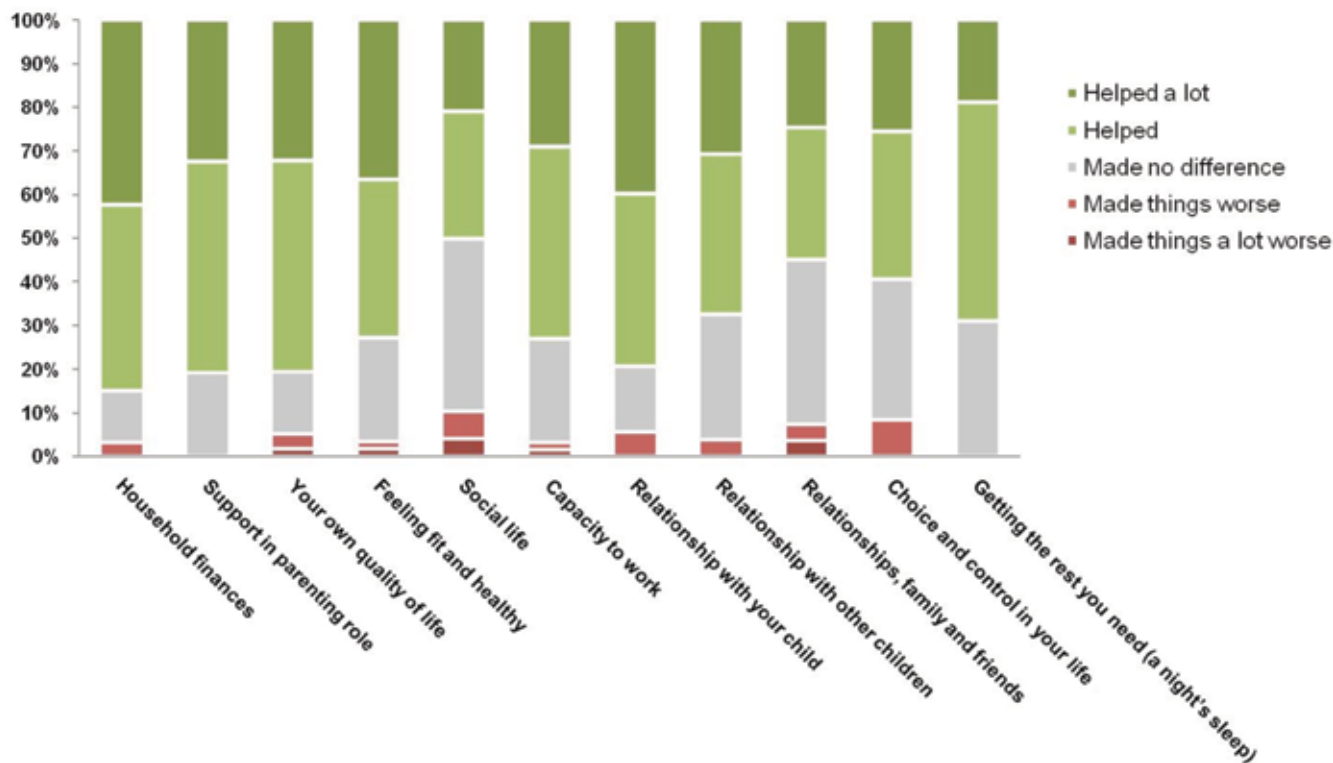
These outcomes are based on a slimmed down set of statements used in the Every Child Matters Outcomes Framework. The questionnaire has been designed in consultation with families and professionals in our members' sites and follows a similar process to that in use across the country in adult services.

Reported change in areas of your child's life



Graph 1: Outcomes for Children and Young People

Reported change in areas of parent's life



Graph 2: Outcomes for Families

These results are taken from an evaluation currently underway in one of our member authorities. It logs the results from 67 families who responded to our questionnaire. There are a further four evaluation programmes running with our members. Results from these will be added in to provide a wider picture.

Both graphs evidence an average 50%+ improvement in outcomes for child and family.

Self-directed support and individual budgets make a real difference to families; valuing the whole family and their desire to offer their disabled child a healthy, safe and fulfilling home life.



Excerpts from a discussion about individual budgets and self-directed support with families in an In Control Children’s programme member children’s service. This discussion was titled ‘What’s working?’

- everything at home is settling down
- everything as a family – we have control over the money and we have a family life
- the flexibility we have – we can make changes if we need to
- having a ‘great’ carer inspires confidence to do new things – it has opened up all sorts of opportunities
- it has changed family life for the better
- we have a bright hope for the future for our son...now
- peace of mind and ownership
- it stopped the family going into crisis
- family and son decide – helps son start speaking up, making his choices, it gives the family more control, it’s not just about son but brothers and sisters

Parents in Newham at a recent evaluation meeting spoke of the positive impact having an individual budget has had on the lives of their sons and daughters and on their own family lives. They also spoke of the difficulties they have experienced in being part of a pilot where the children’s service is learning how to make individual budgets and self-directed support work. Their input has informed the second part of our response which discusses the key actions of children’s services in delivering self-directed support.

Self-directed support and individual budgets place the control of support in the hands of the child, young person, their family and those caring for the child.



Zubair Bawa explains, in his own words, what it means to his son Asim and his family having an individual budget.

IB money is allocated according to the Resource Allocation Points System oppose to old system of Social Service Assessment Care Package.

“Choice” given to the child and the family, how Support Plan can be written and amended according to what child wants/needs.

More “choices” of how and where the IB money can be spent, meaning that the support child receives can be organised in a way the child wants/needs which ultimately gives child “Control” of the way he lives his life and because of this, it is evident that Council is very broadminded by allowing/giving power to the child and parent/s to choose how the money can be spent and on what service the child wants/needs. I have broken down this further below:

- a) the Council has worked really hard with parents to get the support plan and IB basics structure in place. The Council has guided/ supported parents all the way through.***
- b) able to choose the “right” support worker according to the child’s wish/needs.***
- c) Being able to make changes to child’s support arrangements.***

d) feel that the child is safe and cared for in the absence of a parent.

e) child has achieved, improved and learned a lot in terms of self-confidence, independence, learning skills, social development, making friends, bring more active and most of all he now able to catch-up of the activities/things he missed in the past as a child.

f) his physical health and emotional wellbeing has also improved.

g) the IB Review is done in a simple manner but in correct way, the child and parents can share and talk about the problems/ achievements.

h) it’s good to see that the Council is seeking feedback from child and parents about how the IB can be improved.

As a parent we get the break we need, which means good night sleep, being healthy physically and mentally and good quality of life.

Overall child and the whole family quality of life have improved and changed.

I want to say thank you to Social Service Dept of the Newham Council and In Control for improving my son’s quality of life and giving my son IB support which he really needed, without your support, this would have not been possible, I really mean that.

Zubair Bawa (parent of Asim Bawa)

Self-directed support and individual budgets offer a simple, transparent approach to the allocation of limited resources (from education, social care and/or health), thus enabling maximum creativity and flexibility in the use of money in meeting the support needs of children, young people and their families.

The current approach to the allocation of financial support relies on the completion of an assessment and then the writing of a care plan. Only when the care plan is complete (setting out how the child or young person is to be supported) will an application be made for funding to deliver the plan. Currently a care plan is likely to consist of some 'block contracted' provision, possibly with some element of direct payments costed at the number of hours per week the child or young person needs. Care Plans prescribe the use of resources and restrict the creativity and flexibility we see as soon as we change the steps in this process⁵.

Using a self-directed support approach, following the completion of an assessment whether using the Common Assessment Framework or a Core Assessment, a Resource Allocation Questionnaire is completed in partnership with the family. This means the family are party to all decisions being taken about the size of budget needed to fund support for their child. The result of the Resource Allocation Questionnaire is an 'indicative allocation'. It is then the task of family, child, young person and supporting people to write a support plan which uses the indicative allocation alongside all the other resources the family has to draw on. In Control defines the resources a family and/or individual has to draw on as 'real wealth' (see fig 3).

This approach of making available an upfront allocation of money resource which can be used flexibly and creatively, and in many examples, make good use of the real wealth of the family means driving an agenda of efficient and effective use of limited resources.

Self-directed support and individual budgets are central to personalisation for people of all ages and support needs; they need to be accessible to all children and young people in the same way that they are accessible to any eligible adult.

In September 2010, it became an expectation that all new entrants to adult social care would be offered a personal budget. This means that all young people deemed eligible for support from adult social care would have a personal budget which would be used as part of their support plan to provide the support they need to live an active adult life. For most disabled young people this is completely different to their experience of support. Although there are a few examples, mainly members of In Control's Children's programme where young people already have an individual budget and a support plan, and a larger number of families and young people with direct payments, it is a new world of person-centred working, creativity and flexibility that they are entering.

Halton, a member of In Control's Children's programme, has piloted the allocation of an individual budget to families with very young children. Often small, these budgets have enabled families to decide how best they would like to get some support or take a short break. Families are learning skills which will serve them well as their child grows up and eventually enters the adult world. The families' experience of support will be completely different.

Newham has taken an approach of linking a small allocation of funding (up to £3,000) with the completion of a Common Assessment Framework (CAF), using the Aiming High for Disabled Children Grant. This has meant the first response to identified support needs does not come from the specialist Disabled Children's Team but at the very first time support needs are identified, and was targeted at Aiming High Priority A and B groups where there was a need for a short break identified; i.e., the method of early intervention is based around the use of a small individual budget and the rest of the 'real wealth' brought to the table by the child and family.

Self-directed support and individual budgets challenge all those supporting disabled children, young people and families to deliver support tailored to the individual needs of the child or young person.

In Control has worked closely with KIDS, sharing knowledge and practice. Kevin Williams, Chief Executive of KIDS explains the challenges of individual budgets and self-directed support.

Although KIDS is committed to inclusion, person-centred planning and the rights of individual disabled children, until recently all our structures were based around 'services' and not 'people'.

KIDS has been shaped by the following parameters:

- *the local authority is our customer*
- *we provide 'Wholesale Services' which are purchased in bulk by the local authority*
- *we are highly regulated*
- *our marketing is aimed at 150 local authorities*
- *our finance systems are geared up to manage low numbers of large value invoices*
- *we have contracts which we are used to being stable for three years*
- *our staff 'learn on the job' in group settings.*

For KIDS, personalisation means the following:

- *the Disabled child/family are our customer*
- *we provide 'Retail Services' which are purchased individually, family by family*
- *these services may be lightly regulated*
- *our marketing is aimed at 700,000 disabled children*
- *our finance systems need to manage high numbers of small individual transactions*
- *customers will buy what they require when they need it – no guarantees*
- *our staff will be working on their own – and need in-depth training*

KIDS is taking the following practical steps:

- a new national database of every child we work with so that we can relate to every family and efficiently feed into national eCAF
- staff training to emphasise meeting the needs of the family
- raise profile of KIDS amongst families – don't focus on local authorities
- new accounts software system and setting up credit card booking system
- a new web-based booking system www.directshortbreaks.org.uk for families to book KIDS one-to-one support whenever they want it, at the time they want
- a new E-learning package for KIDS staff.

Self-directed support and individual budgets maximise the potential inclusion in the mainstream world of activities, learning and opportunities for disabled children and young people.

In Gloucestershire, particular attention is paid to Step 2 of the Seven steps of self-directed support (see figure 4).



Figure 4: Step 2 – The seven steps of self-directed support

Following the completion of the CAF, the Community Lead Professional (CLP) team explore with the family the different mainstream options available where many of the child's support needs could be met; i.e., they start by thinking of the child as opposed to the disability. They then, using small amounts of resource if needed, support the child in joining and participating in mainstream activities and provision, for example local nurseries or summer play schemes.

At this stage, the CLP team make every effort to only access mainstream or universal services. It is only when they exhaust these options that they move to the use of an individual budget. Families consistently report their appreciation of the work of the CLP and the positive outcomes for their child in participating along with other children of their age in the local community and in mainstream children's provision.

This approach is focused on making best use of the families' real wealth along with the opportunities and provision within the local community. It is self-directed support because the family remain in control of how their child is supported and their common aspirations of their child having a life like all other children is central to all decisions and plans made.

Self-directed support and individual budgets work across social care, health and education

Across our members, often at an individual level, we have worked across the three sectors to bring funding together from different streams and use them as a single virtual budget to develop a single plan which delivers outcomes agreed by each of the funders.

We recognise the current statutory regulations across the three sectors are different and as such have had to work within these to make this happen. We have supported flexible allocations from children's social care which can be managed as direct payments by families. With regard to health funding, we have supported the setting up of a small number of User-led Trusts which manage the health funding via an agency, and we have also supported the bringing together of health funding with social care funding which is made available via a children's social care service as a direct payment.

Working with education funding (learning support funding) has proved more challenging to date. However, our work in partnership with ibk initiatives, MENCAP and others, with post-16 funding in Sheffield⁶ evidences that it is possible to manage a virtual individual Learning Support Fund (LSF) as part of a single plan where an education provider manages the individual LSF. The Resource Allocation System, commissioned by the national Learning and Skills Council in 2007⁷, is now in a revised format a central part of the YPLA Transition Paperwork. The Resource Allocation System, which identifies a young person's individual Learning Support System is in use in Sheffield and has been used for the past two years.

To develop a sensible approach to individual budgets, where funding from different sources is flexible and able to be used as part of an individual budget, In Control sees the development of consistent approaches across social care, health and education as of paramount importance. Social care funding can be taken by a child and family as a direct payment, legislation is on its way which will see similar flexibility being applied to some parts of health funding. In Control sees it as an absolute necessity that this is extended to education for any child or young person where the mainstream schools provision is not able to offer the child or young person the additional support they need to ‘participate in learning activities with an identified learning outcome’. In the first case, this means moving to a situation where ‘additional learning support funding’ is allocated against a child’s learning support needs and then used as part of a combined individual budget. We have a strong range of examples of this approach where the individual LSF is part of a virtual budget; meaning that it is managed by a learning provider as part of an integrated approach to meeting a young person’s support needs.

In Control, however, sees a further move as necessary. We believe strongly that learning support funding should be made available as a direct payment, using the same model as is already well established in social care.

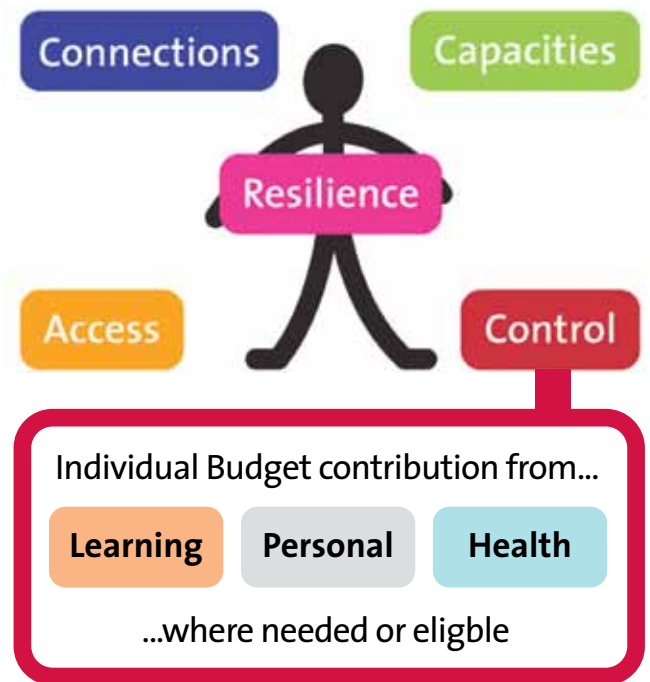


Figure 5: Integrating funding around an individual child’s support needs as the ‘State’s investment in a child and their families Real Wealth’

The focus of self-directed support is enabling children and families to make best use of all their real wealth. This graphic explains how an individual budget comprising of one or more funding streams becomes part of the real wealth upon which the child and family will base their support package. To make this achievable, a simple, consistent approach to allocating money from funding streams is necessary as is a simple, consistent approach to explaining who and why can receive this funding.

Delivering self-directed support and individual budgets

This set of actions is based on four years of work with children's services as part of In Control's Children's programme. We are drawing on examples of good practice across the country, which together set out the key actions for the government and children's services delivering personalisation for disabled children, young people and families.

In this chapter, we set out the different actions needed to be taken by a number of key agencies, departments and organisations to facilitate this transformation of the support received by disabled children, young people and their families. We have set out actions for the Government, local children's services and the voluntary and private sectors.

The Government, much in line with In Control's emerging work on the role of community, see most of the delivery of support moving from the statutory sector to the community and voluntary sector. There is no simple definition of community, apart from a local geographic population and opportunities and activities which join this population together. The voluntary sector, local authorities and national government all have a role in supporting the emergence of local communities as not only the place we all meet but the space in which people find the support they need.

Following each statement of action is a small piece outlining work linked to In Control's Children's programme; each statement is based upon development and real change.

The Government will set out in its Green Paper for SEN and Disability its expectation to see a single whole-life approach to self-directed support and individual budgets for disabled children, young people and their families.

There can be no sense in having one approach for children and another for over 18s. There are differences in how self-directed support can work; however, the basis of using the seven steps of self-directed support are already prevalent across the adult sector, being tested in the health sector and developed by 40 children's services in England is inarguable.

Families should be in control of how their child is supported in all settings and for all their needs; they need support to do this from specialists across the social care, education and health spectrum; self-directed support and individual budgets will enable them to take the control they feel able to take and to share the planning with experts and specialists when necessary.

In Control's work with children and families has informed our developing understanding of what 'whole life'⁸ means, where the focus is the individual and not the different needs. Individual budgets and self-directed support are essential features of the whole life approach, and need to be a consistent offer across all ages and/or support needs.

The Government will set out in its Green Paper on SEN and Disability its expectations about which funding streams will be available to be used as part of a child's individual budget.

In Control set the boundary between that which remains within statutory or commissioned mainstream/universal resources and that which can be individualised as ‘**additionality**’. Simply explained, we set the boundary where it is not possible to meet the individual’s support needs within existing mainstream and universal provision without the availability of additional individual support, whether learning, personal or health related.

If we stand back from thinking about sectors of funding and think about the whole child in their family context In Control sees the allocation of an individual budget as being based on the need for additional and individual support to make a simple set of outcomes real for a child and their family.

In our paper setting out a Round Table Discussion in June 2010⁹, all participants agreed that the global outcome is ‘a life like all other children’. To date we have used the Every Child Matters outcomes:

- Stay Safe
- Be Healthy
- Enjoy and Achieve
- Make a Positive Contribution
- Achieve Economic Well-being

Using outcomes as a basis for resource allocation, planning and reviewing has given us the tools to embrace funding from a variety of sources, although to date this has proven difficult.

All funding works together to deliver a global set of outcomes, how the money is used is based on the individual child or young person’s support needs and their family’s circumstance and real wealth.

The Government will, in setting its expectations of flexible funding streams linked to additionality, ensure that all regulations restricting the individualisation of funding and the potential control of that funding being placed with the family are removed.

As explained, the potential linking of funding streams in work across our membership and being able to offer families the opportunity to control that money has been restricted by regulation and people’s understanding of what is and what is not possible. Much of the responsibility for unblocking funding streams lies with children’s services; however, the Government can aid this through a consistent definition of an individual budget, what funding can and should be part of this and how this individual budget can be controlled by the family.

Children’s services will work closely with parents and families; ensuring that family representatives are involved and have a say in how self-directed support is introduced and how all disabled children and those caring for them are involved in a real and meaningful way.

From the outset, all our work has been informed by the views and the experiences of family members, for example, the Resource Allocation System has benefited from many parents’ views on language and content. When we started work, there were not many examples of real and meaningful participation by family members; this is not the case now.

Gloucestershire have, for some years, had parent representatives sitting on their Joint Commissioning Group; Newcastle have put family involvement and leadership at the centre of their programme of work to develop both information resources and support provision. In Calderdale, the Parents' Council has taken responsibility for supporting all the families involved in the piloting of individual budgets with support planning; in Newham, a similar group of parents, called 'Parents' Exchange', hold a monthly exchange of information and a chance to meet up with others.

Children's services will ensure that there is an open door for families to seek information, advice and guidance on local opportunities, support networks and activities which their child can participate in.

In many ways, not a new development; ensuring families can access support when they need through offering an open and accessible 'door' has been a long-term development for children's services. This illustrates why some of the actions highlighted here are familiar and how the whole strategy is not simply about starting from scratch but about building on good practice in an area.

The key here is accessibility, and then ensuring that all families know how to get help when they need it; via school, a GP, health visitor, nursery, via support groups or other pathway. In Control's children's programme has been, with a small number of members, exploring the role of children's centres in terms of their links with support networks, other services and their role already of holding information about what is happening locally. However, a children's centre is unlikely to be most families' first place to visit when looking for help with supporting their child.

Children's services will make every effort to include the child in local activities, services and education, and where this cannot be clearly achieved without additional individual support, an individual budget is allocated to that child.

In Gloucestershire, they have developed a CLP team (based on their piloting of Budget Holding Lead Professionals). The CLP team, as explained earlier, complete a CAF and then seek to find opportunities and activities with the local mainstream/universal services for the child, often needing to access a small budget to support any training or small equipment needed to include the child and meet their specific needs. Only once this has been exhausted is there a need to turn to using an individual budget. This is a good example of how self-directed support, in this case without an individual budget, delivers a prevention/early intervention approach to meeting the needs of disabled children and young people.

Children's services will provide all families and children, from the outset, with clear information about their responsibilities, the responsibilities of the children's services, the self-directed support process and any agreements regarding money management, contingency, risk management, crisis management, review/audit. That children's services ensure that families are given the support they need to understand this information.

Highlighted by many families involved in early pilots has been the lack of good easy-to-follow information about the 'do's' and 'don'ts', how to plan, what it means to take on a direct payment and how reviews will work. Many of our members have now developed this information which is shared across our network.

Children's services will ensure that all families know how to get help when there are changes in health, family circumstances or a crisis which affects the child.

No support plan can be written which can take account of any or every thing that happens in a child's and their family's life over a year; families should always feel able to ask for help, should know who to ask and should be involved in all discussions, re-planning or change in support.

Newcastle Children's Services, using Aiming High funding, has commissioned In Control and Paradigm to develop, working with key local organisations, a group of families who will lead the development of information resources on the Family Information website and the City Council website. The outcome of this work will be a solid and useful bank of information designed by parents for parents and families using personal budgets to get support for their disabled son or daughter held by the Family Information Service, whilst the City Council website will carry information about process, contact information and crisis support. Both websites will link to each other.

Children's services will adopt an approach to resource allocation which enables them to tell families what financial resource is available to contribute to the meeting of the support needs of the disabled child or young person. This approach will be based on 'transparency' and 'participation'. Families will understand how resources are being allocated and they will participate in the process.

Children's services working with In Control have, over the past four years, developed a consistent approach to the allocation of an indicative budget. Although formats are different, the basic approach of using the Every Child Matters outcomes to allocate funding remains the same. Initially drawing on the outcomes framework for Every Child Matters, the approach allocates points against the amount of support a child needs to make an outcome real for them; for example, the outcome is 'I am safe with the people who share my home and who look after me at home'. The points represent the amount of support for this to be true. There is no measurement of deficit or impairment which is challenging to families and professionals alike, both have said though that they appreciate both the outcomes and also the transparent approach to resource allocation where families and professionals sit together and complete the paperwork. Basing allocation on a transparent and participative approach is essential; decisions about allocation can no longer be taken behind closed doors, this historic approach is inefficient and generates a culture of animosity and challenge where families feel they have to fight for the support their child needs. The consequences of this are all too familiar; those who fight strongest and hardest get higher levels of support than those who are not or do not fight. Transparency and participation tackle this head on; families on the pilots across the country consistently talk of their appreciation of being involved in this part of the process.

We have worked on a similar approach for the allocation of post-16 additional learning support and are about to embark on a similar outcomes-focused approach for health funding for children with long-term health needs.

Children's services will ensure there is a choice of support on offer focused on helping families making best use of all their own 'real wealth' and local resources and which may include an individual budget. That this choice of support will centre on commissioned support in the voluntary and community sector from organisations rooted in the life of local communities.

We all live in a geographic community, we all contribute to the community and wider society through taxation, we spend some or all our money in our local community, we often participate in community groups based around interests or decision making, we all benefit from the informal networks of friendships and support which exist in every community.

Using an individual budget to make the best use of all that is available locally will mean people using their money sparingly and individually to get the support they need. This will mean a complete change in what support people of all ages will be looking for; evidence to date backs up the premise that if given real choice people will move away from purchasing specialist services and look to employ personal assistants and make best use of the mainstream/universal opportunities available to them locally.

For children's services, it will not be enough to focus on the support provision needed by families. Prior to moving to needing an individual budget, families will need support to help them make best use of what is already available locally.

The In Control Children's programme has led us to explore the breadth of the lead professional role, and explore how children's centres, already a local children's community hub, can add to their expertise and skills, and help families to access local opportunities and activities.

Children's services will support the development of a 'choice of support' that will include a number of different longer term 'money/delivery management/ brokerage' options.



Individual budgets have to be available to all; how they are used, who manages the finance and the plan, who recruits and employs the staff is all part of the next step. Looking across the whole population of families with a disabled child it is clear that many families will want additional help to take their plan live, to manage the budget and staff, and to keep an eye on how it is working.

In Middlesbrough, the in-house services for disabled children saw this as an opportunity for them to extend what they offer and are now acting as budget holders for two young people. There are other small instances of provider services managing a budget on behalf of a child and their family; however, the provision of support with longer term management has not been a key part of most pilots, possibly due to the small scale nature of many pilots. The feedback from families would indicate that this is one of the most important parts of the whole jigsaw and children's services will have to invest in support to families if this agenda is to succeed.

There is potential here to link with similar developments in the adults' world; an achievable outcome of such a link could be the commissioning of a whole life support service which offers support to children, young people, families, adults and older people. Such a support service would change the experience of many families when their son or daughter moves from children's services into the adult world.

Children's services, in agreeing to fund a support plan, will be agreeing that this plan will deliver three simple outcomes or variations based on Every Child Matters.

- Having a safe and healthy life at home and in the local community
- Being able to learn, aspire and achieve
- Being able to participate in family, community and school life

Work with our members has clearly shown the positive impact of basing allocation, planning and review around a common set of outcomes. In our work over the past four years, we have used the five Every Child Matters outcomes:

- To allocate an indicative individual budget
- To structure a support plan, guiding families and professionals towards evidencing how the support plan will make these outcomes real for the individual children
- To support the 'agreement' to fund a support plan by providing a children's services with a common set of outcomes across every plan, i.e., supporting consistency when it comes to funding specific supports
- To review a support plan, by asking 'Have these outcomes been achieved...?'

Using outcomes gives a transparent explanation to all concerned about the basis upon which the decision to allocate an individual budget has been made, i.e., an individual budget is needed to ensure that the additional support needed achieves the outcomes.

Children's services will support children and families to explore child-centred, flexible and creative ways of getting the support needed. Children's services, through their commissioning activities and partnerships with community, voluntary and private partners, ensure the provision of good-quality support options. Families will have easy access to this local offer of support and can use this information in the development of their child's support plan.

In Control runs an Organisation Network which now has over 220 members; in the children's world, In Control are working with Action for Children, Barnardos and KIDS, supporting them to redesign their offer of support and to think through how other parts of the offer to children and young people may be able to play a part in helping families self-direct the support their child needs.

In many of our areas we have, with the children's services, held events for provider services where we have shared what is happening both nationally and in the local area. All of this is done with the view that it should help start services in thinking about what they currently offer and what they will need to be offering in the future.

Children's services will continue to commission/ provide a 'sufficiency' of support enabling them to respond to crisis, periods of ill health or changes in family circumstances. It is the duty of every children's service to ensure that they are able to meet the support needs of any child assessed as a child in need. For disabled children, the vehicle for meeting these support needs will be an individual budget whether managed by a lead professional, a voluntary organisation or a family member. The children's service will always need to be able to respond to crisis, changes in health or in family circumstances or if a support package should break down.



Thinking more widely

Self-directed support and individual budgets are central to the personalisation agenda. However, they are not the sole focus. Taking funding from many mainstream and universal services and personalising it would have a detrimental impact on many children’s experiences of taking part, playing, building friendships, learning, relaxing and enjoying family time

A focus on self-directed support and individual budgets has to be balanced with a focus on developing an increasingly accessible, attractive and inclusive mainstream provision or universal offers of activities and opportunities for children and young people to take part in. The long-term vision has to be one of all children and young people being able to take part in mainstream activities and opportunities and only where their participation requires additional support should there be a need for an individual budget-funded support package. To make this a reality, there is much reliance on good-quality and well-informed commissioning, i.e., commissioning focused on delivering such an outcome for all children and young people in the area.



Personalisation: a whole system approach

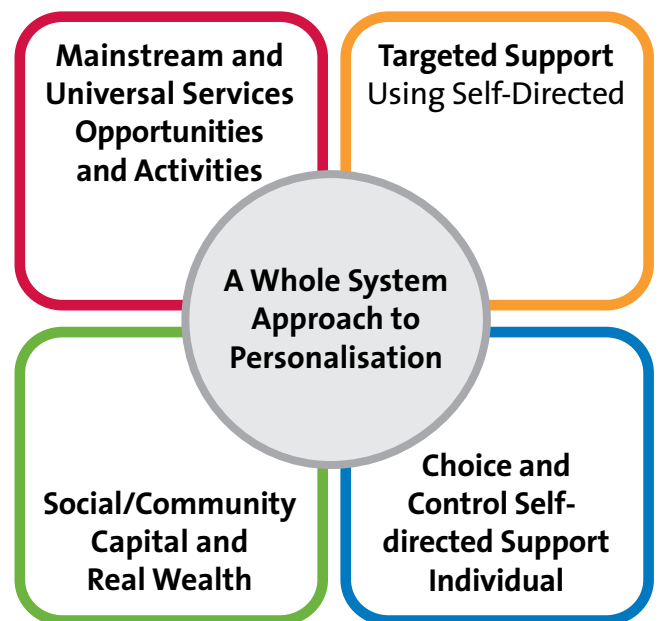


Figure 6: The Four Quadrants of Personalisation^{10,11,12}

Self-directed support and individual budgets are but one of four parts of personalisation as described in this graphic. A whole system approach to personalisation will focus on all four sectors.

Social / Community capital and real wealth

Making best use of all the resources and real wealth in the local community. For example, family networks, friendships, allotment associations, brownies and scouts, neighbourhood watch, volunteers. Underused in the past, investment in this quadrant will increase in line with emerging government policy; it is In Control's intention to ensure that this investment is not sporadic and un-organised but shaped under the banner of helping people to live full and meaningful lives.

Targeted support

Open to all, easy-to-access, low-level support dependent on situation or circumstance, working with the child, young person or family using a self-directed support approach. For example, teenage pregnancy services, parent and toddler groups, Connexions, youth services, play schemes, family support services.

Mainstream and universal services, activities and opportunities

Where the whole community meets: leisure centres, libraries, shops, open-spaces, schools, nurseries, churches, mosques, temples, synagogues, city centres, holiday facilities.

Choice and control

To support children, young people and families when they are not able to make use of the mainstream/universal offer without additional support, and/or targeted support identifies the need for additional individualised funding to help a child, young person or family in crisis. Using a self-directed support approach and an individual budget to provide the support needed for the child to have a safe and healthy home life and to make use of the mainstream/universal offer of activity, opportunity and service.

In many ways, figure 6, although useful in that it demonstrates the breadth of actions needed to make personalisation real, is misleading. Targeted services, mainstream and universal services and individuals are all constituent parts of local communities. We need to move to a situation where communities are recognised as the one place we all meet and the first place we turn to when we need support. It is the local authorities' responsibility to ensure that communities are supported in having an infrastructure in place which means it can be the place we turn to for support; in part, this will mean local authorities supporting local communities to commission the support services and wider range of opportunities which reflect the needs of all local people.

In centring support infrastructure within local communities, we see the importance of thinking outside of the existing silos of children's and adult services, thinking across the ages and how community resources can reflect the whole population as opposed to distinct groups banded by age or support need.

Children's services will, in embracing the whole personalisation agenda, recognise the need for skilled commissioning, the need to invest and support the real wealth and social capital in local communities and embed self-directed support as the single and simple approach to helping children and young people who need support.

Conclusion – our vision

In Control sees children, young people, adults and older people as whole people not as a different array of needs which may be met by different services or funding streams.

In Control sees it as necessary to move to a whole life approach to personalisation; one which has a central spine of self-directed support, where the child, family or individual person are in control of how they live their lives and able to self-direct how they are supported, treated and live.

Our vision is one of ‘welcoming’ communities where all are able to have a life like those of their peers and colleagues. Where children, young people, families and adults are not treated by label, but where they are treated as whole people in the context of their whole life.

The Green Paper SEN & Disability, due for publication in early 2011, offers an opportunity to make a lasting change to disabled children and their families’ experiences of growing up and living a full and challenging life. Real life is not without mistakes, risk or success; to date, we as a society have sought to protect and shelter disabled children and adults from real life. Work in the adult sector is already starting to move away from that historic stand point; this Green Paper offers the Government the chance to start the same moves for disabled children, young people and their families. This Green Paper can form part of bringing to life the Government’s vision of a big society; self-directed support, individual budgets and the wider personalisation agenda will be essential for delivering a real, inclusive big society in which all are welcome, all are valued and all are able to take part and contribute.

For more information about In Control, our new Vision 2020, our work with children’s services, adult services and health services, our organisation network and our People Power! campaign, please visit our website:

www.in-control.org.uk



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