

Green Paper: Children And Young People With Special Educational Needs And Disabilities - Call For Views

Response Form

The closing date for this Call For Views is:
15 October 2010

Your comments must reach us by that date.

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Please tick if you want us to keep your response confidential.

Reason for confidentiality:

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Please mark an X in the box below that best describes you as a respondent.

<input type="checkbox"/> Parent/Carer	<input type="checkbox"/> Child/Young Person	<input type="checkbox"/> National Voluntary Organisation
<input type="checkbox"/> Children's Service	<input type="checkbox"/> Local voluntary Organisation	<input type="checkbox"/> School/College
<input type="checkbox"/> Local Authority	<input type="checkbox"/> Headteacher/Teacher	<input type="checkbox"/> SENCO
<input type="checkbox"/> Governor	X Other (please specify)	

Action for Children is a UK-wide charity that supports and speaks out for the most vulnerable and neglected children and young people in the UK.

This consultation response is based upon our experience of supporting nearly 156,000 children, young people and their families in nearly 420 projects across the UK. This includes our family support services, as well as a range of services for disabled children who have the most complex and multiple needs, those with associated health conditions, and those with behaviours that others may find challenging. Working with over 12,000 disabled children and young people, Action for Children is the largest voluntary sector provider of services for disabled children and young people in the UK.

This response complements a series of submissions we have compiled for other reviews including the Graham Allen review on early intervention, the Frank Field review on poverty and life chances, and, the Clare Tickell review on the Early Years Foundation Stage. These responses are uploaded on the following page:

<http://www.actionforchildren.org.uk/content/178/Responses>

Q1) Are the SEN and Disability statutory frameworks - including the SEN statementing process - helping children and young people to get what they need? If not, what changes could help?

Yes

No

Not Sure

Please see our response for question 3

Q2) How can we identify children's special educational needs earlier, and make sure that they get the support they need as quickly as possible?

Summary

- At a local level we believe an inter-agency approach must be developed to ensure problems are picked up and dealt with as early as possible. Those who deliver services need the freedom and autonomy to deliver to the greatest impact.
- Children and family centres should be reconfigured to provide joined up health and social care early intervention services
- We must build on best practice from the Early Support Programme; extending the programme's principals beyond the early years to support children throughout their childhood and adolescence.
- There must be greater linkage between mainstream and specialist services so that the likelihood of identification increases and knowledge and good practice is shared across agencies.

The importance of early intervention

The importance of building resilience and emotional wellbeing is increasingly recognised as a factor determining long term outcomes of children. This is particularly important for those children with SEN or who are disabled.

Everyday, Action for Children helps some of the most vulnerable and socially excluded children and young people across the country. From our work running Sure Start Children's Centres, delivering short break services, programmes to reduce youth offending, to helping those leaving care or young disabled people into independence - we are seeing the growing importance of addressing their wide ranging emotional needs.

In the current public spending climate and with a renewed focus on outcomes, it is of paramount importance for the new government to consider where earlier intervention with at-risk groups could save taxpayers money and help reduce overall public expenditure.

We have known for years that we need a paradigm shift in the way we invest in services for children and families to investing in addressing problems early rather than picking up the pieces later. The delivery of effective services on the ground necessitates joined up working, pooled budgets and the development of stable professional relationships. The ability to promote and protect mental health is not

exclusively in the gift of one agency, profession or government department.

Local authorities are being given increased autonomy and independence, but this must come within a revised statutory framework to ensure everyone is working towards the right outcomes for children and young people. At a local level we believe an inter-agency approach must be developed to ensure problems are picked up and dealt with as early as possible. And those who deliver services also need the freedom and autonomy to deliver the greatest impact.

In the longer term, we are seeking a new settlement to enable local children's services to embed early intervention, increase efficiency and break the cycles of deprivation and neglect in the UK. To achieve this children and family centres should be reconfigured to provide joined up health and social care early intervention services, and five year service contracts are necessary to ensure effectiveness, delivery and to achieve payment by results.

Early Support Programme

It is clear that the early support programme has for many families enabled them to negotiate a system that can be so overwhelming, in particular when a child is born with a disability or when a child is first diagnosed. It has, where delivered well, been a lifeline for families.

We do believe that whilst this programme is incredibly beneficial for children and their parents in the early years, the principals of the programme must be rolled out to cover disabled children and young people through all ages and stages. As picked up in a later section on transition, children whatever their age, will need a support system and someone to navigate them through the various transition stages they will move through - transition is more than that transition from children's to adult services.

The best practice from the Early Support Programme and its principals must continue beyond the early years to support children throughout their childhood and adolescence.

Early support services

Action for Children's extensive range of services for disabled children starts from the early years. We understand that services can be delivered effectively in different ways from a number of bases.

We aim to ensure all our universal services are available to disabled children and their families, promoting opportunities for them to be included from the earliest age. This includes the support delivered through our Sure Start Children's Centres (see above for specific examples of practice from our SSCC).

Our service in the South West provides co-ordinating provision for children and young people with disabilities, providing workers to accompany the children to the centre where they would not otherwise be able to attend on their own. In the longer term it develops their confidence, skills and experience – all of which is essential in terms of developing school readiness and enhancing longer term education prospects.

Other pre-school services include: early years crèches, specialist parenting programmes (such as the NAS EarlyBird and EarlyBird Plus programme for parents of children on the autistic spectrum) and access to speech and language, occupational and physiotherapists.

With the support of Action for Children Furness Children's Centres, parents and carers are now saying:

'My child now plays better with other children – she's talking a lot better'

'I notice his communication more'

'I have learned to take the time to play and listen'

Early identification and the Early Years Foundation Stage (EYFS)

We know that for families it is essential that there is an improvement in the speed and efficiency of diagnosis and assessment, so that children with additional needs are identified earlier.

The early identification of special educational needs is crucial to ensure that individual children's needs are recognised and acted on. There must be greater links between mainstream and specialist services so that the likelihood of identification increases and knowledge and good practice is shared across agencies.

We know many practitioners working with children under five feel that the EYFS framework is already sufficient in supporting and enabling them to highlight any developmental delay of an individual child. However, this must be the case across the board. It is vital that staff are trained well and professionals work together to accurately identify special educational needs and the impact of family background on a child – e.g. children attending nursery with very poor communication skills. Staff must also be trained to identify and raise concerns if a child is not reaching key milestones. This must be done in a way that recognises that children will develop at their own pace.

Involving children and parents in the process of identifying additional need is crucial. There needs to be awareness in frontline staff of children's skills, abilities and knowledge at different stages and how to involve parents more in identification of special needs. Action for Children is aware of instances when children with disabilities have come to our projects and the parents were told that their children did not have a disability and that they would 'catch up'.

Helping children to progress –using the EYFS framework

Practitioners must observe, assess and plan in order to move a child forward. EYFS is an essential mechanism in that it includes direct observation of children and provides a framework for this to happen in a wide range of learning contexts.

Data from observations can be used to plan interventions. Effective use of assessment frameworks, such as the EYFS points system, can support a greater understanding of individual need (CfBT [2010] *Effective early childhood education programmes: case studies*).

Children's Centres

The Government must protect the investment in Sure Start Children's Centres so that they provide the localised, community shaped early-years resource that can also deliver targeted support to the most disadvantaged. There has been significant investment in Children's Centres over the last 13 years, with centres now an accepted, accessible asset sitting at the heart of our communities. The new government must re-configure this asset to harness the return on the investment already made (in terms of buildings, people, networks and crucial support services).

We would like to reconfigure these early years' hubs to help deliver the Government's localism agenda and construct the Big Society. Through the co-location of services, such as relationship support, services for children with SEN, disabled children, legal services, sexual health clinics, child and family health services and debt advice, efficiencies can be made while also improving focus and impact.

In Action for Children's centres across England we are providing a number of successful services which support the needs of disabled children and their families. This work includes:

- Providing rooms and support for health related clinics, auditory, sensory, eye, teeth etc.
- Parents groups specifically developed with deaf parents/children (Cumbria)
- Parenting support for a mothers with autistic children displaying challenging behaviour (Bury)
- Centre opens at weekends to offer weekend breaks for children and/or parents to have some fun activities in centre or out on trips (Northumberland)

Being empowered to make decisions

Action for Children is committed to participation, ensuring that the wishes of the children and young people we work with (even where expressed non-verbally) are recognised and responded to. Disabled children and young people must have a say in their lives.

Furthermore, parents must be empowered to make decisions regarding their children and their family; they need to know where to go for information and should not have to wait for a professional to say what they should do.

Q3) How can we improve the processes for special educational needs and disability - in schools, in assessments, and across all services - so that professionals can spend more of their time with children and their families?

Summary

- The current assessment system is inefficient, costly and does not put the needs of the children and families it is designed to support at the centre.
- Processes are bedevilled with concerns about data sharing and professional ring fencing of information within disciplines. Real and substantial improvements to assessment systems for families and disabled children and young people will not be made until these key issues are resolved.
- Disabled children with complex needs can be assessed by a shocking number of professionals, who cover the same ground and have limited mechanisms for information sharing or joint working.
- The cost effectiveness of the *Team Around the Child/Team Around the Family* approach to supporting families with disabled children must be taken into account when decisions on streamlining assessments are being made.
- Assessment processes should focus on what a child or young person can do as opposed to what they can't do.
- There must be sufficient professional time available when undertaking assessments to ensure a flexible response can be given.
- It is vital that children do not fall through the gaps or thresholds for assessment resulting in their needs not being recognised or met

Cost to the state of multiple assessments¹

For parents of disabled children, the major challenge is not their child's impairment, but the management of the range of agencies involved in their care, including social care, play and leisure and health and education services. The burden of attending multiple assessments, repeating information about their child to different agencies and professionals, being placed under pressure to stress what their child cannot do and repeating painful information can push parents to breaking point.

Assessments of need can be undertaken at any time, but are likely to be most frequent at key stages. These key stages include diagnosis/early years (age 0-5), starting school (age 4/5), changing schools (age 11), and planning transition to adult services (14-19).

A system which requires multiple assessments at each of these key stages, rather than the sharing of information between agencies, is wasteful and costly to the state.

Anna Gill, Chair of the National Parent Carer Forum Network task group has submitted a case study to EDCM demonstrating the full range of professionals involved in her son Jamie's life at the diagnosis/early years key stage and at transition to adult services. Jamie has complex needs and at the diagnosis/early years key stage, there were 23 professionals involved in his care. Each of these professionals carried out at least one assessment to determine the support they would provide.

¹ Information taken from EDCM briefing to HMT, Streamlining assessment for families with disabled children – policy measures and funding implications 2010. Action for Children is a campaign network member of EDCM

In March 2010, research into the unit costs of short breaks by the then DCSF determined 'the estimated average unit cost of a core assessment in London is £710.12 and £504.79 out of London'². Although there will be some variation in terms of time taken, salary level and resource cost, for the purposes of this briefing we will consider each assessment as costing the out of London average of approx £505.

For Anna Gill and Jamie, this represents **a cost to the state as follows:**

One assessment (minimum) at diagnosis/early years key stage by each of the 23 professionals: £11,615

There are approximately 100,000 disabled children with complex needs in the UK. **If each of these children were subject to the same assessment process as Jamie, the cost to the state would be as follows:**

£11,615 assessment cost for 100,000 children: £1,161,500,000

There are 770,000 disabled children in the UK, a large proportion of whom will undergo multiple assessments at key stages. Although this calculation uses the children with most complex needs as an indication of spend, it is clear that the total cost of assessments of disabled children to the state is likely to be much greater.

The current assessment system is inefficient. Based on the example given by Anna Gill in Appendix A, a disabled child with complex needs can be assessed by a shocking number of professionals, who cover the same ground and have limited mechanisms for information sharing or joint working.

Cost to the state of multiple assessments – the solution³

Early Support model

We welcome David Cameron's proposal to ensure that parents of disabled children have a 'passport through the system'. We are confident that this can be achieved by empowering every local area to deliver a 'local offer' to families, delivered jointly by relevant agencies such as social care and health, including a minimum package of support. As part of this, we recommend that the voluntary sector should be resourced to support local areas to develop a **Team Around the Child/Team around the Family** approach to assessment based in multi-agency locations. This model was developed through **Early Support – an approach that research by the**

² The Cost of Short Breaks, 2010, Centre for Child and Family Research, University of Loughborough

³ Information taken from EDCM briefing to HMT, Streamlining assessment for families with disabled children – policy measures and funding implications 2010. Action for Children is a campaign network member of EDCM

⁴ Early Support: An Evaluation of Phase Three of Early Support, 2006, University of Manchester in collaboration with University of Central Lancashire

⁵ As above

⁶ As above

⁷ Early Support: An Evaluation of Phase Three of Early Support, 2006, University of Manchester in collaboration with University of Central Lancashire

⁸ The contribution of Early Support to Aiming High for Disabled Children and the transformation of services for Children with SEN and disabilities, Elizabeth Andrews for DfE

University of Manchester deemed to be extremely popular with both parents and practitioners, as well as 'cost effective compared to no Early Support'.⁴

If Anna Gill and her son Jamie had had access to Early Support, the professionals involved in Jamie's care would have worked together to ensure that he received a holistic, multi-agency and coordinated assessment that was undertaken as far as possible in the same place, at the same time and provided as early as possible with minimum waiting times. This would dramatically reduce the cost to their local authority and PCT, as it would have removed the need for multiple assessments at £505 each.

In addition, they would have benefited from an 'improvement in multi-agency working and significantly improved practice in the domains of: agencies co-operating to plan, manage and develop services effectively; the co-ordination of ongoing support for families; making straightforward and smooth the processes of referral, identification and initial assessment.'⁵

Research into the Early Support pilot programme determined that the 'average cost of **Early Support per child (£s) in 2004 to 2006**' was **£1415 per child**'⁶.

- **As this cost was for two years of provision, this equates to an annual cost of £707.50 per child.**

The cost implications of the delivery of the Early Support *Team Around the Child/Team around the Family* approach to the 100,000 disabled children in the UK with complex needs, are as follows:

- **100,000 children at £707.50 per child, per year: £70,750,000**

Extending the Team Around the Child/Team around the Family model beyond early years – a 'passport through the system'

Early Support has introduced the *Team Around the Child/Team Around the Family* approach to early years services. However, it has been recognised that families with disabled children require ongoing support – a 'passport through the system' - as their child grows up. Every time a family reaches a key stage in their child's life – including diagnosis/early years (age 0-5), starting school (age 4/5), changing schools (age 11) and planning transition to adult services (14-19) – they are once again thrown into confusion and are required to undergo a further round of multiple assessments.

'Early Support: An Evaluation of Phase Three of Early Support, 2006, University of Manchester in collaboration with University of Central Lancashire' found that 'as the number of years increases and the number of families served increases, the investment cost per family of Early Support decreases.'⁷

In a 2010 research paper for the DfE on the contribution of Early Support to improving services for disabled children, Elizabeth Andrews concluded that:

'Positive experiences of *Team Around the Child* approaches were widely reported. There was a marked consensus that it was desirable for frontline service delivery on this model to be extended up the age range for older children and younger people'⁸.

In December 2009, the 'Lamb Inquiry: Special Educational Needs and Parental Confidence' recommended that parents should have access to similar multi-agency teams based in schools or partnerships of schools.

We would therefore ask that the the relative cost effectiveness of the *Team Around the Child/Team Around the Family* approach to supporting families with disabled children is taken into account when decisions on streamlining assessments are being made.

Implementing the Early Support approach cost pathfinders a fraction of the amount that Anna Gill's local authority and PCT spent on assessments alone.

Assessment based upon a deficit model

In general terms we would like assessment processes to focus on what a child or young person can do as opposed to what they can't do. Too often assessments for disabled children are based upon a deficit model rather than one which draws out their strengths and aspirations.

Children who do not meet the assessment thresholds

It is vital that children do not fall through the gaps or thresholds for assessment, for example if they are SEN but not statemented, they may not have their needs fully recognised and met. The statementing threshold is set at a level of need that many children with SEN will not meet. These children do still have additional needs which must be met. The education system must support this to happen and ensure that children are able to access the most appropriate provision that meets the individual needs of the child and enables them to reach their potential.

The principal of assessment

As a principal, assessments should be a tool or a means from which a range of services should be identified and delivered. Not a repository for conditions and needs to be stored with no actions attributed to them.

Further more, the process of improving assessment efficiency and effectiveness needs to develop in line with two priorities:

1. All disabled children and young people should be included in the local Common Assessment Framework procedures.
2. That the systems required to develop effective self-assessment should be prioritised in line with current development of the personalised agenda.

Both these priorities should lead to:

- efficient, better and more effective information availability for families and carers, especially where there is an effective Budget Holding

Lead Professional (BHLP) system in place

- self assessment systems should lead to a much higher level of transparency and greater participation
- less duplication in assessments
- access to local services rather than leapfrogging into specialist provision and a greater understanding by families of why they are able to access services
- ownership by families of their assessment, leading to greater levels of empowerment.

Current assessment processes are bedevilled with concerns about data sharing and professional ring fencing of information within disciplines. Real and substantial improvements to assessment systems for families and disabled children and young people will not be made until these key issues are resolved.

Q4) How can we ensure all schools and colleges have high expectations for children and young people with special educational needs and disabilities, including their future potential and contribution to society?

Summary

- We must have high expectations for all children and young people irrelevant of any additional needs they may have.
- The focus must be on outcomes and not process, setting clear outcomes from the start.
- Disabled young people should enjoy the same opportunities as their peers, including accessing transport, volunteering, participation and peer befriending.
- Schools and colleges must make links with the services that the young people will be accessing in the future.
- Schools and colleges should be supported to use person-centred planning tools.

Having high expectations for all children and young people

Society in general must have high expectations for all of our young people irrelevant of any additional needs they may have; schools and colleges must also have these expectations and furthermore - so must the parents and the children and young people themselves.

To engender these expectations, we must focus on what these children and young people can do as opposed to what they can't do – in the same way we

should in the assessment process.

We must enable the young people to see (for themselves) that they do have the abilities and potential to get a job and contribute to society.

The distance travelled for individual young people must be measured, and their achievements seen in this light. For example:

“the achievement of an apparently small outcome, such as learning to use a spoon to feed themselves, may have profound impact”. *(Extract from forthcoming Centre for Child and family research, Loughborough University interim report on Action for Children outcomes in residential short break services)*

Capturing/ recognising outcomes for disabled children and young people

(Extract from forthcoming Centre for Child and family research, Loughborough University interim report on Action for Children outcomes in residential short break services)

Existing research suggests that outcomes for all children in need are difficult to accurately capture and measure (Holmes et al, forthcoming). A recent report published by Ofsted states that too much focus is placed on checking that pupils are getting additional services, and too little on how much this support is actually helping children progress (Ofsted, 2010). Outcomes need to be measurable, such as attaining qualifications or gaining employment. However, Dewson et al (2000) argue that for those children with the highest levels of need ‘soft outcomes’ such as developing interpersonal skills or confidence may be more appropriate goals, although it is harder to measure them.

To this end, we have commissioned research that has identified these ‘soft outcomes’ have been achieved for children and young people accessing Action for Children short break services over the past 6 months:

Level of need	Progress against outcomes in a six month time period identified by child need type (%)				
	Achieved	Improved	Not Changed	Deteriorated	No Result Recorded
High levels of complex	5.9	30.0	4	0.0	59.6
Lower levels of needs (all other children)	2.3	25.2	10	1.9	60.3

Working in partnership to identify and achieve child focussed outcomes:

It is essential that all services working with children and young people co-ordinate their activities and work to the same outcomes, in our forthcoming research we have found evidence of positive working relationships between agencies and our short break services:

Overall, families were very positive about how the three homes shared

information with other professionals with 23 (85%) reporting that information was shared appropriately. Around two-thirds of families reported that the targets set for their children were linked to work being undertaken at their child's school or with other agencies working with their child.

Nearly three-quarters (15:71%) of the staff members that submitted surveys agreed that partnerships with other agencies help to achieve the best outcomes for children.

Extract from, Working Outside the Box: An Evaluation of Short Breaks and Intensive Support Services to Families and Disabled Young People whose Behaviour is Severely Challenging. Summary Report, Roy McConkey, October 2010

Working with schools and colleges

Work must be done with schools and colleges so that they can see and understand the achievements of young people already in education, employment and volunteering.

They must also be supported to develop meaningful opportunities for young people, again focussing on what they can do – there is a wealth of best practice evidence that can be drawn upon to highlight this point. Greater flexibility in current curriculums/ syllabuses would further enable this to happen.

Schools and colleges must make links with the services that the young people will be accessing in the future. This helps to establish if particular services will be suitable, and young people and families will feel more confident if schools/colleges are aware/knowledgeable of what options are available. Furthermore, this would be assisted if schools/ colleges used person centred planning tools.

Finally, schools and colleges have a role to play in helping families to allow their young people to grow up as other young people do - a move from protection to empowerment. Young people with disabilities need to be able to make mistakes and learn from them as their non learning disabled peers do.

Disabled young people enjoying the same opportunities as their peers

Action for Children believes that while many disabled young people must have access to specialist support and services. They must also be able, where appropriate, to access the same universal youth provision and opportunities offered to their peers.

Many disabled young people experience social isolation. In order to counteract this, disabled young people should be helped to engage with their peers and to play an active role in their communities, via social networks and participation in sport, leisure, play and cultural activities.

Supporting young disabled people to use transport independently

A key aspect to living independently is being able to travel freely to work, the shops, to see friends and family, and generally being able to take yourself anywhere without relying on others. This is just as important for disabled

young people as it is for their peers – if not more so. Being able to travel freely can be the key to their independence, and having the skills and confidence to use public transport must be invested in.

More must be done to support disabled young people to become independent users of transport. This means that those working within public transport from planners to operators and conductors must recognise the additional needs that disabled young people may have when travelling. They should be sensitive to their needs in a non-stigmatising way.

Volunteering

While volunteering is not an alternative to employment, many young people use volunteering as an opportunity to broaden their horizons and test out future career paths and to expand their social opportunities.

Volunteering is a positive and rewarding experience that most young people benefit from through their school life or other extra curricular activities. It is therefore important that disabled young people have the same opportunities to broaden their horizons. Action for Children promotes volunteering for young people who have used our services.

The benefit of this has been to provide the young people with a constructive alternative to further education and paid work, thereby smoothing their transition into the adult world and providing them with an opportunity to give something back to the services they have left.

Participation

Action for Children is committed to participation, ensuring that the wishes of the children and young people we work with (even where expressed non-verbally) are recognised and responded to. We work hard to ensure that disabled young people have a say in their futures.

We also believe that the young people who use services should be fully involved in their design and delivery, and are empowered to have their voices heard and to facilitate change both locally and nationally. This is no different for disabled young people. Involvement must not be tokenistic, but one of meaningful engagement, where participants can see and understand its purpose and benefits. Action for Children is, for example, currently supporting two young people on a local authority transitions panel.

Peer befriending

Disabled young people are no different to their peers in that they wish to spend time with people their own age who have similar interests.

Action for Children believes more must be done to encourage peer befriending to ensure that disabled young people don't miss out on building positive relationships with their peer group.

Q5) How can we improve the choices of schools and services available to parents and improve opportunities for them to be involved in decisions that affect their family?

Summary

- Personalisation is a way to give individuals more choice and control over the services they use, shaping tailor-made services together to help children and young people to achieve better outcomes. However, we know families with disabled children have complex lives and the personalisation agenda must reflect this.
- Individual budgets must be designed with the specific needs of disabled children and their families in mind from the start.

Personalisation

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 the services they use, shaping tailor-made services together to help children and young people to achieve better outcomes.

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.

Service-users should produce the solutions to their needs with staff; service-improvement will be based on service-user experiences.

Nevertheless, families with disabled children have complex lives and the personalisation agenda must reflect this.

Furthermore, in research that we are publishing in the coming months we have found an alarming experience of a family who did receive direct payments where they had control of the care their child received only for that to be taken away – this devalues all of the work that had previously been done with the family to construct a personalised package of care.

'We did not want our child to go into the unit. We had no choice when our direct payments were cut by approx 70% 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).

Extract from forthcoming Centre for Child and family research, Loughborough University interim report on Action for Children outcomes in residential short break services

Individual budgets

We are concerned that some families may feel that the management of individual budgets adds an extra level of complexity that has a negative effect on their ability to lead an ordinary life.

Individual budgets must be designed with the specific needs of disabled children and their families in mind from the start.

Parents of disabled children want to take control of their lives. For many, this will mean having the option of individual budgets or personal health budgets and helping to shape the services they receive through participation in parent forums. Others however will need the support of key workers or brokers to help them to navigate the system and ensure that co-ordinating services does not become a full time job.

Additional support must be given to those young people in receipt of individual budgets, who are making the transition to adulthood. It is essential that both the children's individual budget and the adult individual budget dovetail.

Person-centred planning

Action for Children believes that person-centred planning can be a positive opportunity for young people to make choices about their future and for their wishes to be heard. Person-centred planning helps young people incorporate every aspect of their aspirations for their future, as well as their practical needs.

It is important that the final plan becomes a live document that the young person can keep with them, amend where appropriate and take through their adult life. By doing this, the young person will have a document that outlines who they are, explains their views, preferences, wishes, aspirations and intentions for the future.

Nevertheless developing an individual plan can be a time consuming process, and this is not a quick fix solution. It is important to ensure that families receive support from professionals who have a good knowledge of the personalisation agenda and the processes for individual budgets.

Q6) How can we improve the transition from school to adult life for young people with special educational needs and disabilities and the support provided for their families throughout?

Summary

- Transition is a process that children and young people go through from the early years up to their adult years – this must be reflected in support services.
- Disabled children must have a key worker or support worker who can navigate and support children, young people and families through all transitions they go through.
- A good transition to adulthood is one that provides young people with the tools and opportunities to move onto adulthood in the way they choose, doing the things they want to, with the people they want around them.
- We believe that during transition, young people should have an advocate – it is important that the views of young people are not lost between what adult services can deliver, what children's services recommend and what their family wants or needs.

Transition throughout childhood and adolescence

The transition through childhood to adolescence and into adulthood has a number of key milestones along the way. The most readily recognised are the moves from early years into primary school, primary to secondary school and the move from secondary school to further education, employment and training. These transitions can be hard and difficult to adapt to.

However, for the most vulnerable children and young people, in particular those with SEN and those who are disabled there are additional transitions that they must make which are not as easily recognisable. Yet these youngsters must manoeuvre them at the same time as working through the same stages as their peers.

For those with SEN and who are disabled their transitions are through assessment processes, changes in their physical, mental and emotional needs and through adaptations in the services that support their needs.

Key to supporting children and young people throughout their lives are the relationships they build up with their families, friends and with services.

Therefore, disabled children must have a key worker or support worker who can navigate and support children, young people and families through all transitions they go through. These workers will interpret differing models of services, funding criteria and entitlements. For example, Action for Children Disability Lincolnshire supports parents on visits when their child is moving to a new setting and also invites staff/key workers from the new setting to visit Disability Lincolnshire before the move takes place.

What is a good transition to adulthood for young people?

A good transition is one that enables young people to develop independence, roles and relationships through choice, and provides opportunities for social interaction, community participation and appropriate, meaningful activities. Put simply, a good transition is one that provides young people with the tools and opportunities to move onto adulthood in the way they choose, doing the things

they want to, with the people they want around them.

Continuity of provision through transition

Action for Children is aware of the distress caused when services supporting young people and their families through childhood end and they move on to adult services.

We believe that services should be developed to bridge the gap between the end of children's services and the beginning of adult services. This will ensure young people do not face the end of all the services they have relied upon and trusted at a time when they need increased support.

This view is supported by research we will be publishing in the coming months:

Parents were conscious of the major changes that they faced once their young person reached adulthood plus service staff were dubious if the same form of short break would be available:

"While they are children they are protected but then you know all of a sudden they're adults and not only are we as parents expected to put them out there but then there's all this change but not only of them being adults but their safety net almost is taken away and sometimes I worry that its going to be yanked away. . Cause he's going to stop school and then this (short breaks) is going to be taken away from him and other clubs and things that he goes to that's going to get taken away and its almost as if one door is shutting and then another one. I haven't had any input yet from transition services so I don't really know what to expect and that's my worry."

Extract from, *Working Outside the Box: An Evaluation of Short Breaks and Intensive Support Services to Families and Disabled Young People whose Behaviour is Severely Challenging. Summary Report, Roy McConkey, October 2010*

Action for Children has developed a number of continuous services that are a constant in young people's lives when everything around them is changing. These services include short breaks and residential education provisions.

Transition between children's and adult services

We know that some young people, once they leave children's services, have little or no provision due to countless reassessments and the different models of eligibility criteria used in adult services. This can be incredibly distressing and destabilising to the young person and their family. This 'cliff edge' experience, where services suddenly stop, creates a sense of powerlessness.

In many cases, the need for services is greater than the available provision, meaning that some young people are left with no continuity and poor or little service provision. This can be detrimental to the young person's development and self-esteem. Without the support services that have followed them through their lives to date, it can be both daunting and lonely. Adult services must work hard to ensure disabled young people are allocated provision that is suitable and can cater for their individual needs. A service that cannot fulfil their needs could counteract the positive work and support that children's services had provided over a number of years, putting the young person in a

more vulnerable and marginalised position.

Action for Children uses a variety of methods to work with disabled young people to ensure that their voices and needs are not lost between children's and adult services.

Supported living services

Action for Children Kingfishers is a supported housing project for 18 to 25 year olds with learning disabilities. We enable young people to develop independence skills, take responsibility for their lives and to manage the transition from childhood to adulthood. The ultimate aim of a young person's placement with Kingfishers is for them to have developed the skills to enable them to live in their own homes in their community with minimal support.

In this service we have found that through providing intensive care and support to 7 young people with moderate learning disabilities to increase their independence, the Kingfishers project estimates they have saved the state over £2,185,000 for these 7 young people when calculated over a ten-year period.

Benefitting from the support that Kingfishers provides means that when they leave the service less floating support will be required than would otherwise be the case, with the total cost calculated at £ 1,095,000 compared with £ 3,280,000 for floating support alone over 10 years.

The Kingfishers project can demonstrate how individuals have benefited from intensive support early on, which can then be decreased as their independence levels rise, demonstrating clearly how their early intervention work can improve outcomes and save money.

Services supporting disabled children and their families throughout their lives:

Short breaks

As a leading provider of short break services, Action for Children understands how valuable these services are to disabled children and young people and their families. We therefore commissioned research (undertaken by nef consulting, part of nef – the new economics foundation) with the Every Disabled Child Matters campaign that explored the social and economic value created by short breaks.

The research concluded that significant savings could be made to the State if short breaks were provided to all the families with disabled children who need them. It also provides a clear case for sustainable funding for the effective delivery of short breaks services. Finally, it concluded that failure to support these families in the long term would result in substantial additional costs to the State.

Through independent analysis of data, nef consulting calculated that the State could make an estimated annual saving of **£174 million** if short breaks were effectively delivered to all those eligible to receive them. This saving has been

based on the following data:

- decreased cost of long-term residential care from reductions in the number of disabled children placed outside of the family home: **£135 million**
- decreased cost to health services from reduction in parents', families' and carers' stress: **£18 million**
- decreased cost to schools of educating siblings with behavioural and emotional difficulties: **£21 million**

Unfortunately our forthcoming research shows that these services are already being diluted due to expenditure cuts.

The impact of expenditure cuts

Site A accepted a 3% reduction in funding in spring 2010. It made several changes to accommodate this, including changes to staff working patterns which led to all staff working a mixture of day and night shifts rather than dedicated night shift staff as this was more cost efficient and a one week summer closure when all staff take one of their weeks of annual leave.

Site B is only offering 250 nights per year and is closed every other weekend.

One of their parents commented:

'The service provided by the unit is excellent. However, the resource needs to be available 52 weeks a year. Its limited funding makes it inflexible and greatly restricts its beneficial impact on local families' (Parent, site B).

Extracts taken from forthcoming Centre for Child and family research, Loughborough University interim report on Action for Children outcomes in residential short break services

Keyworkers

Action for Children believes that co-ordinated advice, support and reassessment of needs are what make the difference for disabled young people and their families during transition – a keyworker is essential to this process.

Action for Children believes that a keyworker is essential to navigate and support young people and their families through their transition period. Many agencies can be involved with the transition process, with differing models of services, funding criteria and entitlements.

A keyworker should co-ordinate this process, dealing with agency requests for information, ensuring they are proportionate, making sure that the young person and their family have a clear understanding of the options available to them, and keeping the young person at the centre of their transition process. The need for keyworker support will be increased when more young people begin to use direct payments or individual budgets. Action for Children recognises that these mechanisms will enable young people to build their own

care package; however, they must be fully supported in doing so.

“My keyworker listens to me. I am treated as an individual.” (quote from a young person using Action for Children services)

Advocates

Based on the views of some service users, we know that transitions can be a time of sadness; this is mainly because there are breaks in emotional ties with services and individual carers who have provided them with support. In addition, those people may have officially (but in most cases unofficially) advocated on behalf of the young person, expressing their wishes to family, friends and other services.

Unfortunately for some children and young people, transition can be the first time they have been asked what they would like to happen in their lives. Up until this period, their families, friends, carers and services may have decided what they feel is right for the young person.

We believe that during transition stages, children and young people should have an advocate – it is important that their views are not lost between what services can deliver, what services are recommended and what their family wants or needs.

Q7) Ideas and examples of what's working well

Children's Centres working with the Aiming High initiative making cost savings

Bournemouth Aiming High Short Breaks service provides a co-ordinating service for children and young people with disabilities and their families. Located within its local Children's Centre it provides workers to accompany young people to the centre where they would not otherwise be able to attend on their own; in the longer term developing the confidence, skills and experience of service users.

Whilst this service is a great benefit to the children who use it, it is also a good example of how savings can be made when universal and targeted services work together. Savings are made as the only costs are for a co-coordinator sitting under the Children's Centre manager and the cost of the resources for the young people i.e. equipment. There are no additional costs for computer, building or networking.

Crèche facilities for disabled children

Action for Children Disability Lincolnshire provides crèche facilities for children with disabilities and additional needs aged 0-4 years old. As part of its services, Disability Lincolnshire provides parents with the opportunity to meet other parents, project staff and professionals both formally and informally. This provides parents and carers with support, skills and the confidence to recognise and meet their child's needs.

Continuity of support through the transition to adulthood

Redwood House provides a specialist service for up to six young people under 26 years old who have diverse and complex needs and who have completed their education at Action for Children's Penhurst Specialist School. The service prepares the children for moving on from the school.

Redwood House is not only an extension of the work of Penhurst School but an independent care and training provision for young people with profound and multiple learning needs. As an adult care home, it is inspected by the Care Quality Commission and fulfils all the criteria necessary for developing the young people's skills for life and living. Young people are helped to develop their life and living skills, and can access therapeutic services and appropriate medical care.

Residential Short Breaks and Transition Service

There is great emphasis at Action for Children Yew Trees Residential Short Breaks and Transition Service on empowering and supporting young people as they adjust to adulthood and the many changes that are taking place in their lives.

Action for Children Yew Trees offers residential short breaks and needs-led crisis support for young people aged between 16 and 21 with a learning and/or physical disability. Much of the care and support provided is based around activity groups, such as youth club-type activities, sensory storytelling, cooking and craft activities, football and independence skills.

Transition key-working

Action for Children Pembrokeshire Children's Centre has established transitions key-worker posts, funded by adult social services. The transitions key-workers co-ordinate the transition planning and provide advice and information for the young person and their family, continuing to be involved until young people reach 25.

The key-workers develop relationships with the multiple agencies already involved with the young person ensuring that this is a fully young person-centred process. Interventions are co-ordinated and focused on delivering services that fit around the young person and their needs, with their views and opinions seen as a starting point, not an after thought. Key-workers use a variety of methods to obtain and record young people's views, for example the development of family support plans.

The result for the young person is that, as far as possible, they have driven the plan for their future, built on their short, medium and long-term aims.

Supported living

Action for Children Kingfishers is a supported housing project for 18-25 year-olds with learning disabilities. Young people develop independence skills; take responsibility for their lives and manage the transition to adulthood. The aim is to develop young people's skills so they can live in their own homes with minimal support.

Kingfishers was recently evaluated by the Norah Fry Research Centre, who concluded that the following factors have been successful in supporting young people to become confident adults:

- Use of a holistic approach, taking an interest in the tenants' employment, accommodation and social lives, as well as practical skills
- Communicating exceptionally well with other agencies and working hard to maintain good relationships with families
- Risk assessments are used positively to overcome barriers
- The quality of the staff group is exceptionally high and is maintained through supervision, clear boundaries and support
- Peer support is encouraged

Peer befriending

The project included a peer befriending scheme for young people who had a learning disability and whose needs could not be met through traditional short break services. Young befrienders were trained and assessed using a model that looked at their values, skills and abilities.

The group was located within a town centre youth provision establishment, in order to minimise transport difficulties and to give the young people greater access to community activities. The young people choose activities to undertake with other local young people. Group numbers were kept small to be similar to a group of friends.

Some individual links were made between the young people, including two young people who attended a computer group together. Although the arrangements were more complex than they would have been for a more typical pair of friends joining a course, this was achieved in a sensitive manner.

Community short break service

The Re:d Centre in Bury currently works with around 110 disabled children and young people each week, providing short breaks, play activities and social opportunities, as well as offering support, information and advice to families and professionals.

The centre provides community-based short breaks such as after-school short breaks where children are collected from their school and spend the afternoon in the centre, or weekend short breaks where children enjoy a range of activities, trips and visits during a morning or an afternoon session.

Parents can drop in to the centre at any time. They can also access a resource library to find more information on their child's impairment and associated needs. The centre also provides services for siblings of disabled children, including drop-in sessions and holiday workshops where they can talk about their feelings and experiences in a safe and non-judgmental environment.

Residential Short break service

Action for Children's Warren Park service works with children and young people aged between 8 and 18 who experience a wide range of impairments, including severe learning difficulties. 50 per cent of the children are on the autistic spectrum.

Warren Park is a purpose-built centre offering residential short break services and day activities. The short break service provides regular overnight support for 30 children and young people. The level of care is agreed through an assessment process and varies depending on individual need.

The Day Activity Unit includes a large play area with specific play/activity rooms such as a computer room, a sensory room, a soft play and ball pool, and a large garden with specialist play equipment. The After School Club provides social and learning opportunities while also supporting parents with work and other commitments, and the Holiday Club provides activities during school holidays.

A bit about you: 100 words

- *Tell us a little about yourself and your role*

Permission to use:

- *Please confirm a contact name from whom permission has been granted to use the example in the Green Paper*

Emma Scowcroft
Policy Manager
Action for Children

Q8) Please use this space for any other comments you would like to make.

Comments:

Q9) Please let us have your views on responding to this consultation (e.g. the number and type of questions, was it easy to find, understand, complete etc.)

Comments:

Thank you for taking the time to let us have your views. We do not intend to acknowledge individual responses unless you place an 'X' in the box below.

Please acknowledge this reply X

Here at the Department for Education we carry out our research on many different topics and consultations. As your views are valuable to us, would it be alright if we were to contact you again from time to time either for research or to send through consultation documents?

X Yes

 No

All DfE public consultations are required to conform to the following criteria within the Government Code of Practice on Consultation:

Criterion 1: Formal consultation should take place at a stage when there is scope to influence the policy outcome.

Criterion 2: Consultations should normally last for at least 12 weeks with consideration given to longer timescales where feasible and sensible.

Criterion 3: Consultation documents should be clear about the consultation process, what is being proposed, the scope to influence and the expected costs and benefits of the proposals.

Criterion 4: Consultation exercises should be designed to be accessible to, and clearly targeted at, those people the exercise is intended to reach.

Criterion 5: Keeping the burden of consultation to a minimum is essential if consultations are to be effective and if consultees' buy-in to the process is to be obtained.

Criterion 6: Consultation responses should be analysed carefully and clear feedback should be provided to participants following the consultation.

Criterion 7: Officials running consultations should seek guidance in how to run an effective consultation exercise and share what they have learned from the experience.

If you have any comments on how DfE consultations are conducted, please contact Donna Harrison, DfE Consultation Co-ordinator, tel: 01928 794304 / email: donna.harrison@education.gsi.gov.uk

Thank you for taking time to respond to this consultation.

Completed questionnaires and other responses should be sent to the address shown below by 15 October 2010

Send by post to:

SEN and Disability Frameworks Team
Special Educational Needs and Disability Division
Department for Education
Sanctuary Buildings
Great Smith Street
London
SW1P 3BT

Send by e-mail to: send.callforviews@education.gsi.gov.uk