









Children and young people

The personal response

Developments in personalisation for children, young people and families

This conference was a partnership event:

Local Government Improvement and Development

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Claire, Nic, Clare and Judith

Cover photo – Katie Clarke, Calderdale Parents Forum

Page 33 – My Fantastic Life, Cambridgeshire

All event photos by Pete Griffith www.peterdgriffith.com

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Foreword



John Dixon
ex-Director of West Sussex Children's
and Adults' Services

People from a broad cross section of groups working with children and their families came to this conference to explore issues of personalisation: from the third sector, from local government including both officers and elected members, from the health service, from government, and of course parents and young people themselves. Most came as converts already, but some who came were definitely undecided as yet, and that added valuably to the debate. These are still early days in the development of personalisation in this sector, and it was widely noted that this conference and other events like it are likely to be looked back on in the future as seminal.

Participants were very much agreed that we currently do a significant disservice in the fragmentation of support services, notably at points of transition, and in the sharing of control over services with families. This is the same feeling which has impelled the 'social movement' which has driven forward personalisation in other areas; but everyone was agreed too that a simple transplant from, say, adult services would not work:

developments need to be organic and tailored, and be shaped by the aspirations of children, young people and families themselves, as well as by those working in the field.

The dissatisfaction with the current arrangements stems from strong feelings that:

- We do not work together well, especially across adults' and children's services, and so tend to be more service focussed that people focused.
- We may focus on the needs of the adult rather than giving weight to the needs of vulnerable children in a family.
- If the adult does not met the threshold for eligibility the fact of there being vulnerable children will not usually add to 'eligibility points' to trigger entitlement to a service even though this may lead to an expensive intervention by children's services.
- Planning for children's needs when they grow up does not start early enough, which means at least by the age of five to seven.

- Transitions are often a nightmare for families...and for workers.
- Eligibility criteria between adults' and children's services do not fit and assessments are repeated. For both families and workers this is associated with an immense complexity and weight of paperwork and IT.
- Parents are often not regarded as of equal standing with professionals.
- Information availability is often poor.
- There are changes of worker at apparently arbitrary ages, despite considerable evidence to show that continuity is one of the most highly prized service qualities by young people and families: this means that there can be changes of support at 14 and at 18 (and at other times).

None of these things is easy to surmount, and many reasons could be put forward for why it is too difficult. But as in the recent developments in adults' services, the most challenging obstacle by far is cultural change, not practicalities or even resources. Even at a time when money is desperately short and getting more so, we should believe that the people who should be able to take decisions over how the money allocated to them is used, where they are entitled to it, are the families and people who use services. There should be an equal relationship between families and professionals, with our knowing that almost always families know their own children best; of course some people are not good parents, like some people are not good professionals, but we do have to negotiate a basis of trust. And we need to realise that everyone, however disabled, can make some level of decisions, and take some responsibility; it is just a question of how much support they need to do that.

The conference also recognised that we already have a great deal in place to build on, in existing good ideas, good practice and determination to make a difference. In children's services as well as adults' services and the health service as well as among families themselves there is an expectation of change, and a desperation to spend the scarce resources we have better.

'Think Family' has an overwhelming logic, supported both within and beyond government. As you will see from this report, both speakers and workshops explored a huge range of possibilities, and came up with many compelling messages for ourselves, for our colleagues, and for government. I hope these will contribute to shaping a better partnership with children, young people and families with public services.

Introduction



Claire Burgess
Local Government Improvement
and Development

The notion of children and young people, their families and carers having a real opportunity to identify their strengths, identify their needs, the things they would like to change for the better and then having direct access to resources to do this makes absolute common sense. Too often we hear how our systems fail to provide for vulnerable children and families where a member has complex needs. As a result of this the whole family is often affected in terms of life outcomes and, we know from people's stories, they can be left feeling powerless, hopeless, angry and frustrated and more stressed than necessary.

Personalisation as a social policy is not new. It has been around for over 20 years as different governments have aspired to improving outcomes for vulnerable groups through the efficient use of limited resources. Personalisation as a term covers a whole spectrum of approaches ranging from how mainstream and universal services use personalisation to maximise inclusion of all individuals, to targeted support for those

identified as having additional needs in the community, such as the Budget Holding Lead Professional model where a lead professional has a delegated budget to support with the commissioning of a whole package of support to meet the needs of an individual and their family or carers using the Common Assessment Framework, right through to the use of a resource allocation system and the entitlement to an individual budget.

Personalisation: policy drivers and initiatives

	NHS & Community Care Act – care management		
4000			
1996	Direct Payments Act – legalised Direct Payments		
2001	Valuing People – goal of citizenship		
2003	In Control – self directed support and individual budgets		
	Improving the Life Chances of Disabled People and In Work Benefit Calculation – limited individual budgets		
2006	White Paper 'Our heath, our care, our say'		
	DH funded individual budget pilots begin		
	DCSF budget holding lead professional pilots begin		
	Budget holding lead professionals (BHLPs) – children with additional needs in the community		
2007	DH – Putting People First - personal budgets for adults		
	DCSF-Aiming high for disabled children		
1	In Control starts work with LAs to develop individual budgets for children with disabilities		
	DCSF – BHLP pilots for children in care		
	DCSF – Family Intervention Programme		
2008	Darzi report 'High quality care for all: NHS next stage review'		
2009	DCSF funded individual budget pilots for children with disabilities		
	DoH Personal Health Budgets Programme		
	Think Family and Total Place		
2010	DWP – Office for Disability Issues - Right to control trail blazers		
	DfE – Community Budgets		
2011	Possibility of personal budgets for C&YP with Special Educational Needs		

Adapted from a table produced by Clive Miller at OPM

At a practical level personalisation is about a whole system approach as Nic Crosby describes in his section on 'Personalisation, individual budgets and self-directed support.' It is also about an approach that sees an individual's needs right from birth through to old age. One of the challenges for personalisation now is how to integrate the various developments to provide seamless transitions either as a result of age, changes in circumstances or changes in needs. This is a significant issue for those in receipt of individual budgets as well as those supporting them. Perhaps most significantly, and relating to the above, it is about cultural change, for families, professionals, providers, strategic and political local leaders and government.

For those of us involved in planning and developing, supporting and implementing the personalisation agenda across a range of care groups this seemed a good time to take stock of where we have got to in children's services. The conference provided an opportunity to bring together a whole range of people who have experienced personalisation from different perspectives to talk, listen, share and debate the learning, knowledge and experience we already have and to explore the challenges and questions for the future.

Personalisation: the culture change

Features of role	Traditional service	Personalised service
Aim	Providing care	Helping people live their lives
Focus	Care tasks	The person and their social networks
		Personalised support and use of other
Scope	The defined service	services
	None or little	
Support planning	involvement	Some or detailed involvement
Risk management	Risk averse	Enabling risk taking
Relationship to		
people	Doing for	Supporting and enabling

Produced by Clive Miller at OPM

Personalisation Challenges and opportunities



Based on a presentation given by Clare Gent, Strategic Development Manager, Action for Children

Introduction

The values of personalisation have long guided Action for Children's work - we tailor our work to local circumstances, in partnership with children and young people, families, communities and local organisations. We see personalisation as a way to give individuals more choice and control over whether they use services and where they do: shaping tailor-made services together to help children and young people and their families to achieve better outcomes.

Individuals, with their own preferences and strengths, are considered best placed to determine what they need and how those needs can best be met. Children, young people and their families should be able to make decisions based on high quality support and advice, with a range of flexible and responsive services available for people to choose from. We are committed to empowering children to overcome the obstacles in their lives that hold them back and high quality participation is seen as a

good vehicle to empower children and young people to shape their own destiny. Our participation work with the most vulnerable children and young people has given us experience of different ways to offer choice and influence.

Our 'Backing the Future' research by the New Economics Foundation identified a number of benefits from a co-production approach: these stretched beyond immediate improvements in service design to those which promote children's psychological and social wellbeing.

Another key finding from the research is:

"by releasing the power and resources of children, families and their social networks, paid staff are able to engage these skills as part of the solution"

¹ Backing the Future: why investing in children is good for us all, New Economics Foundation 2009 www.actionforchildren.org.uk/uploads/media/36/7857.pdf

 drawing in resources to strengthen this 'core economy' is a role third sector organisations can play particularly well.

Challenges

Maintaining the viability of services

Historically our short break services have enjoyed the luxury of block contracts which enable economies of scale; a degree of predictability and stability over the life of the contract: and the ability to recruit, train and retain skilled staff. Block contracts also enable the third sector to bring added value from their fund-raising ie Action for Children can fund accessible outdoor play equipment, research and pilot innovation. There are a number of significant risks and challenges for providers regarding the ongoing viability of services in the shift to an Individual Budget (IB) marketplace:

- High quality can be difficult to achieve without investment, for example, in staff development
- Providing lower volumes of service can increase cost which could in turn reduce the viability of the service – we will need a critical mass to make a service viable. Is this where cross regional commissioning needs to develop? (many of our existing service are delivered to children with tier 3 and 4 needs so they are low incidence high cost services)
- Children and families who are happy with existing short break services may lose out if they close because not enough people want them
- Personalisation will bring a redistribution of business risk that leads to the provider carrying much higher levels – is there a more equitable way of sharing the business risks attached to a market place created and maintained by families?

 Traditional short break services provide a safety net: for example, all our overnight services offer well used emergency support. If these disappear what 'safety net' can be put in place?

We would like to work closely with commissioners to revise our contracts to enable families to purchase a service directly whilst having the right balance of investment to maintain their viability during the period of transition to increased direct purchasing.

Menu of choice

We are strongly committed to being able to offer disabled children, young people and their families a choice in how they are supported. For too long we have seen assessments that focus on defining which existing commissioned services a child and family can be fitted into rather than flexible, responsive support based on individual need.

The personalisation agenda articulates clearly the need for a strong market place of services to ensure there is choice, however, in times of austerity it is unclear how the marketplace for short breaks will develop or indeed retract. IB pilots to date have had the safety net of commissioned services running alongside new ways of providing support but this may not be sustainable in the current financial climate. The challenge of creating a broad market to match diverse need is one that stretches us all and simultaneously we need to unlock the potential of local support networks to reduce disabled children and their families' isolation and vulnerability.

It is unclear at present what people will use their individual budget for – information from the IB pilots indicate a move away from traditional services but to date the scale of this is too small to gauge the overall impact. Evidence also suggests families move away from traditional services as they grow in confidence in using their budget.

There is a growing opinion that costed menus of choices should be openly available and actively marketed so that families can make informed choices. There is currently little transparency about the cost of services and the subject is in many ways taboo and deemed too commercially sensitive to share. We need to price our services in a transparent way that fits the market, which brings a number of challenges, particularly where we deliver a range of co-located services and budgets are not disaggregated. Without transparency of cost how can parents judge which service offers them best value for their budget?

It is clear that some commissioners are already challenged with the financial balancing act of offering direct payments and commissioning services as the following quote from a parent exemplifies:

"We did not want our child to go into the unit. We had no choice when our direct payments were cut by approx 70 per cent with no warning... we have no issue with the unit – the staff are fantastic BUT we had a very good set up with our direct payments... I don't want to send my child away – I want to be able to pay someone to help me look after her in our home' (Parent, Site B)."²

Cultural and organisational change

As a large voluntary sector provider we will undergo substantial cultural and organisational change moving forward.

We undertook a readiness survey across key people in the organisation – and established that many staff needed to be better informed.

Some of our other activities in preparing for change include:

Research

We are collating and sharing key messages from research and the IB pilots and will commission market intelligence on emerging trends in LAs and further research with families.

Strategic planning

Our strategy prioritises developing our response and readiness for personalisation and a cross departmental project team is developing and delivering our plan. We anticipate developments in personalisation impacting on all areas of service delivery from education, early years support, young carers, young people with mental health needs, supported housing and so on.

Partnerships

We are developing our partnerships with other relevant organisations such as In Control, KIDS, small local third sector organisations and volunteering charities as we believe this will make our services more sustainable and collaborative.

Workforce

In some of our services parents approach staff directly to ask them to take on additional directly purchased work. This needs careful management: if we consider our role in supporting families and the investment in staff development that commissioned services offers this presents a challenge.

² Evaluation of the impact of Action for Children Short Break Services on outcomes for children – Interim Report November 2010, Centre for Child and Family Research, Loughborough University

www.actionforchildren.org.uk/content/180/Research

Remodelling traditional services

The transformational funding for the Aiming High for Disabled Children programme has enabled us to remodel traditional residential short break services to become flexible and responsive in delivering a range of options for families. As an example our service in Staffordshire provides access to sport. leisure and play activities for individuals and groups of children; a much reduced number of residential short breaks; group activities and short breaks. They use a team around the child approach to minimise the number of carers supporting a child. Aside from strong leadership in the service a key change has been in the staff contracts moving people on to annualised hours contracts which vastly increase flexibility and responsiveness in the workforce to facilitate continuity for the child and family. Through tailoring the support required we can help to achieve better outcomes and greatest efficiency.

Moving forward we anticipate fewer children using specialist services and more children accessing support through universal services. We have been able to develop a number of short break options from our universal children's centres.

Business model change

With the developments in personalisation we anticipate changes to how services are commissioned. We are already seeing an increase in Framework Agreements which will enable the flexibility to support individual purchasing. We would like to have more discussions with our commissioners. We would like to see contracts revised in a way that enables families to purchase the service directly whilst maintaining the right balance of investment to ensure the viability of the service during a period of transition to increased direct purchasing. When tendering for short break support in England

we are increasingly being asked what personalisation will mean for the service: part of our response is endorsing personalisation as a mechanism for sustainability.

One challenge of framework agreements is the need to invest in the process and develop readiness, before it is called upon and hence requiring some shift in resourcing. The impact on cash flow and resources may be prohibitive to small third sector providers. As the Individual Budget market develops we anticipate a significant increase in back office activities in terms of, marketing, contracting, invoicing and managing payments for each individual service user.

As a large third sector provider with a well developed portfolio of universal services we are in a strong position to deliver support from these bases if specialist services shrink. Our opportunities to deliver short breaks linked to our children's centres have demonstrated positive outcomes.

We will need to develop new marketing relationships where we market our business to the consumer rather than the traditional business to business model. We believe there is a need to do this collaboratively across the market and are currently exploring investment in developing the KIDS Direct Short breaks web portal which enables families to book a short break as and when they need it. The model also has the potential to process individual payments and operate as the vehicle for significant back office activity. We see this as part of the solution to reducing the back office overhead costs attached to managing large numbers of individual contracts with families and workers with contracts for small numbers of hours.

One of the big challenges we anticipate is the need to implement entrepreneurial model development quickly through enabling managers to be responsive at a local level.

Opportunities

Provider of choice

We aim to be the provider of choice for disabled children and their families and we believe the only way to do this is to deliver a range of reliable high quality options that are flexible and responsive. Many of our short break services are rated as outstanding by OFSTED and we know that quality and reliability will be key to families choosing to buy our services. We also recognise that for many families an existing service will not be their solution, they may prefer to recruit a local person known to them, to provide a highly personalised support plan.

We already have some experience of young people and families directly purchasing support.

We see personalisation as an opportunity to sustain support to families over the artificial age divide that funding streams result in and we are able to work with young people up to the age of 25.

Outcomes

We see personalisation as a vehicle to achieving much greater alignment between support planning and ensuring the delivery makes the optimum difference to the lives of disabled children and their families. We are actively developing our practice in setting outcomes with children and their families and associated SMART targets to evidence and shape our approaches to ensure we understand their impact. A key feature of our work is the ability to collaborate with schools and other key support providers to ensure we maximise continuity and thereby children's development potential. Loughborough University is currently undertaking research in this area on our behalf. We strongly support co-production through the practice of involving children and families in service

design, delivery and evaluation. Let me give you an example: when we asked parents using a drop in facility, they identified difficulties with a start time of 10am which left them with a gap between the school run and the start of drop in time – the simple action of changing the start time to 9.15pm has led to significantly higher numbers of parents using the facility. For children we want to ensure we can offer support to enable them to be aspirational and have the chance to develop their independence and personal interests and have the opportunity to try out new activities to support their development.

Person centred planning

We had a positive experience of being linked in to the DfE IB pilot in Newcastle where children's centre staff supported children and families with person centred planning. This was small scale but demonstrated very positive outcomes. An example was enabling a young person to move away from traditional short break support to enjoy a bespoke and tailored plan. This enabled them to take on a volunteering opportunity and develop new interests and talents through new arts, sports and leisure activities in their local community.

From our experience in the pilot I offer the following points for consideration:

- One family withdrew as they viewed the budget as being too low.
- A flexible approach to the time needed for support planning is required as some families needed longer. There was funding for this in the pilot – where will it come from in the future?
- Need to consider capacity within the family to manage the financial demands.
- Person centred approaches take time: recognising child's skills, talents and encouraging everyone else to do that was

the most rewarding and enjoyable element reported by staff involved in the pilot.

- Time needed to research services and activities and to share this task with all individuals supporting the plan.
- Process enabled families to realise their level of choice which has implications for providers to tailor services to individuals.
- Benefits to our work generally: keeping the child at the centre, developing a progress path which concentrates on the needs of an individual child.
- Working as an 'isolated' planner was challenging. If more than one worker had been involved more sharing of ideas and resources would have added to the pilot.

We will invest in wider staff development in this aspect over the next year, albeit uncertain about how support planning will be delivered moving forward.

Brokerage

Providing independent brokerage is a real challenge for both LAs and providers. We are considering our role as a broker. Is there a conflict between brokerage and provider roles? There are elements of brokerage in some emerging models. In Cambridge for example, we are providing a brokerage role where children's aspirations for accessing universal leisure services are matched with local provision; training is offered to providers to support them with making reasonable adjustments and Action for Children offers interim support for the child with the objective of them being able to continue the activity without specialist support. If this is needed we will extend our brokerage role to support families making longer term arrangements.

Partnerships

We are keen to extend our partnership working with other third sector providers, as noted earlier, and we see the personalisation agenda as a good opportunity to both think and act locally alongside other service providers to benefit disabled children and their families

Personalisation, individual budgets and self-directed support



Based on a presentation given by Nic Crosby, In Control

Headlines

- Over 40 children's services are already embarked on introducing, piloting and rolling out individual budgets and selfdirected support for disabled children and families.
- There are over 700 individual budgets in use, providing support for children from 2 years and upwards and across a very diverse range of support needs from being in care to having some learning difficulties.
- A growing partnership of services are committed to working together to further the opportunities for families to take control of how they live their lives and ensure their child gets the best support they can.
- The government have signalled their intention to widen the opportunities for individual and personal budgets for disabled children and their families across social care, health and education.

Introduction

By November 2010 four years of work by In Control and a growing number of children's services have produced a good understanding of how individual budgets and self-directed support can work and do work for disabled children and their families. This work began in 2007 with seven children's services; when we started out we did not presume that the structures for Personal Budgets being introduced in adult services would necessarily transpose directly to the children's world. We took work from the adult sector and began to work out how a similar intent to give families control using a mechanism of personalised funding could work. The last four years have produced a wealth of learning, understanding and real practical examples of how personalised funding, most commonly in the form of an Individual or Personal Social Care Budget do work and how they radically improve outcomes for children and their families

The presentation given at the conference 'The Personal Response' in November 2010 set out our learning, stories from children, young people and their families and our understanding of a common and simple pathway fro all children and families.

Outcomes for children and families

We have, this year, begun to collect outcomes from children, families and workers involved in piloting individual budgets. This process has focused on two approaches; firstly talking directly with families and professionals, and secondly using a consistent set of questions, based upon a set of outcomes originally drawn from the Every Child Matters Outcomes Framework to capture improvements in the child and family's life. A more detailed exploration of these discussions and outcome measurement can be had in our 'Personalisation: Children, Young People and Families, Briefing 3: Evaluation' (December 2010).

Headlines

- Families consistently report an improvement to their life as a family unit, the ability to plan around their family life and make sense of the support their child needs in the context of day-to-day family life.
- Many parents speak of clear improvement to their child's health; this is often supported with feedback from professionals and schools.
- Parents feel safer and more confident in the support being given to their child.
- Parents report improvements in their child's quality of life and in their own quality of life including getting more rest and a better night's sleep.

- Parents talk of their son or daughters growing independence and new friendships and relationships with other children and young people.
- Parents appreciate being able to change support, and their appreciation of being flexible about when and how their child is supported.

The following two graphs set out outcomes measured for 67 children and families in Newham and Middlesbrough as a result of pilot activity over the past two years.

Figure 1: Outcomes for Children and Young People (Middlesbrough and Newham 2010)

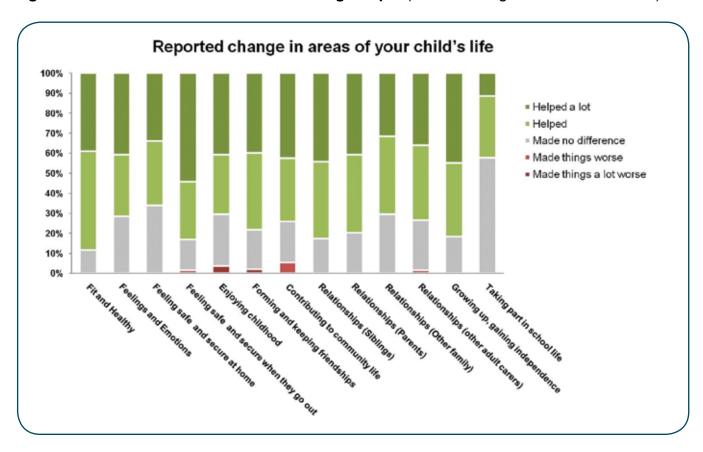
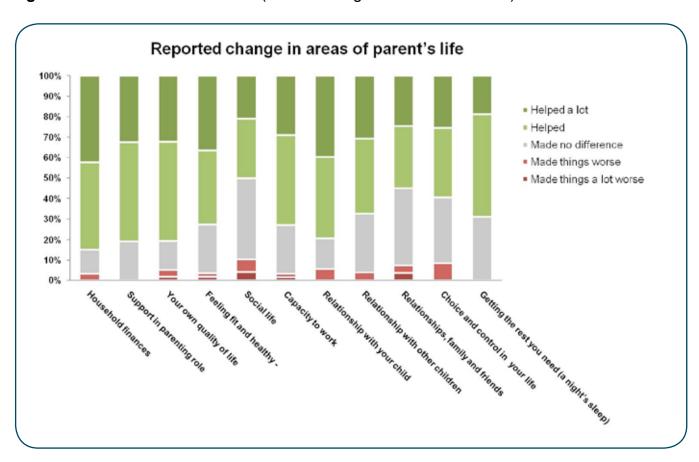


Figure 2: Outcomes for Families (Middlesbrough and Newham 2010)



The two graphs speak for themselves logging an almost consistent improvement of over 50 per cent across an array of outcomes. Key findings include increased feelings of safety, evident improvement in 'enjoying childhood', impacts on household finances and relationships at home and with others in the community.

The outcomes reported in these graphs are supported with testimony from many families in Middlesbrough, Newham and across our wider children's programme membership³. They include stories from young people involved in work to develop the role of the Budget Holding Lead Professional for children in care and leaving care, large personal health budgets for young people with complex health support needs, stories of how families have used their child's individual budget to get very different and individual short breaks (most often with the child and with support) and stories of what they learned through the support planning process and the flexible approaches this helped them to adopt in creating an individual support package for their son or daughter.

A simple and consistent pathway

When we started this work with children's Services in 2007 we used the existing 'seven step' model developed by In Control in its work with adult services which sets out a simple pathway based on an Individual budget and called 'The Seven Steps to self-directed support'. Over the past four years we have worked to revise this basing revision on our learning of what makes sense in the children's world. We explore this in greater detail in a recent paper 'Enabling self-directed support for Children and Families' (November 2010)⁴.

³ Stories can be found at www.in-control.org.uk/children Further resources are listed at the end of this chapter.

⁴ Enabling self-directed support for Children and Families, Crosby, N. and Miller, C. In Control and OPM 2010

Figure 3: The seven steps of self-directed support⁵



⁵ The seven steps of self-directed support based upon a version of the seven steps published on The Centre for Welfare reform website September 2009 www.centreforwelfarereform.org.uk

This pathway begins with the family identifying a need for some help in supporting their son or daughter; most often this may be at an early point in their child's life when they are being supported by a health visitor. However, whether or not the family has a health visitor or health professional there need to be many different access points where families can take forward their need for support.

Step 2 is one of the two steps given attention in this paper following the presentation on 25th November. Step 2 focuses on supporting the family in realising and making best use of all the resources they have; this may or may not include an individual budget. In Control explains these resources as the 'real wealth' of the child and family. This links with world wide practice in taking a solutions focused approach to resolution of problems and support needs and links, as explained in a separate paper with the solutions focused approach to safeguarding children called Signs of Safety⁶.

This emphasis on realising and using one's wealth is vitally important: money alone will not suffice in meeting support needs,

in fact the more of a child and family's real wealth is used in constructing support the harder and more efficiently an individual budget can be made to work. Individual budgets are not specifically a money saving approach to meeting support needs, rather individual budgets are a highly effective and efficient way of allocating and using limited resources. Individual budgets and the allocation mechanism (Resource Allocation System) simply allocate, as fairly as possible, whatever budget there is available to meet the support needs of disabled children being supported by the children's service.

⁶ www.signsofsafety.net

Figure 4: Real wealth

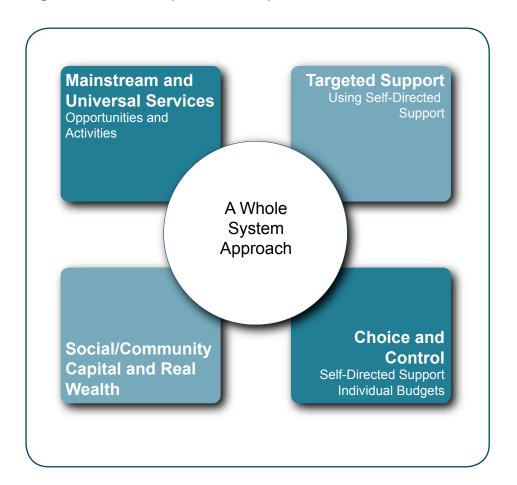


Step 3 sees the development of a support plan using said real wealth. This step has seen much attention and many different ways of offering families support. It has also seen many of the biggest challenges for family due to lack of support and information from the children's service. Some examples of support to plan include:

- · training to social workers
- training and support to family groups
- training children's centre staff and enabling them to support families
- exploring a variety of different supports including social workers, family networks and voluntary organisations.

The second step to receive specific attention is that of Step 6 'Living my Life'. Figure 5 starts to explain how much wider personalisation is than simply individual budgets and self-directed support. Personalisation explains a system wide approach to supporting children, young people, families, adults and older people. Individual budgets are one part of this under the title of 'Choice and Control' however activities need to take place across the four quadrants.

Figure 5: The four quadrants of personalisation



- The mainstream or universal world of services, shops, activities and opportunities need to be as accessible as possible to all children.
- Targeted services need to be easy to access and focused on supporting the child, young person or family in an individual way; this links with a lot of learning from work on developing the role of the lead professional as a budget holder.
- Social capital, ie the opportunities, activities and social networks within local communities need to be supported, invested in and used more.
- Choice and Control denotes the use of personalised funding where, without such additional support the child and family are unable to make best use of the mainstream/universal offer and where the child has specific and individual social care, educational or health support needs.

In a similar way to an emphasis on 'real wealth', seeing personalisation as 'whole system' again stresses the importance of not simply seeing this as an agenda dominated by individual budgets.

Summary

This presentation brings together four years of work by In Control with over 40 children's services who are all members of In Control's Children's Programme 'Taking Control'. The original intention behind starting 'Taking Control' was to see the development of a lifelong approach to personalisation at the centre of which sits the child, family, adult or older person in control of how they live their day-to-day life; how they learn, grow, work, play, socialise and live. With individual budgets now being used in some areas as the first means to support a very young child and their family we have begun to see what a lifelong pathway might look like. Embracing the governments intention to widen Personal

Budgets to SEN and long term health conditions will continue to challenge us, will further deepen our learning about how we ensure that families stay in control and how personalisation is a system wide approach to supporting all children and families as opposed to an agenda simply focused on individual budgets and self-directed support.

An overview of the workshops

Three workshops offered at the conference were '360 degree' stories from local children's systems (Newham, Cambridgeshire and Islington). They included input from a young person or family member with experience of using an individual budget, the experiences of the pilot lead and input where possible from a commissioner or more senior manager.

At the fourth workshop Judith Smyth (OPM) explained the need for strong local leadership from commissioners so that they could make the whole system changes (including cultural and behavioural change of frontline practitioners) needed to embed and mainstream personalisation.

Islington – Across children and adults services

Simon Cross and Tracy Caton

Simon, as self-directed support lead for Children in Islington sits in the self-directed support Team which works across children's and adult's directorates. This workshop shares work to pilot individual budgets for young people in transition, associated work around transition support and some of Islington's ambitions for improving transition for disabled young people as they move in to the adult world. http://www.communities.idea.gov.uk/comm/landing-home.do?id=1685686

Newham – Use of individual budgets at the front door and in specialist services

Marita Ludlam, Helen Younan and Kimmy Stewart

Over the past two years Newham Children's Services have explored two ways of using individual budgets for disabled children. firstly, working with families already in receipt of a package of support from disabled children's services and transferring them to having an individual budget, and secondly as one of their approaches to extending short breaks to children and families not currently supported by disabled children's services. This workshop shared work, learning and evaluation data from Newham and included input from Kimmy Stewart who manages an individual budget for her son.

All presentations http://tiny.cc/81dqq

Cambridgeshire – Enabling access to sport, play and leisure activities

Richard Holland, Anita Hewson, Brian Sulman, Janine Allway and Linda Simmons

Using individual budgets with young people is one important way of helping disabled young people gain independence skills and learn about planning. This workshop explains work being carried out under the Aiming High programme which includes introducing individual budgets to young people, but more importantly goes hand-in-hand with working with providers and commissioning youth clubs. This is a workshop which sets out a

wide approach to supporting young people as they grow in to adulthood.

Commissioning and personalisationJudith Smyth – OPM

Personalisation and individual budgets only become a reality for the majority if leaders of children's services systems make it happen. This means that strategic commissioners need to redesign whole systems to enable personalisation and individual budgets as follows:

Firstly, the children's partnership board needs to agree must do standards for all those working with children, young people and families across the area. Where there is a commitment to individual budgets this has to be explained to everyone in the system. Typically commissioning standards which will apply to all service providers including:

- working appreciatively with parents build on family's strengths
- · working aspirationally
- safeguarding
- personalisation and individual budgets
- using CAF, lead professional and team round the child approaches⁷.

Secondly, the partnership should agree a commissioning policy which describes the way in which the authority and commissioning partners intend to relate to a mixed market of service providers, how they will demonstrate contestability and what their attitude to outsourcing to different sectors is. Where there is a commitment to personalisation and individual budgets this will mean that the authority will try to reduce the size of block contracts in favour

of framework contracts with a range of providers, and will try to keep resources back for use by lead practitioners (including social workers) for use in buying goods and services that people need.

Thirdly, new style children and young people's plans will describe proposed changes to the system. Personalisation will feature in the chapters about improving the lives of children with disabilities, looked after children and also in the chapter about targeted preventative work.

There are many barriers to change including:

- poor strategic and political leadership
- too many pilots/projects, programmes, meetings and performance indicators
- lack of understanding about commissioning among people at all levels of the system so that there is confusion about roles and functions
- poor understanding of the cost and value of services especially those provided within the local authority.

A fourth 360 degree workshop was planned with Gloucestershire Children's Services, titled 'Personalisation to meet need in universal, targeted and specialist services'. Gloucestershire were unable to attend the conference, however they shared reports and paperwork with all those who attended. This workshop would have set out how personalisation is viewed as a whole system approach in Gloucestershire Children's Services.

Further information can be obtained from sarah.spurway@gloucestershire.gov.uk for children and young people and families with additional needs in the community and sarah.hylton@gloucestershire.gov.uk for children and young people with disabilities.

⁷ For example must do standards often include the golden threads identified in the C4EO reports Narrowing the Gap and Grasping the Nettle www.C4EO

These workshops provided participants with real in-depth knowledge and experience from sites, putting individual budgets and self-directed support in to the wider story of what personalisation means for children and families and illustrating this with real stories from people involved.



Newham Workshop



Challenges, questions and discussion

The purpose of this session was to be able to learn from one another about how to overcome some practical challenges, including budget cuts and policy change.

Government is currently very interested in choice, personalisation and individual budgets as well as reducing costs and introducing more efficiency into public service delivery.

The groups were invited to pose questions to the Minister that the hosts will pass on through the Conference Report.

People split themselves into groups and discussed the following sub-headings.

Based on an 'open space' discussion in groups facilitated by Judith Smyth (OPM)

1. Developing and managing provider markets

The group had the following question for the minister:

"How will we be able to ensure that smaller providers are able to continue to provide services?"

The group were concerned about small community based providers who seem to be overlooked by commissioners in some places; they felt that smaller providers need to be supported to avoid monopolisation. They felt that local authorities, larger charities and CVS could support consortia to develop as umbrella organisations locally.

Payment by result was discussed – this may work with individual budgets but there were concerns that this would be difficult to



fund and complicated for service users and brokers.

The group were concerned that for profit private service providers might reduce quality unless service users and brokers were very vigilant. Trust would be more difficult to establish.

The new localism policy was discussed. Local authorities and communities need to be clear about what they want for themselves. They will have different policies on local employment, local community involvement and development and work with larger national charities and for profit businesses.

It was acknowledged that localism might enable smaller providers to thrive in some areas, and for individual budgets to become the norm, this would not happen in other areas and then we will have a postcode lottery for services.

2. Supporting and promoting a 'social movement'

This group had the following question for the minister:

"Will you support parents who are involved in this social movement so that there are more individual budgets?"

The group felt that in accordance with 'Big society' principles a strong grass roots social movement in support of personalisation and individual budgets was developing. It involves many parents and some frontline workers. Members of this group were keen to see this movement grow with the full support of the new coalition government.

It was noted that parents can get involved in the commissioning process. Parent forums can influence commissioning standards, policy and children and young people's plans. They can provide advice to other parents and run local campaigns. The group felt that it was important for parents to keep up the pressure on professionals and practitioners too. Parents can provide valuable support to providers wanting to support personalisation; and their voices are powerful in driving change.

There is still work to do to break down some professionals' perceptions of parents and their ability to make the right decisions for their children. It has been recognised that social workers can sometimes find it hard to let go of their traditional job role and hand over the monetary control to parents.

3. Getting health on board

This group had the following question for the minister:

"Can we please have some clarification of the role that health and well being boards may play in relation to disabled children and personalisation?"

Local authorities are now expected to establish a local health and wellbeing boards however the group was concerned about the role of these boards in relation to children's partnerships, disabled children and individual budgets. They have the potential to make transition between children's and adults services much better than now.

Good local authorities are already using these groups to push forward some of the system wide changes that need to be made to enable individual budgets but there are fears that many will fall behind and use the anticipated changes in the NHS as an excuse for inactivity.

4. Implementing change and learning from others

This group had the following question for the minister:

"How committed are the government to personalisation? What help will you be able to give particularly to the voluntary sector to support individual budgets?"

Where good practice is happening it will need to be shared. It will be particularly useful to spread knowledge and experience of successful change to structures, systems and cultures which support individual budgets. The voluntary sector may need support to change. Participants felt that central government guidance would be helpful.

5. Influencing political leaders

This group had the following question for the minister:

"How will local councillors and Ministers forge a cross party consensus on personalisation so that all local authorities are providing equal services to their communities?"

A good flow of information to elected members is very important. A councillor in the group argued that cross party support is increasingly important as it will be difficult to implement top down change without it.

There was a feeling that it is important to be careful of taking examples directly from other sectors as children's services have different statutory duties and decision making powers. Since the needs of children can differ from one family to another the lead professionals need to be trained in effectively assessing and facilitating the personalisation approach. As commissioning decisions are delegated to individuals and their lead practitioners there will still be a need for strong strategic commissioning including performance management of the system and some participants were not clear about the local authority's future role with that. Others felt that if the local authority was commissioning well they could hold many different service providers to account through service level agreements and contracts.

The group wanted the Department for Education and the Department for Health to work better together to provide guidance on personalisation and individual budgets. The group also felt that local leadership from elected politicians was very important.

6. Changing culture across organisations

This group had the following questions for the minister:

"Local authority culture in some places is stuck in the past with services (from all sectors) still 'doing unto' rather than 'doing with. Individual budgets require a real shift in power, culture and frontline behaviour. Is it likely that central government will issue guidance on this that will accelerate local change?

When you develop the new national indicator set will you include personalisation and individual budgets? Will you include useful qualitative measures of effectiveness and guidance for commissioners?"

There is greater value across the board when measuring impact of services on quantitative evidence and statistical data. There is a lot of valuable work that providers do that cannot be measured by quantitative data always, but through qualitative reporting. Currently, this is not valued as much by commissioners. It is important to make sure that it is valued and also to promote ways of recording qualitative data efficiently enough for commissioners to look at in a consistent way. All service providers need to know how this can be done.

How can you ensure an inclusive approach in the take up of individual budgets?

One way of ensuring an inclusive approach is through the commissioning process itself. Guidance documents such as Narrowing the Gap produced by C4EO include some of these 'must-do' standards which can urge commissioners think strategically which includes working well with families, which in the longer term can contribute to an inclusive approach. There may also need to be additional brokerage support for some people with particular disabilities or from minority ethnic groups to enable them

to participate fully in individual budgets and planning processes.

7. Influencing up

This group had the following question for the minister:

"How do we engage with our regional associations of Director of Children's Services now that regional government has gone?"

People recognise that is important to influence Directors of Children's Services and get their buy in because this will enable change to happen.

"How do we manage the lack of a shared terminology for example different definitions of personalisation and direct budgets?"

There need to be clear definitions of personalisation and individual budgets so that people do not get confused between the two when implementing these. If these definitions are decided locally it will cause a difference in what people are receiving across the country so therefore it would be better if these are issued nationally by central government so that they are mainstreamed.

"Is it true that personal assistants will get a pension and other employment rights out of direct payments?"

Participants were confused about this and asked for government guidance.

8. Other funding

This group had the following question for the minister:

"How do we build on the best of our Aiming High work when funding for this and related work is being cut?"

The group agreed that in the best places which used evidence of what worked and was good value for money to redesign local systems it may be possible to reduce waste and sustain outcomes through individual budgets; however they were worried that local leaders would not be able to do this without help from central government and there were considerable risks of worsening services and continued inefficient use of resources.



Panel question and answer session

The panel consisted of Clare Gent, John Dixon, Nic Crosby, Kimmy Stewart (parent from Newham) and Claire Burgess and was chaired by Judith Smyth.

Q: With regards to localism will parents still be getting together regionally and nationally? How will parents know if they are getting a good deal if they don't know what other local authorities are offering their families?

A: A parent's suggestion was to use local parent forums, regional parent forums and perhaps a national network of parents and carer forums, so these can all link back in to one another. If the funding disappears for these forums, will this continue? So how do we know good practice is shared?

What is also a concern is that parents who haven't got the time to go to forum meetings and how they will know what is going on. Another parent raised the point that it is an involved parent's role to make sure that other parents who are harder to reach and who do not come out of their homes are aware of what is going on. Although everyone is scared about what is going to happen, everyone needs to keep their ears and eyes open.

A lack of information available to parents is not new. It has been a long term concern within the social care sector that appropriately formatted and easily accessible data is not available to a parent which means they can potentially have a bad experience with the service.

Parent networks can access government funding to support VCS through cuts – this funding should enable parent networks to continue to advocate, support and lobby on

behalf of parents. In Control is rolling out a 'People Power' membership scheme for all and everyone to sign up and support others across social care, health and the children's world. This membership is growing fast with well over 1000 public members.

It is important to remember that local areas don't know what localism and the Big Society is going to mean for them so it is the role of the local authority to more knowledgeable and practical about what they can do with their budgets. Finance will be given to local authorities in lump sums so they need to know how they are going to manage that. Part of managing that will be through a dialogue with the community. There will be more opportunity for parents and community organisations in the important decisions that need to be made.

Local areas need to be more savvy about meeting community needs. Localism will force a dialogue with parents and the community and networks will be vital to this. Community budgets could be used in the future to support parent networks

Q: Can community budgets be used to support parent carer forums?

A: A community budget organises public spending by place, rather than by individual organisations or service. Community budgets will reflect local priorities in tackling families with complex needs, making funding more transparent to local people and making it easier for local citizens to get involved in deciding how the funds are spend and services deliver. In this context if there is a local need to support parent carer forums and this is an agreed strategic priority then in principle the budget could be used to support parent carer forums.

Q: Over the last two to three years, provision for disabled children has really improved under Aiming High. Because March 31st 2011 looms over us, is all of that hard work under threat?

A: It is very important for local authorities not to 'cut' services too quickly. There are currently many mainstream funded services that are not as efficient as they should be. This needs to be considered for change so that cuts to service do not just focus on the new but on the old too. Frontline workers and strategic leads need to make sure they are able to influence this. It is also important to remember that the way in which the cuts have been made through central government does not have prescriptive implications for local authorities; they have the fluidity to make these decisions collaboratively.

It is also important to acknowledge that everyone is afraid and fears the changes to come. It is in fact more important in these times to fear 'fear' itself as we need to look past this and make the best decisions and reform possible.

Q: There is no prescribed duty on personalisation. Will this threaten existing good practice?

A: The alternative is to stick with existing systems which we know have serious flaws and need to be changed. There are concerns that personalisation projects will be seen as areas to cut in the current financial climate as they are relatively new and not well embedded yet into mainstream offers. However, equally councils will be looking at new more efficient ways of working that clearly demonstrate added value to outcomes for children, young people their families and carers.

There are challenges for local political and strategic leaders to work without prescription from central government to meet local need. Many of the principles and values relating to personalisation are the same principles and values that the new coalition government is putting forward for its localism and Big Society agendas. In this context there potentially will exist a climate for personalisation to flourish.

The policy context

At the time of this conference we approach a new era in terms of social policy with a number of factors that will have an impact on the development of personalisation across children's services. Significantly these are:

- a new coalition government
- the recession and significant budget deficit with the Treasury looking at new ways of doing things to maximise outcomes for less money and looking for efficiency savings
- a focus from the coalition government on devolving funding and accountability to local areas where decisions will be made about local priorities and where to spend the resources devolved from central government
- a vision of a 'Big Society' where individuals and communities have more control over their destinies – empowering communities, redistributing power and fostering a culture of voluntarism
- new legislation across major policy areas over the coming months
- cross party support for outcomes focussed needs based approach to personal support.

There has been significant development of the personalisation agenda across children's services over the last five years, supported by pilot funding and grants. The problem comes when this funding comes to an end and the models developed need to mainstreamed. This is a particular concern to young people and families concerned

that the support they have in place will have to finish if and when the pilot or pathfinder comes to an end or because of their age they move onto adult services where the criteria for funding to meet needs is often different.

There are currently several pieces of key legislation out for consultation and key new policies and initiatives which will support the development of personalisation across the whole of children's services. These are:

- Equity and Excellence: Liberating the NHS White Paper.
- The Schools White Paper The Importance of Teaching.
- The expected Green Paper for SEN and disability.
- The Early Intervention Grant with three themes:
 - · children's centres
 - · targeted youth support
 - · families with multiple problems.
- Community Budget pilots 16 pilots across 28 areas.
- DfE Families with Multiple Problems Programme.

Children's services has a wealth of experience and knowledge to draw on over the last 20 years to rise to the challenge of delivering more personalised, innovative and responsive services to meeting the range of children, young people and families with additional needs.

As a partnership of organisations we see the personalisation agenda for Children and Young People as bringing together many of the best developments in children's services with the move to putting the child and their family in the driving seat. We all see the forthcoming Green Paper on SEN and Disability as the opportunity to sink 'Choice and Control' into the children's world in the same way that it now underpins the

approach to supporting adults. In turn this gives us an opportunity to explore whole life and lifelong support mechanisms focused on using a self-directed support approach from the moment you need support for your child through to old age and end of life support.



Being 'in control' is being included, informed and being treated as an individual. Pictured here: Brian Sulman, Janine Allway, Jack Whitley and Nicky Griggs.

Conclusion Judith Smyth, OPM

One of the biggest strategic challenges for UK government at all levels is to renegotiate the relationships between public services (whoever is providing them) and service users and the public. Personalisation and individual budgets through which we can establish co-production and sometimes co-payment relationships provide the answer, particularly now that we know that we can achieve better long term outcomes as well as budget savings.

However this means a whole system change which relies on excellent leadership from people who understand that they are first and foremost strategic commissioners able to shape services round service users rather than around the needs of professionals and traditional services.

Localism is potentially helpful because it removes some of the central government controls which have been identified as barriers to individual budgets. However people at this conference were worried that local leadership was not strong enough to rise to the challenge without central government support. They also worried about the post code lottery. The questions for the Minister reflect this and we look forward to being able to circulate the answers and offer any support we can to the government departments as well as local government in response to the considerable 'social movement' now behind personalisation and individual budgets in the coming months and years.

Further reading

Personalisation: Children, Young People and Families. Briefing 1: In Practice, Crosby, N. In Control 2010

Personalisation: Children, Young People and Families. Briefing 2: Round Table Discussion, Crosby, N. In Control 2010

Personalisation: Children, Young People and Families. Briefing 3: Evaluation, Crosby, N. In Control 2010 (to be published December 2010)

Enabling self-directed support for Children and Families, Crosby, N. and Miller, C. In Control 2010

Self-directed support and Signs of Safety: Exploring Safeguarding, Crosby, N. and Wheeler, J. In Control 2010

Learning Together: Commissioning and personalisation, Miller, C. Commissioning Support Programme, 2010

Personalisation for Disabled Children and Young People, A Literature Review, Rowe, S. National Children's Bureau 2010

A Fair Start, Developing Personalised Pathways for Disabled Children, Murray P. The Centre for Welfare Reform and the University of Birmingham, 2010

A Whole Life Approach: Local Authority Guidance, Brewis, R. Crosby, N and Tyson, A. In Control 2010

In Control Phase 3 Report – 2007-2009

In Control Phase 2 Report – 2005 – 2007

In Control Phase 1 Report – 2003 - 2005

Individual budgets and the Budget Holding Lead Professional: A Comparison, Miller, C. OPM 2008 A Whole Life Approach to personalisation for Children and Families, Crosby, N. and Duffy, S. In Control 2008

BHLP Final National Residential Conference in Reading, 8th – 9th April 2008, Report for DCSF and pilot sites OPM, June 2008, www.opm.co.uk

Common Assessment Framework (CAF) and Individual Commissioning (formerly BHLP) Annual Report, March 2010, Gloucestershire County Council www.gloucestershire@gov.uk

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