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# Making it Personal:

A Family Guide to Personalisation, Personal Budgets and Education,  
Health and Care Plans



# Making it Personal

A Family Guide to Personalisation, Personal Budgets and Education,  
Health and Care Plans

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Funded by the Department for Education KIDS  
'Making it Personal' programme

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# 1: Introduction and policy context

This guidance is an update to the 2013 parents' guidance and forms part of a suite of new guidance commissioned by the Department for Education (DfE) to support the personalisation agenda and the implementation of the Children and Families Act 2014.

The suite also includes guidance for commissioners, providers, case studies, e-learning modules and guidance for Family Information Services.

All can be accessed via the KIDS website at [\*\*www.kids.org.uk/mip2\*\*](http://www.kids.org.uk/mip2)

## Who this handbook is for?

This guidance is a revised version of the handbook, *Taking a Personal Approach: a Parent's Guide to Personal Budgets*, published in February 2013, and forms part of a suite of new guidance commissioned by the Department for Education to support the personalisation agenda and the implementation of the Children and Families Act 2014.

The suite also includes guidance for commissioners and providers, case studies, e-learning and guidance for Family Information Services. Although each guide is targeted at a specific audience, there are some stories and examples that are shared across the different guides. If you are a parent with an interest in how to work with providers, or a commissioner who wants to better understand the family perspective, then you might want to look at more than one of the guides.

Throughout the document, we illustrate the changes in practice that personalisation necessitates with examples and case studies identified in yellow, as well as pointing you to helpful tools.

All the guides can be accessed via the KIDS website [www.kids.org.uk/mip2](http://www.kids.org.uk/mip2)

There is an introduction and some information about personalisation, then the guides are all structured around the four elements of the commissioning cycle as set out by the Commissioning Support Programme:



The Commissioning Support Programme's definition of commissioning is widely accepted as the universal definition of commissioning - the process for deciding how to use the total resource available in order to improve outcomes in the most efficient, effective, equitable and sustainable way.

See [www.commissioningsupport.org.uk/](http://www.commissioningsupport.org.uk/)

**Important note:**

Throughout this document, when we refer to parents we mean parents and/or carers or anyone with parental responsibility.

When we refer to children or a child, we mean children or young people (legally, this is up to age 25 in education, and 18 in social care and health)

When we refer to school, we mean a school, post-16 institution or early years provider.

When we refer to 'he' or 'she', this should be considered as representative of both sexes unless indicated otherwise.

We make no assumptions about the individual background and experience of each reader.

## Why use the guidance?

Being responsible for any child is rewarding and brings both joy and challenges. Being the parent or carer of a disabled child or young person brings an extra element of challenge, unique to each family. Most families with disabled children need some support. As with all families, this might come from other family members – grandparents, aunts, uncles – or friends. And there is often great support in local schools and communities from people who simply welcome disabled children along with everyone else, including them in everything and making adjustments where they're needed.

Some disabled children need more than this natural support; for example, to enable them to learn effectively at school, stay healthy, join clubs, and do things with friends.

Over the past few years, there have been some exciting developments in the policy and practice of designing and delivering services and support for young disabled people and for children and young people with special educational needs.

The Children and Families Act 2014 was given Royal Assent on 13th March 2014. New legal duties relating to special educational needs and disabilities (SEND) came into force on 1st September 2014 and sees the biggest change in policy and practice with regard to children and young people with special educational needs and disabilities since the 1981 Education Act.

Central Government has funded pilots to try out individual budgets for families with disabled children as well as personal health budgets. Most recently the SEND pathfinders have been testing how to use personal budgets and new planning processes across education, health and social care.

**See:** <https://www.gov.uk/government/publications/individual-budgets-for-families-with-disabled-children> for information on the evaluation of the individual budget pilot for families of disabled children, July 2011.

**See:** [www.personalhealthbudgets.england.nhs.uk/topics/latest/resource/?cid=8603](http://www.personalhealthbudgets.england.nhs.uk/topics/latest/resource/?cid=8603) for information on the personal health budgets evaluation.

**See:** [www.sendpathfinder.co.uk/](http://www.sendpathfinder.co.uk/) for information about the SEND Pathfinder programme

The Act (<http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted>) includes new duties on Local Authorities and the NHS to jointly plan and commission services for all children and young people with special educational needs and disabilities. This includes the following specific duties:

- to work together more effectively and cooperate at both the strategic and operational levels
- to include and work with young people and their families - putting them at the centre of everything using the principle of, 'nothing about us without us'
- to carry out co-ordinated assessments and where necessary work with young people and their families to produce Education, Health and Care plans (see Part 3 of the Act, points 36-37)
- to work with local people and services to produce a Local Offer (see Part 3 of the Act, point 30)

The Act is also underpinned by some key principles that reflect what young people and their families say about what they want:

- A focus on planning for whole-life outcomes including higher aspirations for young people
- A focus on working with the skills and connections that families bring and on keeping support close to home
- Assessment and planning from 0 to 25 years to help avoid the often difficult experience of transition from children's to adult services
- The right to ask for and to have personal budgets for parents/carers and young people who have an Education, Health and Care plan
- Much greater focus on working in genuine partnership with young people and their families and on young people and their families having access to the information they need to make good decisions
- A focus on acting early and getting support at the right time.

Appendix 3 of the Making it Personal guide for commissioners has more detail of all the policy drivers and initiatives related to personalisation ([www.kids.org.uk/mip2](http://www.kids.org.uk/mip2))

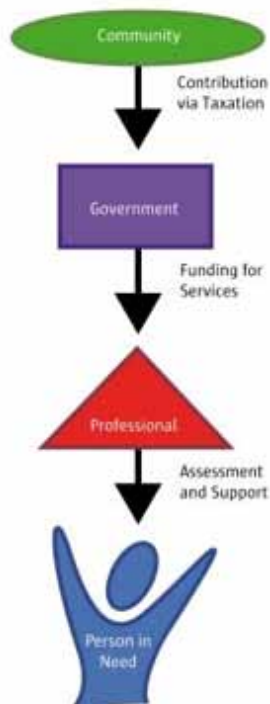
All this means is that the focus is on all services for disabled children; in education, health, social care and in mainstream community services, working in a personalised way. This means putting the child at the centre and everyone involved – the child, the family, friends and neighbours, people in the community and professionals- working together to support that child to achieve his potential.

Working together means that the child and family are involved from the start in thinking about what needs to happen and what good support looks like. They must be in the driving seat in terms of making decisions about what will work for them. Services must focus on the child and family's whole life, not just the part of it that they know about and treat each child as an individual person with unique skills, talents, aspirations, preferences and support requirements.

## 2: What is Personalisation?

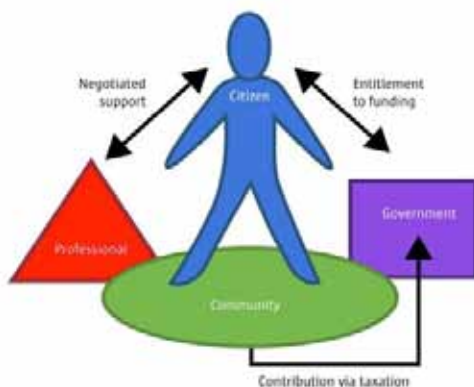
Personalisation is often thought about as simply to do with personal budgets that children, young people and families can use to buy services and support to improve their outcomes. Personalisation is about much more than this: it's about a fundamental change in how we think about and organise services and support, and particularly how we think about disabled children, young people and their families.





Traditional services have seen children who have individual support needs as being 'in need'. Professionals have assessed them and then allocated services and resources based on what they believe to be best for the child. Professionals have been 'gate-keepers' of services, money and other resources.

This is known as the 'gift model' of service delivery.



Personalisation challenges this approach and sees individual children and their families as citizens who are entitled to take control of their lives and be supported in ways which make sense to them.

It is about children and families directing how they are supported.

This 'citizenship model' of service delivery makes it clear that children with individual needs and their families are part of the community.

Shift to Citizenship: From Gift to Entitlement © Simon Duffy 2009 (developed at In Control 2005)

So personalisation really means an approach to health, social care, education and support services that sees children, young people, or adults as individuals with unique skills, talents, aspirations, preferences and support needs. It also sees the young person and their family as part of, and firmly rooted in, their local community.

Personalisation is about putting the individual person in the centre and everyone involved with that child working together as equal partners to support them and enable them to achieve their potential in all areas of life. As equal partners, the child or young person and their family are actively involved.

The idea of putting the child at the centre of planning their care and support is not itself new. What personalisation adds is the active participation of the child and their family in managing their own lives, and a wide range of opportunities and activities around them.

This diagram of the 'whole system' helps us understand how society and services support disabled children in a family centred way.



Figure one: Adapted by In Control from the Quadrants of Personalisation developed by OPM

**Universal services and the mainstream** is what's available for everyone locally – schools, leisure centres, shops, libraries etc.

**Targeted services** support children or families by providing services that are required by one or more people: for example, speech and language therapy or one-to-one support in school.

**Social capital and community wealth** means the groups, clubs, societies, places of worship etc. that are in every community – people and places for sharing interests, activities and mutual support.

**Choice and control** – self-directed support is individual support for disabled children and families, where it's needed. For example, help to eat or drink or get about, or support to go shopping or to the cinema.

A truly personalised approach thinks about support from all four of these quadrants.

### **A note about co-production.....**

One of the core principles of the SEND reforms is to make sure that children, young people and families are involved in the decision making processes at both an individual and strategic level. We often hear this talked about as 'co-production'.

The New Economics Foundation - [www.neweconomics.org](http://www.neweconomics.org) - use the following working definition to describe co-production:

*"A relationship where professionals and citizens share power to plan and deliver support together, recognising that both partners have vital contributions to make in order to improve quality of life for people and communities."*

This is a very different concept from more traditional consultation and involvement processes that young people and families have been used to!

There is a great animation about co-production at [www.nomorethrowawaypeople.org](http://www.nomorethrowawaypeople.org)

There is also a toolkit about co-production on the personal health budgets website - <http://www.personalhealthbudgets.england.nhs.uk/Topics/Toolkit/MakingPHBshappen/WorkingTogether/>

# 3: Understand

If we want to support a disabled child in an authentically personalised way, we need to understand who he is, what he enjoys, what he aspires to, what support is already available and how services work locally. If we take time to really understand, we will have a much better chance of getting him the right support so that he can be truly himself, achieving his potential in all areas of his life.

This section is about understanding:

- What you've got as a family
- Your community and what they offer
- Your child and what it will take to get them a great life
- What formal services and support can offer and how they work

# Understanding what you've got as a family

When you have a non-disabled child, family life is lived exclusively within the left-hand side of the diagram below - in the blue and purple boxes. Living with a disabled child often means that a family needs support from the boxes on the right hand side. The trouble is, it is easy to focus on the orange and green boxes and forget to think about the ordinary stuff, the skills and knowledge a family brings, as well as what's already there in the local community.



Understanding what you've got as a family means thinking about your **'Real Wealth'**

'Real Wealth' is a concept used to describe a child and family's resources in a holistic way. It's not just about money. "Real Wealth" is the sum total of a family's resources: its financial assets, but also the connections, skills and abilities that it draws on every day as individual members of the wider community.



The 'Real Wealth' model was first published by In Control in 2008 in: 'A Whole Life Approach to Personalisation: Self- Directed Support for Children, Young People and Families', Crosby N and Duffy S (2008)

## **'Real Wealth' is made up of:**

### **People**

This is about the ability to bond and communicate with others and having a loving relationship between parents and children and wider family networks. It is also about social networks; families can only thrive if they are connected to, valued by, and have a sense of belonging within their local communities.

### **Access**

Families need to be able to access community activities and buildings and to feel welcome there. They need good, accurate and timely information that is welcoming and inclusive. Organisations need to understand the different elements of access – physical, sensory, social, cultural and psychological – and to be flexible to make sure they are accessible to everyone.

### **Skills and Knowledge**

'Real Wealth' recognises that each family member has their own skills, abilities and personal qualities, including their disabled child or young person, and looks for opportunities to use and develop them. This includes building social connections and finding ways to join in with what's happening in the community, giving people who don't know disabled children the opportunity to discover how much disabled children have to offer.

### **Assets**

Financial assets may include a personal budget as well as other sources of income.

### **Resilience**

'Real Wealth' looks at a family's physical, mental and emotional wellbeing – their inner strength. The other four elements of 'Real Wealth' contribute to sustaining natural resilience. Events that happen to families with disabled children and the way others treat them can strengthen or weaken this resilience. Encouraging a community in which everyone both contributes and benefits supports families to develop a feeling of belonging and gives them a sense of responsibility rather than a feeling that they have a negative impact.

### **So, families really using their 'Real Wealth' might look like this ....**

- One of the Mums of a girl in Lucy's primary school is now confident to have Lucy round for play-dates.
- Jim in the village shop got me Jamie's first personal assistant - I was having a chat with him about needing some support - he suggested Josh and introduced me to his parents.
- We found David, Lucy's keyboard teacher through a friend of a friend.
- When Jamie went with Josh to Paris, I bought their flights and the hotel and gave Josh beer money....but he didn't want (or get) an hourly rate.
- Sarah's teacher helped me realise that my problems with reading and writing were getting in the way of helping Sarah's learning. She helped me get onto an adult literacy course and now I feel much more confident.

# Understanding your community

It is important to see your child as a member of your local community. Can he join in with the things that other children of his age are doing? Disability legislation means that ordinary, mainstream services should be open to all children, and providers have a legal duty to make reasonable adjustments for individual disabled children. It might not be possible if it costs too much, but many adjustments are simply about people's attitudes and willingness to do things a bit differently. It may be that your child requires some extra support and the people working with you and your child will explore the possibilities with you.

## Working with a local leisure centre

James is a young man of 14 who goes to mainstream school. His mum, Molly wanted to support his independence by enabling him to use his local leisure centre to go swimming on his own one night a week after school. One option would have been to get a personal assistant to support James, but with support from James' school and by working with the leisure centre and some of James' school mates, Molly was able to make it happen by putting the following in place:

- James' form tutor talked to his class and four boys who already went swimming after school agreed to take it in turns to walk with James
- Molly went into the leisure centre to meet with the receptionist and the manager and explain what she hoped they could do - offer a bit of extra support
- She then followed this up with the below letter that they agreed to share with all the leisure centre staff as well as his one page profile to help staff know more about some of the particular ways of supporting James:

*"Some of you will know our son James as we come swimming quite regularly along with our daughter, Lucy. You'll know that he is a really good swimmer and loves jumping in! James goes to Bishop's School and has just started Year 10. He also has autism*

*"James is starting to do lots more on his own and this term he will be coming swimming after school on a Wednesday. He'll walk down from school with one or two of his friends and then go back in time for the late bus home to Anytown . It leaves school at 5.30pm so he will need to leave the leisure centre at 5.15pm. He is a pretty good timekeeper, but if any of you happen to see him dawdling around this time please do give him a nudge.*

*"James is really independent but he's also 14 - so if he does anything he shouldn't (like being noisy, or running in the pool - or any of those other things that 14 year olds do) please do tell him off. Too many words confuse him so stick to short instructions rather than a complicated explanation; 'James, stop' or 'James be quiet'.*

*If for any reason you need to tell us about something, please feel free to call. Many thanks.*

Molly Smith

Sometimes, disabled children need a more specialised service, or simply want the opportunity to do things with other disabled children. As part of the SEND reforms, from 1st September 2014, every Local Authority has to tell you about the services that are available for disabled children locally by publishing a Local Offer. This is information about the services they expect to be available in their area for children and young people from birth to 25 who have special educational needs and/or disabilities (SEND); and also services outside of the area which they expect children and young people from their area will use.

The Local Offer will put all the information about education, health and care services, leisure activities and support groups in one place. It is not simply a directory of services, but will also explain how young people and their families can access services and support and what you can expect. Knowing what is out there gives you more choice and therefore more control over what support is right for your child.

The Government says that the Local Offer must be developed and reviewed in partnership with children and young people, parents, carers and local services including early years settings, schools, colleges, health and social care agencies.

**Examples of the services they have to tell you about are:**

- Education, health and social care services
- Sports, arts and other leisure activities
- Support with travel to school
- Support when changing schools and preparing for adulthood
- Where to go for information and advice
- Childcare
- Resolving disagreements – mediation, complaints and the Special Educational Needs and Disabilities (SEND) Tribunal

**The SE7 Pathfinder programme has produced a Local Offer draft framework.**

**See:** <http://se7pathfinder.files.wordpress.com/2013/12/se7-local-offer-framework-final.pdf>

They have also shared their journey towards co-producing their Local Offer:  
<http://se7pathfinder.files.wordpress.com/2013/10/se7localofferthejourneysofar.pdf>



# Understanding your child and what it will take to get them a great life

Everyone involved with a disabled child should focus on enabling her to achieve the best life possible. This means supporting her to reach her potential in education, to be as healthy as possible, to be included in her local community, to stay safe and to be ready for adulthood and all that entails. People need to really know and understand your child and share what they know with colleagues working in other services. If you are worried about sharing sensitive health or social care information, talk it through with them. They must take notice of what you and your child think, share their knowledge and understanding with you, and be clear about what information they are sharing.

The focus of the SEND reforms is to put you and your child at the centre of thinking and planning, actively involved in her support at all stages, discussing what she requires, planning how to support her and directing how that support is delivered.

It doesn't have to be complicated. For example, think about the following questions:

- What's important to my child – what really matters to him, now and for his future?
- What's important for my child – to keep him safe and healthy?
- What's working well at the moment – can we keep this up or do more of it?
- What isn't working so well – how can we sort it out?
- What does a good day look like – how can we have more good days?
- What does a bad day look like – how can we reduce the number of bad days?

**There are some excellent person-centred tools to help everyone understand your child. See:**

[www.helensandersonassociates.co.uk](http://www.helensandersonassociates.co.uk)

[www.preparingforadulthood.org.uk](http://www.preparingforadulthood.org.uk)

[www.supportplanning.org](http://www.supportplanning.org)

Darlington Council has a single plan mini book that they have developed as part of their birth to 25 Education, Health and Care plan. It uses person-centred tools to help you collect and collate information about your child and your family

<http://www.helensandersonassociates.co.uk/media/83090/singleplanminibook.pdf>

Here is a video clip of Helen Sanderson talking about their One Plan concept in the 'other resources' section:

<http://www.sendpathfinder.co.uk/infopacks/ap/>

There are lots of examples of young people using person centred thinking tools here:

<https://www.youtube.com/playlist?list=PLjB3u9kDbySGOqkTZhypXvkGW3HigsWJA>

### **One page profiles**

One page profiles are a great way of pulling together the key information people need to know about a young person on just one page. The profile usually shares three key sets of information:

- What people like and admire about me
- What's important to me
- How I want to be supported/what's important for you to know

For more information, including a useful animation, go to <http://www.helensandersonassociates.co.uk/reading-room/how/person-centred-thinking/one-page-profiles.aspx>

You can also find some (free) colourful templates to download at <http://www.sheffkids.co.uk/adultssite/pages/onepageprofiletemplates.html>

## Understanding how services work

Another important aspect of the Local Offer is that your Local Authority must publish information about how the system works locally:

- How they assess and decide children's requirements for support - in education, health and social care
- How they plan to meet those requirements, including local eligibility criteria
- The options for personal budgets, including which services could be part of a personal budget

From September 2014, the current Statement of Special Educational Needs and Section 139a Learning Difficulty Assessment will be replaced by the new Education, Health and Care plan (EHCP) running from birth to age 25 for children with special educational needs.

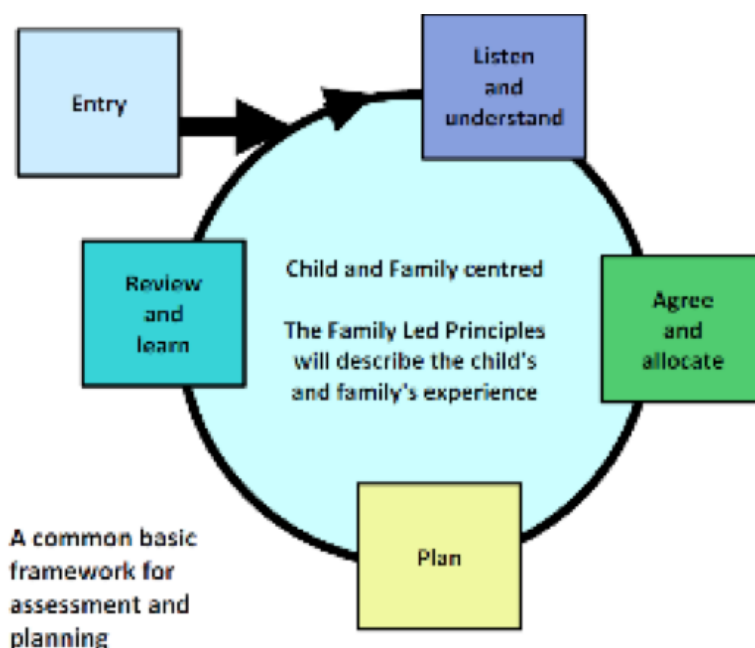
The main differences are that the Education, Health and Care plan:

Is more person centred with the engagement of children, young people and their families central to the whole process

- Has a more co-ordinated assessment process across education, health and care services
- Focuses on whole life outcomes to be achieved for each child/young person
- Runs from birth to age 25

There is a detailed guide to the Education, Health and Care plan process in the appendices but once an assessment for a plan has been agreed, the process follows the four steps as outlined in the graphic below developed by the SE7 Pathfinder programme. They have developed a framework for assessment and planning that you can find here:

<http://se7pathfinder.files.wordpress.com/2013/12/se7-framework-for-assessment-and-planning-jan-2012.pdf>



## Listen and understand

If your child requires support in school, over and above what's available to all children, because of the level or complexity of his special educational needs, your Local Authority will arrange an assessment to consider and agree what support he requires.

An educational assessment automatically triggers a single assessment that looks at a child's requirements for support from health and social care as well. This means that you shouldn't have to repeat the same information over and over to different people from different services.

The assessment process is about gathering information, from you and your child and the people around you who know and understand him.

## Agree and allocate

At the end of the assessment, a decision will be made about the support that needs to be put in place and whether an Education, Health and Care plan is needed. If it is agreed that a plan is needed, the decision should also be made about whether there will be a personal budget allocation.

**A personal budget** is a sum of money made available for children who require additional support over and above what is available to most children through local services. It is not the overall total of all the money that is available to support a child. For example, it does not include the cost of your child's school place or existing targeted support provided by school, such as additional learning support. Some headteachers have contributed some money from their own school budget, although there is no requirement for them to do this. Knowing how much money is available gives you choice and control over your child's support.

## Plan

The Local Authority will work with you to agree outcomes and put together a plan.

## Review and learn

Reviewing how things are going is an ongoing process. There will also be formal reviews.

The Council for Disabled Children has produced a checklist for Education, Health and Care plans (soon to be updated now the final Code of Practice is out):

See: <http://www.councilfordisabledchildren.org.uk/news/july-december-2013/new-resource-our-education-health-and-care-plan-checklist>

# 4: Plan

Planning must focus on your child, what he wants for himself and what you want for him. Everyone should listen to you as the parent and the child himself and recognise that your child may be able to take more responsibility for decisions as he reaches 16 and older.

In the previous section, we talked about understanding your 'Real Wealth' - what you have as a family and in your community. Any plan needs to start with this. For example, if your child is going to go to the local scout group or a sports activity, you might be able to take turns with other parents to take your children there. Or there may be an aunt or uncle who would have your child to stay with them to give you a break. Sometimes the people around families with disabled children would like to help but don't know how. The planning process can explore possibilities and support you to ask for that natural help and support.

During the planning process it is important that:

- Everyone sees your child as an individual and doesn't make assumptions because of his disability or special educational needs
- Everyone uses clear language and enables your child to understand as much as possible for example by using pictures or photos or technology
- Everyone acknowledges what your child is good at and enjoys
- Everyone focuses on results by identifying positive outcomes to be achieved
- The support that's planned will work in the way that's best for your child as an individual
- Everyone who needs to be involved is there to discuss and agree the overall approach

Plans must describe the outcomes that you and your child want to achieve - goals that help him to progress. An outcome is the difference made to a child as a result of someone doing something. Some outcomes may be about keeping things the same, like managing a health condition. Others will be about encouraging your child to develop and reach his potential. All the information that was gathered during the 'understand' process will contribute to the outcomes you agree with and for your child.

An outcome:

- Is what I want, not what someone says is best for me
- Is not written from a service perspective
- Is something I can tell when I have achieved it
- Changes something that isn't working
- Moves towards a future that I want

One of the main difficulties we have when developing outcomes is our tendency to embed the solution into the outcome. We might say that if the problem is a young person's communication with her friends then the outcome is two hours speech and language therapy. But that's just one of many possible solutions. A solution is the resource you need to achieve your outcome:

- It can be an item or an activity
- It can have a cost associated with it, or be free

The other problem is that we are not specific enough with our outcomes, which makes it hard to measure them - outcomes should be SMART (specific, measurable, achievable, realistic, time-bound).

**The problem:** Anna finds it hard to get her friends to understand what she wants and this makes her frustrated. Sometimes she hits out because she is cross.

The outcome: 'I am understood by my friends and I can play with them at the after school club every day without getting cross'

**The possible solutions:**

- Speech and language therapy
- My friends learn my signs
- A communication passport (developed with my friends)
- An iPad and app so I can show my friends what I want

## Preparing for Adulthood

One of the important principles of the SEND reforms is to raise the aspirations for young people with special educational needs and disabilities as they move into adulthood. The Children and Families Act 2014 says that the Preparing for Adulthood outcomes should be a focus of person-centred reviews from Year 9 onwards.

The four Preparing for Adulthood life outcomes are based on what disabled young people say is important to them. Ultimately young people want to have full lives with choices about their future and control of their support.



For more information see: [www.preparingforadulthood.org.uk](http://www.preparingforadulthood.org.uk)

**As part of the SEND Pathfinder programme, Greenwich Local Authority** has been exploring the use of IT to promote person centred planning. In particular, they have worked with families to develop personal Wiki websites where young people and their families can collate information about the young person as well as their plan.

Shane's family has developed a Wiki for Shane that contains all the things that are important to him. To see a demonstration, please click on the links below:

Forty minute version: <http://www.youtube.com/watch?v=wOK84qsB4BA&feature=youtu.be>

Shortened, nine minute version:  
<http://www.youtube.com/watch?v=76q1U31ihw0&feature=youtu.be>



## 5: Do

After all the assessing and planning, this is the time when everyone gets on with supporting your child in the ways you've all agreed. Some of putting the plan into action might be about organising the informal support you have identified, some might be about setting up services that you have agreed.

If you have a personal budget to buy services or support to meet the outcomes in your plan, you need to make some decisions about how to manage that budget.

There are four ways to manage a personal budget:

1. You can take it as a direct payment, receiving the cash to buy and manage services yourself, or you can nominate someone you trust.
2. The Local Authority or Clinical Commissioning Group can manage it for you, organising your child's support.
3. A third party can manage it for you. For example, the cash can be paid to a service provider, or a local organisation can manage your budget for you.
4. You can use a combination of these options. For example, the Local Authority could provide a short break service and speech and language therapy, while you use a direct payment to pay for a personal assistant to support your child to make and meet friends at the local youth club

**It's easy to get confused by the difference between a personal budget and a direct payment - remember:**

**Personal budget** = I know how much money is in the pot

**Direct payment** = one way of taking my personal budget (but not the only way and I don't have to do it on my own!)

Your Local Authority or Clinical Commissioning Group must explain these options to you and tell you what you can spend your personal budget on. They must also tell you about the local organisations that can help and advise you, for example the local Parent Partnership and the Parent Carer Forum.

## Do it yourself through direct payments

The advantage of direct payments is that they give you direct control and flexibility over who supports your child, how and when. Some people worry about the extra responsibility of managing personal assistants or recording how they spend the budget, but there will be local organisations to help you with things like recruitment, employment contracts and payroll.

Your Local Authority will explain how direct payments work: how to record what you spend the money on and how they will check that you are buying the support that has been agreed. You must have a separate bank account and keep bank statements, receipts and invoices. You can put direct payments from all services – education, health and social care – in the same account. They must tell you how much you will get and how often it will be paid into your bank account.

You have the right to request direct payments from all services. For social care, local authorities must offer direct payments. For education and health care, there are some conditions:

- For education direct payments, local authorities have to consider the impact on other children; for example, whether they would still be getting value for money. They also have to get agreement from your child's school if you want to use a direct payment for a service that will be delivered at school.
- For health direct payments, there must be agreement about managing risks and a named person who will be responsible for managing the healthcare that's been agreed in the plan. NHS organisations will also want to ensure value for money.

Your child's requirements may vary according to his health, or the times you are able to support him yourself, or simply because clubs and activities happen at different times. You can vary the amount you spend from week to week or month to month and 'bank' any spare money, for example, to save up for a short break. The important thing to remember is that you can only spend your direct payments to achieve the outcomes that have been agreed in the EHC or support plan.

Being in control means you can also be more creative. For example, some families join together and share the overall cost of an activity for two or more children.

Contact a Family produced a guide; 'Getting Direct Payments for your disabled child'. You can download it here:

[http://www.cafamily.org.uk/media/379527/direct\\_payments\\_ew\\_30\\_july\\_2014\\_kb.pdf](http://www.cafamily.org.uk/media/379527/direct_payments_ew_30_july_2014_kb.pdf)

Skills for Care has produced a toolkit about employing personal assistants. You can download it here:

<http://www.skillsforcare.org.uk/Employing-your-own-care-and-support/Support-for-individual-employers/Employing-personal-assistants-toolkit.aspx>

## Do it through a provider

The advantage of using a provider is that it can save you time and you don't have some of the responsibilities that go with using a direct payment. The potential disadvantage is the reduced control. You may not be able have the same person to support your child all the time or you might have to compromise on the hours they are available, and you may not have any choice over who is employed to support your child.

If you choose to use a provider, you might like to ask them:

- If you can choose the person who will support your child
- If it will always be the same person
- What happens if your support person is absent or goes on training?
- What happens if your support person just doesn't feel like a good match with your child and family?
- How the support person will be managed day-to-day and longer term. How will you and your child be involved?
- What happens if there is any disagreement?

## What you can spend your personal budget on

It is important that you feel able to suggest ways to use your child's budget that are personal to her and your particular family circumstances, as long as it is meeting the agreed outcomes. These are just some examples:

- Support in your own home, whether it's equipment or help with personal and domestic activities
- Equipment to help communication or learning
- Support for your child to join in with local clubs or activities
- Sports or cultural activities
- Short breaks
- Employing personal assistants
- Someone to go with you on a daytrip or short break e.g. so you have more time for brothers and sisters
- Work experience or a work-based learning opportunity

## And what you can't spend your personal budget on

There are some things that you can't use your personal budget for, for example: vaccination or immunisation, health screening, NHS health checks, services that are provided by your GP, prescriptions, and dental charges.

As a general rule, you can't use a personal budget to employ a family member who lives with your child, but there may be exceptional circumstances where this will be agreed.

Even if a personal budget is not possible, if a flexible and 'can do' approach is taken by education, health and social care partners then really innovative arrangements can be made as the following examples show:

Lucy is in Year 10 of a mainstream school, with targeted funding for support throughout the school day. When she and her family were choosing her options for GCSE at the end of Year 9, they wanted to help her pursue her love of music and support her real talent in composing. It was clear that a GCSE syllabus would not offer the best opportunity for Lucy to demonstrate her skills in music— she doesn't use many words to speak and her writing skills are limited. The school knew that Lucy already had private keyboard lessons from David on a Saturday and suggested that his skills might be used in school.

After some careful planning, it was agreed that the school would use some of Lucy's targeted funding to pay for David to come into school for two hours a week to work with Lucy and her teaching assistant on a BTEC course, with the remaining hour of study being supported directly by school. This arrangement has been incredibly successful as most of Lucy's achievements are recorded through video and photographic evidence — at Christmas she gave a keyboard performance to the whole of the GCSE music group. She is about to move into Year 11 and she is set to get a level one qualification.

### **A letter from a headteacher of a special school**

*I have just completed a meeting with Mr and Mrs Smith regarding their son, who attends Anyplace School. Their son currently gets one to one additional TA funding as a result of his personal and medical care needs and the need to deliver a personal therapy programme within his educational programme.*

*Their son's medical and other needs fluctuate and need to be considered in great detail. It has become extremely difficult for the family to complete all the medical interventions and standing time that is needed before their son has eaten breakfast and can be put in the taxi as these can take up to an hour and half, which means he is being woken very early to make sure he spends a reasonable amount of time in school each day.*

*This was only one example and I felt persuaded that the proposal to do things differently, made by his parents would be a good approach.*

*In essence this would mean that an element of their son's funding and transport costs would be transferred to his Personal Budget and the family could then employ staff who could work with him in the best context for his needs. It is proposed that Mondays and Tuesdays would be at school and that Wednesday would be a shared day where education and therapy/ personal care would happen. Thursday and Friday the education would be provided totally in the home environment. I saw documents which suggest that this model could work and examples of planning that showed the educational aspect of the programme would be robust.*

*The family is planning to move over to this provision for the summer term from April. This needs agreement from the SEN team and social care/health partners as well at school and I would be very grateful if you could advise us and the rest of the group concerned how we could move forward from here in good time to achieve this.*

# 6: Review

Reviewing is about checking how things are working (are the outcomes you agreed really happening) and making any changes to the plan that are needed - big or small.

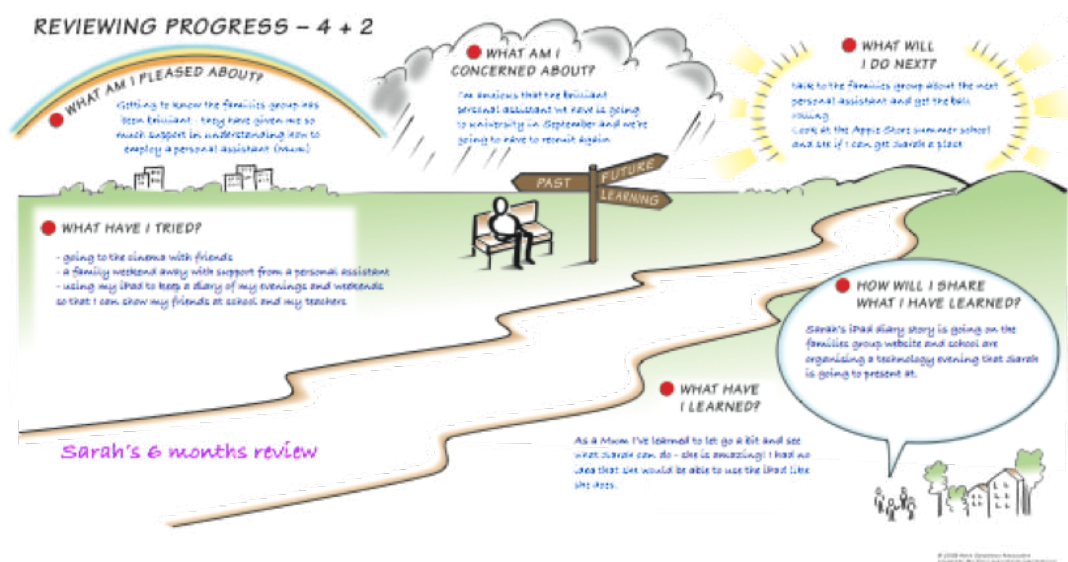
We tend to think about 'a review' as a meeting that happens probably once a year, but while there is a statutory duty for a formal review, most of us keep a check on how things are going on a much more regular basis. You don't have to wait for an annual review to make changes to a plan.

**Charlie's plan** included the outcome of joining his local Cubs on a Friday night, with support from a personal assistant. After a few weeks the older brother of one of the cubs (who the family already knew) said that he would be really happy to support Charlie as part of his Duke of Edinburgh volunteering work with the Cubs. This meant that two hours of personal assistant time was freed up and Charlie's mum was able to use this to enable Charlie to get more support to meet another of his outcomes - learning to swim. Charlie's mum was already taking him to swimming lessons once a week but she was then able to arrange for Charlie to have an extra swimming session with his personal assistant between lessons to practise what he was learning and hopefully get him swimming even sooner!

Good questions to help you and your child prepare for a review are:

- What worked, what didn't work and what have we learnt from this?
- What should we stop, what should we keep doing and what should we start doing?

Helen Sanderson Associates has a useful graphic poster you could use to prepare for a review meeting, or that everyone at the meeting could contribute to as a way of thinking together about how things are going. Here's an example of one filled in:



© Helen Sanderson Associates 2008

You can download the template here:

[http://www.supportplanning.org/Support\\_Planning\\_Downloads/Reviewing%20Progress%204+2.pdf](http://www.supportplanning.org/Support_Planning_Downloads/Reviewing%20Progress%204+2.pdf)



Your Local Authority and Clinical Commissioning Group must involve you and your child in formal reviews and take notice of what you think. Reviews should be used to learn about how your child is progressing towards the outcomes and whether anything needs to change. He may need new or more stretching outcomes, different support, new opportunities or more or less money in his personal budget. If your child has an EHC plan, it will usually be the school that sets up the review. From Year 9 onwards, reviews must also look at your child's options for adulthood, including education, employment, independent living and participation in society.

If you get direct payments, your local authority must review how you're getting on within the first three months. They will check that you want to carry on managing the budget, whether you need any help with it, and make sure you've spent the money on the things agreed in the plan. EHC plans are reviewed annually, although particular outcomes may need to be reviewed more often. Local arrangements vary and your Local Authority will explain what happens where you live.

Remember to celebrate successes and focus on what your child is good at and interested in. Also remember that straight after 'review' in the commissioning cycle is 'understand'. This means that what you learn from the review process should be used to make you plan even better.

# 7: Stories of using a personalised approach and personal budgets

There are now many stories from around the country of young people and their families using personalised approaches to get the outcomes they want. As the Special Education Needs and Disabilities (SEND) reforms come into force, there will be more local examples. To find examples of how taking a personalised approach has worked for families in your local area, get in touch with:

**Your local Family Information Service:**

<http://findyourfis.familyandchildcaretrust.org/kb5/findyourfis/home.page>

**Your local parent carer forum:**

[http://www.cafamily.org.uk/media/781047/contact\\_lists\\_for\\_website\\_aug\\_14.pdf](http://www.cafamily.org.uk/media/781047/contact_lists_for_website_aug_14.pdf)

**The Preparing for Adulthood website has some stories of older young people getting their own place, going to college and getting jobs:**

<http://www.preparingforadulthood.org.uk/resources/stories>

Lucy's story on page 29 explains how her school working flexibly enabled Lucy to have a much more personalised curriculum.

The stories below are from families who have a range of experiences of personalised approaches and personal budgets from health, social care and education.

Note: some of the stories are from the original Individual Budgets Pilot for families of disabled children that ran from 2009 - 2011 in six local areas to test the concept of Individual (personal) budgets. You can read the series evaluation reports here:

<https://www.gov.uk/government/collections/individual-budgets-for-families-with-disabled-children>

## Lyrena

Lyrena lives at home with her mum, dad and brother. Her mum had the following to say about social care personal budgets:

*"We were originally on direct payments but I wasn't too happy with this ... it changed all the time. A worker came out and explained everything. We then went to a meeting with other families. We did support planning. We enjoyed that – it helped you make sense of it. We were told how much money we would have. I thought, 'Yes, I can get on with it now.'*

*"We got the right person to support Lyrena. As a family, we love camping so we updated some of the equipment we had. We go camping lots and lots of weekends throughout the year.*

*"Lyrena is a great dancer and goes to the local community centre with her 18-year-old PA. "She loves going to the Zumba class. Lyrena has such a good relationship with her PA – she looks up to her. Lyrena is following a healthy eating plan. This, together with her dance classes, helps her to stay fit and healthy.*

*"We wouldn't change anything. The money came in quickly so we could get on with it. It has been spot on and it is easy to get on and do it. We would welcome any opportunity to help think about future plans and other ways the budget can be spent. Having the budget made me happier than before."*

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## Deanna

Deanna is 10-years-old. She has multiple impairments, including communication difficulties with no speech, physical impairments that affect both her fine and gross motor skills, sensory impairments and epilepsy.

In winter 2009, Deanna's family got a letter from social services asking if they were interested in being part of an individual budget pilot. The family attended a two-day workshop along with social workers and other parents, learning how to plan and work out outcomes and spending.

How the family spends their budget depends all on the outcomes that have been agreed for their child. Direct payments was all about paying for carers – a person, or a club, whereas, 'individual budgets is much more flexible and you can spend it on anything as long as it is meeting outcomes for the child. You can buy equipment so, for instance, we could buy a bike. You have to think about your child, their needs and the Every Child Matters outcomes.'

A lot of it is personal assistant time in holidays and at weekends. This gives Deanna one-to-one time with another adult. She goes out and enjoys a variety of activities whilst her family has time away from their caring responsibilities. The personal assistant can also come along to family events to support Deanna so the whole family can attend functions and days out with friends.

The plan has made the extended family understand who Deanna is and what her family wants for her future. They are all now seeing Deanna as a child first and seeing they can all have a vital role in her life. The plan can be used within school – the school can transfer information within the plan straight onto their paperwork. Everyone can work together to support Deanna, focusing on the same goals. The plan is sent to the clubs that Deanna attends so they too can understand her and work with her effectively.

There is real partnership working to ensure Deanna is at the centre.

Since having an individual budget, the whole family's confidence in caring for Deanna has increased, because she is getting the care she needs in a way that suits the family. Everyone is a lot more relaxed, refreshed and energised.

## Daisy and Tim

Daisy, eight, and her brother Tim, seven, both have a diagnosis of autistic spectrum disorder and live with their grandparents. In September 2009, Tim and Daisy's grandmother self-referred to the disabled children's team following the death of their grandfather because she had reached a crisis point where she felt unable to continue caring for her grandchildren.

A number of temporary measures were put in place to help the children to remain with their grandmother. This meant the family was dealing with a wide range of providers that had been selected by the local authority. Daisy and Tim joined the individual budgets pilot, with a view to giving the family the opportunity to choose how they would like to meet their needs. A joint person-centred plan was drawn up as well as considering their grandmother's needs as a carer.

The family chose to consolidate their support and to manage their own services. The family

receives direct payments, which they use to pay a childminder before and after school, and for a monthly two-night break. The residential weekends were negotiated and agreed between the family and the childminder, and provide excellent value for money.

## Sabine

Sabine is a 16-year-old young woman who has Down's Syndrome and associated learning difficulties. She and her family were involved in a personal budget pilot. They chose to manage their budget with the support of a key worker.

The original amount of support she received paid for four hours with her personal assistant and she also attended two youth groups. Following the pilot, Sabine's budget was increased so that she could employ the personal assistant for eight hours per week, giving her mum and dad some time together at weekends.

They also used their budget to pay for family gym membership and driving lessons for her older brother. The driving lessons have been hugely beneficial for the family because it means Sabine can rely on her brother as well as her parents and he can help in an emergency, for example if the school bus doesn't turn up. It also means that Sabine and her brother can go out together.

The key worker took the lead on support planning and the social worker worked closely with her to ensure that the support plan was agreed. Both the social worker and the key worker knew the family well before the pilot and had a good relationship with the family.

The family felt that the support planning was very positive and helped them to be realistic. They had not realised the impact of things like the disruption of routine and this helped them to see how the stresses of everyday life could be managed better. The family felt that it was crucial that the person supporting the planning knew them really well and could prompt them and think creatively about how things could be improved.

This family felt that although the key worker would be the appropriate professional to do the support planning, they would need a social worker to complete the figures and get the budget approved.

The impact of the personal budget for Sabine's transition from children's to adults' service was very positive. When she was allocated her adult social worker, the support planning was shared and it enabled the new worker to get a good picture of the family. The budget was agreed quickly when Sabine turned 18.

## Fi

Fi is 20-years-old and is in her second year at university, studying Economics. She has cerebral palsy. Fi found out about direct payments and personal budgets through her personal tutor at her college who was supportive and wanted to help her lead an independent life as a university student.

After finishing her A-levels and enrolling at university, Fi and her family started the process of receiving direct payments.

Getting into the system was the hardest part and also took the longest time.

At first, Fi used an agency, which wasn't the best experience. She had 12 different carers in her first year, which resulted in a lack of consistency. Carers wore a uniform and gloves and were not flexible about the times they would come. This was a very impersonal experience, which made Fi decide to employ her own personal assistant.

She used the internal job search facilities at her university to advertise her personal assistant job and now has a team of three personal assistants who are all fellow students living on campus or nearby.

Another advantage of managing her own support is that Fi has control over when she spends her direct payment money, which was impossible with the agency. During term breaks, she stays with her family and does not use a personal assistant. This way, she can build up money to use at other times. Fi is banking money so she can go on holiday with personal assistant support. This was not possible before.

Having a personal budget has given Fi complete independence from home and put her family's mind at rest, knowing that she has the support she requires. As Fi has recruited her personal assistants herself, she is in control of choosing the support she receives. Fi wouldn't choose what is not right for her and this gives the family reassurance too.

## Alexa

Alexa's Mum talks about their personal health budget:

*"Alexa is four and we have been in receipt of personal health budget money now for about a year. It has been very good for both our daughter, and for us as a family.*

*"It gives us the opportunity to arrange respite care for Alexa to fit around her needs. It means we consistently get the same people looking after Alexa.*

*"This is brilliant because they understand her needs and Alexa builds a rapport with them. It also means we do not continually get strangers in our house!*

*"The personal health budget money is not just for respite. Alexa has a number of defined outcomes that we can purchase items for. We have bought several sensory toys that she has really enjoyed, including a CD player so she can listen to 'A Squash and a Squeeze' in her room.*

*It has also allowed us to get her two very different garden swings, which we wouldn't have been able to get otherwise. The look of pure joy on her face when pushing her in these swings is just amazing. She had never been on a 'normal' swing before. Her communication has come on loads because of it. She is continually trying to find ways of getting outside to go on them!*

*The personal health budget has been very beneficial for our family."*

## Tom

David talks about the personal health budget they have for their son, Tom:

*"Tom is 21 and has Lennox Gastaut Syndrome, is multi-sensory impaired, needs one to one support in all aspects of his life and has life-threatening epilepsy. He also has a great personality, and enjoys music and many sensory experiences, including eating and trips out to hydrotherapy and other therapy sessions when he is well enough.*

*"When Tom was younger, his school worked flexibly with Tom's family to enable him to get the best possible experience at school. Tom's social care direct payment paid for personal assistants who supported him to get up and ready in the morning, then accompanied him into school. Tom's school day usually ran from about 1.00pm – 4.00pm as mornings are difficult. He then followed a bespoke curriculum, joining lessons with a range of year groups according to his interests and his health. Since he left school, Tom still uses the hydrotherapy pool at weekends, as the headteacher is keen for the school to be a genuine resource for the community.*

*"Tom personal health budget came into place in April 2013. It provides 24/7 one-to-one care and support for Tom in a specially designed annex and is significantly less than the cost of residential care. It funds a team of carers, specialist equipment and treatments including physiotherapy. The budget is also used to recruit carers. We placed adverts in the local paper and websites. Before we recruit any new carers we invite them to a 'meet and greet' appointment with Tom. We use a third party organisation to help manage Tom's budget and payroll, and to provide support with HR and training for the care team. This works well.*

*"The personal health budget has brought immense benefits for Tom. Firstly, he chooses who looks after him and how he lives his life. Essentially the pendulum of power has swung to us. We decide in partnership with our local NHS team how Tom is cared for. Also, we can buy equipment that meet Tom's healthcare needs, rather than the NHS dictating to us what we had to buy for him. Thomas also now has more freedom from pain and he has an improved relationship with clinicians. Our son is happy.*

*"Without doubt the personal health budget has significantly reduced costs for the NHS. Before, Tom used to be admitted to hospital due to constipation or epilepsy on a regular basis when he was in residential care. Now hospital visits are much less frequent. Even though the third party organisation employs Tom's carers, the arrangement works out cheaper than the residential placement."*

For more detail of Tom's story, see:

<http://www.peoplehub.org.uk/?p=813> and

[http://www.personalhealthbudgets.england.nhs.uk/\\_library/Resources/Personalhealthbudgets/2014/ThomasDavidStory.pdf](http://www.personalhealthbudgets.england.nhs.uk/_library/Resources/Personalhealthbudgets/2014/ThomasDavidStory.pdf)

## The Jacobs Family

The Jacobs family has three children, two of whom are disabled — Ben who is 11 and Daisy who is six. Dad, Peter shares his thoughts about having a personal health budget.:

*"We have been receiving respite 'hours' for some time now for our two children. It was frustrating to have a fixed number of hours from a specific agency, with no flexibility to carry the hours over to subsequent weeks when we may for whatever reason require some extra support, and no support for other costs in meeting the children's health needs. When we joined the personal health budget programme I wasn't certain what to expect, but experiences have been very positive. Previously the hours allocation was inflexible, but now with the personal health budget, we can save money from respite hours not used in previous weeks and months which gives us confidence that if anything comes up and we need to fund additional respite we can without delay - much better than the old way.*

*"In addition to this, it is now possible to use resources outside of the single agency approach previously used— this meant that on a recent family holiday we were able to recruit carers from an agency in Spain and benefit from some respite whilst away, something unimaginable before the personal health budget.*

*"A final benefit is that we can now cover some costs from the personal health budget that we used to have to pay ourselves— including travel costs for hospital appointments and rain covers for wheelchairs, which is great as travelling to London for appointments is not cheap, and affordability shouldn't be a factor in accessing the healthcare that the children need.*

*"There is of course a slight overhead associated with managing paperwork and bank-accounts— but the benefits noted above far outweigh that negative.*

*"There has been a slight overhead for our family as a result of managing the personal health budget, including agreeing the "outcomes" (ie. what you intend to use the money for – with some things that we thought were reasonable uses not being approved) as well as managing paperwork and bank-accounts. Regardless of disagreements around outcomes we have been much better off being on the personal health budget - the benefits of being on the personal health budgets noted above far outweigh the negatives.*

*"Without a doubt the personal health budget has improved our family life, giving us greater control over putting the money to the best possible use to meet the children's needs. I have no doubt as well that the better understanding of the terms and conditions associated with respite booking through agencies as a result of managing the funds ourselves (i.e. knowing that last minute cancellations still being charged) help minimise waste and therefore allows better use of the money."*

## Sammy

Sammy is eight and lives with her dad and older brother, Jake. She goes to her local primary school. Sammy has a diagnosis of autism and severe learning disabilities and has a full statement to support her learning. Her dad also had four hours a week and one overnight stay a month short break support. Her dad talks about the new approach:



*"When school approached me about getting involved in the Pathfinder I wasn't sure, but it has been great for us as a family. Sammy can be quite a handful and I'm used to getting defensive about how people talk about her, so the planning process was great - hearing teachers and the other kids say what they liked about her was amazing.*

*"It was also really good to start talking about outcomes. I realised that I'd never really stopped to think about what could be different, just what we needed to do. One of the big outcomes was about Sammy joining in after school stuff, as I'd never really thought that this would be possible. School agreed to fund Sammy to join the after school film club once a week and we worked with the local secondary school (where Jake goes) and found two sixth formers who were happy to come and help out and be an extra pair of hands.*

*"School also used some of her budget to buy an iPad, which we use both as a communication aid for Sammy and as a home-school diary (school take video clips and photos of what she's been doing and so do I). We've also started to build up a resource of information about Sammy and how to support her so I can share it with new workers.*

*"We changed the short breaks as well and I've employed the two sixth formers who help for free at the after school club as personal assistants and they are starting to take Sammy out to try new things. The overnight break just wasn't working so we've changed the hours into a budget and that will pay for three weekends away a year as a family, including my sister as an extra pair of hands. It really has changed our lives."*

## Jonathan

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

Jonathan's complex health condition means he receives funding through continuing health care. He was fortunate to be part of a pilot run by what was the Learning and Skills Council giving individual learning support funds. Putting the different funds together has enabled Jonathan to employ one full time personal assistant and two part time personal assistants to support him with activities in the evenings and weekends.

Jonathan's mum reports, *"an amazing improvement in his quality of life. It has given him so much more freedom to explore life. Without this personal budget he would not have been able to do anything like the things he can do now. I would have had difficulty taking him to these things. It is encouraging Jonathan to have a bit of an independent life style. And with Jonathan having his personal assistants I have more time to spend with my other two sons who both have learning difficulties and Jonathan can't stop smiling!"*

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

## Johnny

Johnny is 10-years-old and has cerebral palsy, which significantly affects his trunk, arms and legs, and which in turn has impacted upon his mobility. Johnny also has a learning disability and has high levels of difficulties with his communication. Johnny requires 24-hour care and support at home and in all other environments. His condition worsens in the cold winter months.

Johnny's previous care plan included overnight breaks at a residential unit. His parents did not feel he was benefitting greatly from these overnight stays, as they did not feel the unit fully met his needs.

With their personal budget, the family used some of the money to pay for a worker to accompany them to Tenerife for two weeks in December/January i.e. during the cold weather, to assist with Johnny's care. They also bought a pass for a rehabilitation unit in Tenerife which has specialist physiotherapy services. The pass enabled daily access to the unit, which Johnny really enjoyed. The exercise, physiotherapy and warm weather greatly benefited Johnny's health.

Johnny's parents report a marked improvement in his health and general wellbeing since their return from Tenerife. He has gained weight and looks really well. They feel the benefit of two weeks in the sun has achieved a far better outcome in terms of Johnny's health than many nights in the residential unit would have done.

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## Ryan

Ryan's mum Debi, explains the difference a direct payment has made to her son's life:

*"Ryan has various complex needs and has a personal budget. Previously we were receiving respite - or 'stresspite' as we called it - and as a family we felt it wasn't working and making us feel very isolated. As a working mum I needed more flexibility and choice in how we were supported."*

*"The introduction of a personal budget for Ryan's care gave us the choice and control we needed. We can ensure Ryan is involved in everyday activities and we have been able to build and expand our community network."*

*"We now have a team of five personal assistants for Ryan, with whom he has built strong relationships and we are able to do much more."*

*"Ryan is getting grounded in his own community and gaining real life experiences for his journey throughout life. Ryan is a valued member of society who can give something back and best of all we are ensuring he is part of 'mainstream life'."*

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# Maddy

Maddy's mum, Kate, tells their story:

*"My daughter, Maddy, is now 22. From age 11, she has received direct payments to pay for support from personal assistants. It started then because there was no after-school club/provision once she was in secondary school – it only existed in primary school. As I was working part-time and Maddy always needs someone with her, we needed to employ personal assistants to support her after school, until I got home from work.*

*"From age 11 to 19, I employed around 16 different young people, all aged 16 – 18, to support Maddy. They all came from the local sixth form, which Maddy also attended when we started. There was a natural turnover as the young people left school and went off to university, which all of them did. We employed two girls each year and they shared the three evenings per week. They were usually friends, so sorted out the evenings between them if for any reason one of them had a problem on a work-day.*

*"They were dead easy to recruit – the first personal assistant was the daughter of a local friend, who I'd babysat for many years previously, when her mum and I were in the same babysitting circle. This girl had a lovely friend – she introduced us, and the pair of them job-shared for the first two years. When they were leaving school to go on to university, they found me the next two personal assistants, from the year below – people they knew and trusted, who they thought would get on well with Maddy. This worked throughout Maddy's secondary school life, until the last year when the personal assistants couldn't find anyone to take over for the last year.*

*"But recruiting was still dead easy. I just went and stood outside the high school on the day the GCSE results came out, giving out slips of paper with the advert on. It was a great job for those personal assistants – it was better paid than all the other work they could have got and was at a time that didn't interfere with their social lives or need to be doing homework. Because they were young, they had a great attitude towards Maddy and just got on with what they had to do. I had teachers who refused to help Maddy use the toilet, for example, but these girls just took everything in their stride.*

*"It was also a job that enabled them to demonstrate their honesty, trustworthiness and reliability – all good experience for their CVs. They each had a set of keys to our house so Maddy and they could get in.*

*"The work was straightforward – being in the house with Maddy and just chilling, watching TV or videos and singing along, making a drink, maybe doing jigsaws. But in the holidays, they would catch the train or bus with Maddy and take her to the cinema, or walk into town for a drink and cake together.*

*"For me, it also meant I got more hours from my budget as the girls weren't liable for tax – so a win-win! This summer, one of those girls has come back and worked some casual hours for Maddy – still in touch after four or five years."*

For Further information, contact: [katesibthorp@btinternet.com](mailto:katesibthorp@btinternet.com)

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## Lisa

Jenny talks about her family's experience of getting a personal health budgets for their daughter, Lisa:

*"We are parents to seven children, five of them are adopted and several of them including our birth son have special needs.*

*"Our youngest daughter, Lisa is 10 and joined the family when she was two and a half years old. She has Dyskinetic Cerebral palsy and is micro cephalic. She is fed into her jujenum and has a gastric drain, she also has a naso-pharyngeal airway to help her respiratory problems. Over the last few years her condition has gradually got worse, but she has an amazing sense of humour and is fully aware of what goes on around her.*

*"Until about five years ago we had no support such as respite provision or direct payments, we had managed all our daughter's care ourselves. As time has gone on and her needs have become greater we were given direct payments to help with bath time and one weekend a month respite at a local medical respite facility.*

*"This centre was closed after just 18 months of our daughter attending. The centre had been joint-funded by social care and health care and as the re-provisioning was being sorted out the commissioners started to talk about the possibility of a personal health budget. At first this made me very nervous, it sounded like it may be a way of the professionals wriggling out of supporting us, it was especially frightening as we had seen Lisa steadily need more and more support. Despite this I was willing to be open minded and went on a conference day about personal health budgets, and although none of the material was aimed at parent carers it got my interest.*

*"One thing that we had not liked about the residential respite centre was little ones anxiety at going there. She is an adopted child who came from a background of extreme neglect, she suffers from separation anxiety and we found that every time she went away she became sick the following week, we felt that this was because of attachment issues and that it may well be better to provide the respite within the family home.*

*"Initially the personal health budget took in the same number of hours that we would have had at the respite centre, as Lisa was not on continuing care at this time.*

*"Lisa had a very disturbed sleep pattern, needing me to get up to her at least three or four times a night to help her, so we decided the money would be best spent on having one night a week for me to have some sleep and then three or four times a year have a full 48 hours so my husband and I could get away.*

*"Two years ago, after having surgery for a jujenostomy Lisa had several emergency hospitalisations and seemed to deteriorate. I was exhausted and only get about four hours a night sleep. I burst into tears on our new community nurse who then suggested an assessment for continuing care. The process was very swift, 10 days later continuing care was agreed and extra hours allocated. The beauty of having the personal health budget was that as soon as I knew we would be getting extra hours I was able to employ our main carer for one more night a week. I had also been training up some other carers to help in evenings and decided to train them to be able to do a night if needed.*

*"Last March our daughter became seriously ill again and was in two different hospitals over a month period. Since then she has needed a nasal pharyngeal airway.*

*"She now needs 24 hour support and someone to stay awake with her at night. Having the personal health budget already in place meant that I could start talking to our existing carers about night time cover while she was still in hospital. One of these carers was already very experienced with airway care.*

*"This also meant that we did not have to wait for a package of care to be put in place for Lisa to be discharged from a hospital that was two hours away from where we lived. So we were home much quicker than our friend who has a tracheotomy and had to remain in hospital for several months waiting for school and carers to be trained.*

*"For us the benefits of having a personal health budget have been huge. We have been able to choose carers that fit in with us as a family and that our little one enjoys being with, we have been able to purchase bits of equipment that we would not of been able to afford otherwise.*

*"We have been able to make sure that care was provided in a little girl centred way. Having a great sense of humour and being able to read in silly voices is a pre-requisite for any carer or nurse that works with us.*

*"We have found that being able to build a good relationship with carers who really are fond of Lisa and we enjoy having around has also made the situation easier for our other children. It can be difficult to maintain good professional boundaries, but most of our carers are now friends and we are friends to them. We have mutual trust and respect and therefore it is easier to negotiate a system that works for everyone.*

*"We have been able to take carers away on holiday with us and managed to have 48 hour non stop support over the weekend of our eldest daughters wedding a couple of weeks ago. I don't think this would have been possible through our local contracted agency.*

*"We also have a few hours a week with a local contracted agency, I decided on this as I thought it would build some more resilience into Lisa's package of care, but personally I have found dealing with the agency very frustrating and they seem never able to cover a shift if a carer is off sick. If one of my personal health budget carers needs time off, or is off sick, I just ring around the others to cover the shift. Because the carers know Lisa so well, and us as a family well, it is very rare that they let us down!*

*"We have one organisation holding the budget and another does payroll for us, this is a great help.*

*"It has been a steep learning curve for me, It initially took much longer than expected to get carers in place and I have never been in the position of being an employer like this before.*

*"I really like the flexibility of the personal health budget, in that we can use it to buy other things such as massage therapy that our daughter enjoys and equipment that we may not otherwise be able to fund."*

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# 8: Glossary of terms

The following is a list of key terms, in alphabetical order - it is not intended to be exhaustive.

**Assessment** – a formal process of collecting all necessary information about the child, family, those currently supporting the child, and their situations. An assessment will then inform the next steps in meeting the support needs of the child and their family and which service is best placed to meet the support needs of the child. (See Care Plan and Eligibility.)

**Brokerage** – describes the different types of support needed by a person or a family and child in making a good plan, arranging support and managing support, and a support plan in the longer term, once it has gone live.

**Care Plan** – an official document which states how the support needs identified in the assessment are going to be met.

**Commissioning** – the process for deciding how to use the total resource available for families in order to improve outcomes in the most efficient, effective, equitable and sustainable way.

**Common Assessment Framework (CAF)** – used in most children's services across England as the initial or first assessment following the referral or self-referral of a child and their family

**Direct Payments** – the opportunity for families and/or people to ask for the financial equivalent of the cost of the services being offered to meet their support needs as a cash payment. This is how families take control of a personal budget and receive the 'cash' to purchase the support their child needs. In social care it is illegal to be refused a direct payment unless there are specific issues which lead to concern on behalf of the local authority which mean that they are not able to offer direct payments in an individual case.

**Early Support** – an approach adopted in many children's services to the early identification of support needs and bringing all adults, both parents and professionals, together to set out how those support needs will be met.

**Education, Health and Care (EHC) Plan** – brings a child's education, health and social care needs into a single, legal document. The child/young person must have special educational needs to be eligible for a plan. All children and young people in receipt of a Statement of Special Educational Needs or a Learning Difficulty Assessment will be entitled to an EHC Plan up to the age of 25, as long as they stay within education (except university). The local authority should work closely with parent/carers and the child to make sure the plan takes full account of their views, wishes and feelings. Once an EHC plan has been finalised, the local authority has to ensure that the special educational support in section F of the plan is provided, and the health service has to ensure the health support in section G is provided. The local authority must review each child's EHC plan at

least every 12 months and must include working with parent/carers and the child/young person in a face to face meeting.

**Eligibility** – the assessment will collect information which will enable the service to establish which part of the children's service is best suited and funded to support the child. Eligibility is like a threshold, where a certain level of need means access to a certain team or support service.

**Individual Budget** – the total amount of funding allocated by state services which together add up to the support budget to meet a child and family's support needs.

**Individual Parental Supporters (IPS)** – are trained volunteers who can help and support families. An IPS is someone who is independent of decision-making professionals, and therefore has no conflict of interest that could influence the advice they give. Support from an IPS can include: assisting parents/carers in communicating with schools and other services involved with their child, supporting parents/carers at meetings or reviews, reading through and discussing written documents, for example, letters from the Local Authority, draft statements and advice, providing a 'listening ear' for parents.

**Independent Supporters** - will help to build resilience in families by offering a range of time-limited support such as liaison across different agencies and advice on personal budgets. The level and nature of that support will be tailored to the particular needs of individual families. They will be independent from the local authority and be recruited by the private, voluntary and community sectors. The Code of Practice includes Independent Supporters as part of the offer of advice and support that local authorities should make available.

**Lead Professional** – a role in most children's services which describes the professional, representative of a voluntary service or family representative, who takes responsibility for being the single point of contact for all those involved in supporting a child and their family.

**Local Offer** - provides information for children and young people and their parents/carers in a single place. Local authorities are required to consult with children/young people and their families to ensure they are providing the right information in an accessible format. The local offer must provide information on a number of things, including: special educational provision and other educational provision, health provision, social care provision, childcare provision, training provision, travel arrangements for children and young people to schools, colleges and early years education, and preparing for adulthood, including housing, employment and leisure opportunities, as well as what leisure opportunities are available.

**Key Worker** – similar to the role of the lead professional: the worker attached to an individual child and their family who acts as the single point of contact and support between services and the child and family. This role is often delivered by voluntary sector organisations.

**Keyworking** – aims to ensure the provision of holistic care and support to meet the individual needs of the child or young person and their family. It is defined by a set of functions and is based on person centred thinking and partnership approaches to working. Underpinned by an approach that enables open and supportive relationships, it is a way to facilitate the coordination of an integrated package of support for children, young people and families.

**Mainstream and/or Universal Services** – a term used to describe the services, activities and opportunities the majority of the population use and take for granted as part of everyday life, such as shops, leisure centres, buses, waste disposal, road maintenance, the built environment, public toilets, parks and recreation facilities.



**Outcomes** – what a plan or set of actions must deliver. For a family making a plan with a personal budget, the ‘outcomes’ will be what the plan must deliver. An example of an outcome is ‘to stay safe’. A good plan will show how the different ways a personal budget is being used will mean the child ‘stays safe’.

**Panel** – a term used in services to describe the meeting or group of key professionals who will make a decision about the support set out in the child’s care plan. The decision will either be ‘yes’ or ‘no’ and they may well ask for additional information before they can make a decision. Families are sometimes invited to attend. The term ‘panel’ is used a lot in services; it is part of the budget management and decision-making process.

**Person-Centred Planning / Approaches / Thinking** – an approach to planning which starts and centres on the individual and those closest to them. It values the individual and what they give to the world around them and it explores the individual aspirations, dreams and support needs and sets out action to support the individual in getting the life that suits them and those closest to them. This approach is most commonly used when supporting people with learning difficulties and is part of a good support plan. (See Support Plan.)

**Personal Budget (Social Care)** – the total amount of funding allocated by children’s social services to meet the support needs of the child. Families can choose to access this as a direct payment or to ask someone to manage it on their child’s behalf.

**Personal Health Budget** – is an amount of money to support the identified healthcare and wellbeing needs of an individual, which is planned and agreed between the individual, or their parent / carer, and the local clinical commissioning group (CCG). At the centre of a personal health budget is the care and support plan. This plan helps families to identify their health and wellbeing goals, together with their local NHS team, and set out how the budget will be spent to enable them to reach their goals and keep healthy and safe.

**Personal SEN Budget** – should provide a clear and transparent picture of the resources required to meet the educational outcomes for a child / young person with special educational needs. The EHC plan will clearly identify where services are being funded from and how the budget will be managed. Although funding via schools will be outlined in the EHC plan they will be managed via an organisational arrangement unless the school agrees to allow this funding to be managed via another method.

**Providers** – services offering support to children, young people and their families. Most often this term describes voluntary or private services but can also be used to describe a children’s in-house service.

**Resource Allocation System (RAS)** – a formal approach to making fair and equitable allocations of funding to the whole population of children eligible for support from a funding source.

**Review** – A meeting between key professionals, child and family to look at how support has been going, whether it is delivering the outcomes as set out in the support plan and whether any changes need to be made to improve the plan and support. Reviews can happen on different timescales, most often after three, six or 12 months.

**Self-Directed Support** – this term describes the way in which services will work, i.e. the steps from carrying out an assessment, to the child’s plan being agreed, to longer-term support and review.

**Services** – describing all the different organisations, people and statutory organisations



**Seven Steps** – an approach to self-directed support developed by In Control. This process explains the seven steps from needing help to having a review. (See: [www.in-control.org.uk/sevensteps](http://www.in-control.org.uk/sevensteps))

**Support Broker** – a role taken on by someone who will support the young person/family to plan and find the support they need and, if needed, help manage the plan in the longer term. Support brokers may be funded by the children's service or from a child/young person's personal budget.

**Support Planning** – a child-or family-centred approach of developing a support plan which makes good use of all the resources the family and child have and sets out how the personal budget will be used to make good use of these resources and get the support the child and family need. It will include information about how money will be managed and spent, who is responsible for delivering the plan and what happens if things are not working. The plan will also address any safeguarding concerns.

**Supported Allocation Questionnaire (SAQ) or Self-Assessment Questionnaire (SAQ)** – the name given to the questionnaire part of the resource allocation system; a set of questions which help allocate a fair share of funding to the child and family based on the support needs of the child. It is good practice for family members and professionals to work together in completing the questionnaire.

**Team Around the Child (TAC)** – an approach to supporting children with complex support requirements which focuses on the team of professionals involved working together to deliver child- and family-centred support.

**Voluntary Sector** – charities and other organisations outside of the public (state-funded) and private (for-profit) sectors.

# 9: Useful Resources

The following organisations and websites offer information and advice.

## Some useful websites for further information about Personalisation

- In Control - [www.in-control.org.uk](http://www.in-control.org.uk)
- OPM - [www.opm.co.uk](http://www.opm.co.uk)
- Disability Rights UK - [www.disabilityrightsuk.org](http://www.disabilityrightsuk.org)
- Think Local Act Personal - [www.thinklocalactpersonal.org.uk](http://www.thinklocalactpersonal.org.uk)
- Social Care Online - [www.scie-socialcareonline.org.uk](http://www.scie-socialcareonline.org.uk)
- National Children's Bureau - [www.ncb.org.uk](http://www.ncb.org.uk)
- SQW - [www.sqw.co.uk](http://www.sqw.co.uk)
- Paradigm UK - [www.paradigm-uk.org](http://www.paradigm-uk.org)
- Centre for Welfare Reform - [www.centreforwelfarereform.org.uk](http://www.centreforwelfarereform.org.uk)
- Skills for Care - [www.skillsforcare.org.uk](http://www.skillsforcare.org.uk)
- National Personalisation Network - [www.councilfordisabledchildren.org.uk/what-we-do/work-themes/social-care/personalisation](http://www.councilfordisabledchildren.org.uk/what-we-do/work-themes/social-care/personalisation)

## Organisations that support families with disabled children and young people

- KIDS - [www.kids.org.uk](http://www.kids.org.uk)
- Council for Disabled Children - [www.councilfordisabledchildren.org.uk](http://www.councilfordisabledchildren.org.uk)
- Every Disabled Child Matters Contact a Family - [www.edcm.org.uk](http://www.edcm.org.uk)
- Contact a Family - [www.cafamily.org.uk](http://www.cafamily.org.uk)
- Circles Network - [www.circlesnetwork.org.uk](http://www.circlesnetwork.org.uk)
- Family and Childcare Trust - [www.familyandchildcaretrust.org](http://www.familyandchildcaretrust.org)
- NAFIS - [www.familyandchildcaretrust.org/about-nafis](http://www.familyandchildcaretrust.org/about-nafis)
- Include Me TOO - [www.includemetoo.org.uk](http://www.includemetoo.org.uk)
- MacIntyre - Family Footings - [www.familyfootings.org](http://www.familyfootings.org)

## Useful government websites

- Department for Education - [www.gov.uk/government/organisations/department-for-education](http://www.gov.uk/government/organisations/department-for-education)
- Department of Health - [www.gov.uk/government/organisations/department-of-health](http://www.gov.uk/government/organisations/department-of-health)
- Office for Disability Issues - [www.gov.uk/government/organisations/office-for-disability-issues](http://www.gov.uk/government/organisations/office-for-disability-issues)
- Disclosure and Barring Service - [www.gov.uk/government/organisations/disclosure-and-barring-service](http://www.gov.uk/government/organisations/disclosure-and-barring-service)

# Appendices

For more information on the Code of Practice visit:

<https://www.gov.uk/government/publications/send-code-of-practice-0-to-25>

# Education, Health and Care (EHC) Plans: the assessment and planning process

## Introduction

This guide talks through the detailed process of assessment for and development of an Education, Health and Care plan. It will help you understand your role and what you can expect from your Local Authority. It makes reference to the Special Educational Needs and Disability Code of Practice: 0 to 25 years, 2014 to highlight the statutory timescales and detail specific responsibilities that the Local Authority and other agencies have, but the most important things to remember are the principles that underpin this new process:

## Principles underpinning the assessment and planning process

Your child must be at the heart of the process - you and your child must be consulted during the whole process of assessment and planning, involving your child as much as possible.

- Local authorities should enable you and your child to say what you think and take part in decision-making. For example, they could give time in meetings to hear what you and your child think
- Decisions must be well-informed; for example, by bringing relevant professionals together to talk about and agree what should happen
- Local authorities must take notice of what you and your child think, your aspirations, the outcomes you want to achieve and the support your child will need. They should make sure your child has an advocate, someone to speak for them, if they need one
- Language should be easy to understand, without professional jargon and in accessible formats.
- The local authority should keep you and your child up-to-date and informed, with one person responsible for this if possible
- Support must be tailored to the needs of your individual child
- Local authorities must minimise disruption for you; for example, by combining or co-ordinating multiple appointments, for example by arranging meetings at times that suit you and your family
- Plans must focus on outcomes and pull together the support that will be provided.

**So....this is about the young person and about you as a family and about getting the best possible plan in place to meet the outcomes they need.**

# The Assessment and Planning Process, Step by Step

## 1. Deciding whether to do an assessment

The first step your Local Authority has to take is to decide whether or not to carry out an Education Health and Care (EHC) assessment. They will make this decision by looking at:

- How well your child is getting on academically, what he or she has achieved and how long it takes him to learn. Your child is likely to have had significant support already, over and above what's usually provided in his school
- What the school has done already to meet your child's needs.
- Evidence from professionals about your child's educational, physical, emotional, social and health needs and what is already being done about them.
- If your child is a young person aged over 18, whether he needs more time in education, compared to pupils of the same age who don't have special educational needs, to learn and to get ready for adult life.

Local Authorities can write their own guidelines to help them decide, but they must be open to be flexible. They must not treat particular groups of children or certain types of need the same way. They must base their decisions on each individual child's requirements.

### The following people can request an EHC needs assessment:

- A parent
- A young person over 16 but under 25
- Someone acting on behalf of a school
- Anyone else who thinks a child has or may have special education needs, for example, foster carers, health and social care professionals and early years practitioners

A Local Authority has six weeks from the date they receive a request for an assessment to decide whether or not they should do one and tell you or your young person their decision.

The Local Authority must tell the following people that it is considering whether an EHC assessment is necessary and get information and advice from them:

- The parent or young person
- The health service
- Social care officers
- The school or other educational setting

They must also tell you that you have a right to be involved and submit evidence and they must consult you as soon as they can.

The Code of Practice says, 'Local Authorities should pay particular attention to the views, wishes and feelings of the child and his or her parent, or the young person. At an early stage, the Local Authority should establish how the child and his or her parent or the young person can best be kept informed and supported to participate as fully as possible in decision-making. The Local Authority must arrange for the child and his or her parent or the young person to be provided with advice and information relevant to the child or young person's special educational needs' (See Chapter 9, 9.21)

If the Local Authority decides not to proceed with an EHC needs assessment, they must tell you why and explain the right to appeal, where to get information, advice and support and about local mediation services. They must also tell the professional advisors that they are not going ahead and give you copies of the information and evidence the advisors provided.

## **2. The EHC needs assessment**

An EHC assessment is the process your Local Authority goes through to gather information to help them decide whether your child needs additional support, beyond what is provided in school, to meet his special educational needs. They will contact:

- You or your young person
- The health service
- Social care officers
- Your child's school or other educational setting
  - If your child is vision or hearing impaired, or both, a teacher qualified to teach pupils children with these impairments
  - An educational psychologist, who will normally be employed or commissioned by the Local Authority (she must consult any other psychologists involved with the child)
  - Anyone you or your child asks them to, if reasonable, such as a GP
  - If your child is in Year 9 or later, someone knowledgeable about the support available for preparing for adulthood and independent living

The Local Authority must share anything you contribute with the people they are contacting. These advisors can recommend outcomes for your child and strategies to achieve them and can comment on the amount of provision they think your child requires. They have six weeks to respond.

## **3. Deciding whether to issue an EHC plan**

Your Local Authority will consider all the information they've received about your child. They will also consider whether the special education needs support that your child requires can be provided from the resources normally available to mainstream schools. An assessment will not always lead to a plan because a school may be able to meet a child's needs without one.

If your Local Authority decides not to issue an EHC plan, they must tell you and explain your right to appeal within 16 weeks from the date of the request for an assessment. They must make sure that you know what's available to meet your child's special educational needs in mainstream school as well as any other support available locally. The Local Authority should also give you copies of the information and evidence they've collected during the assessment process.

If, however, your child is not progressing, or not progressing fast enough, despite existing additional support in school, your Local Authority has to consider what further provision your child requires. If they decide that he needs special educational provision, they must write a plan.

#### **4. Writing an EHC plan**

EHC plans must say how education, health and social care services will work together to achieve outcomes for your child, including preparation for adulthood.

##### **What is an outcome?**

An outcome is the difference made to a child as a result of an intervention. It should be personal and not expressed from a service perspective. It is not a description of the service being provided (see the full Making it Personal: a family guide to Personalisation, personal budgets and Education, Health and Care plans for more detailed information about outcomes).

When agreeing outcomes, it is important to consider both what is important to the child – what they themselves want to achieve – and what is important for them as judged by others who have their best interests at heart.

EHC plans are produced in two stages, in draft and as the final version.

Your Local Authority will start by writing a draft plan and sharing it with you and other people who need be involved. You have the right to request a personal budget and your Local Authority must tell you where to find advice and information and about organisations that can help you with this.

Good practice in planning will mean setting out to develop a plan with the young person and their family that will be agreed by all parties. As a family, you should have clear upfront information about the provision and funding available so that time can be spent thinking through how best to get the support needed by your child.

If you request a particular school, your Local Authority must comply, unless:

- The school would be unsuitable for your child's age, ability, aptitude or special educational needs
- Your child's attendance at the school would be incompatible with the efficient education of others or the efficient use of resources

Your Local Authority can't decide that mainstream education is not suitable for your child unless it can show that there is nothing it can reasonably do to deal with any incompatibility. The Code of Practice gives lots of examples of reasonable steps that could enable a child to attend mainstream school.

Your Local Authority must consult your preferred school before naming it in the EHC plan. Also, if you want to use direct payments for support that will be delivered in school, they have to tell the school about it, including how much it will cost and when they will make the direct payments to you. The school has to agree to that support being delivered in school, or it can't happen. They have 15 days to respond.

Your Local Authority also has to get agreement from your local Clinical Commissioning Group (CCG) to any health provision in the plan.

Your child's EHC plan must:

- Say what you and your child think, her interests and aspirations
- Describe your child's SEN and any health and social care needs
- State the agreed outcomes across education, health and social care, based on your child's requirements and aspirations
- Detail the support required and how all three services will work together

## The format of EHC plans

### The principles of EHC planning

- Decisions should be made openly and collaboratively with parent and child
- Plans should describe positively what the child can do
- Plans should be clear, understandable and accessible for everyone
- Plans must consider how best to achieve the agreed outcomes
- Plans must specify SMART outcomes (Specific, Measureable, Achievable, Realistic, Timebound)
- If a parent or child wants to use an innovative or alternative way to receive their support, particularly through a personal budget, the planning process should look at this and identify support and advice to help the family
- Plans should show how education, health and social care provision will be co-ordinated wherever possible and how different types of provision contribute to specific outcomes
- Plans should describe how informal (family and community) support as well as formal support from statutory agencies will help achieve the agreed outcomes
- Plans should have a review date

**The format will be agreed locally but the Code of Practice sets out the minimum contents, below.**

See Code of Practice, Chapter 9, para 9.69 for full details.

- A** The views, interests and aspirations of the child and parent
- B** The child's SEN
- C** The child's health needs which are related to their SEN
- D** The child or young person's social care needs which are related to their SEN or to a disability
- E** The agreed outcomes, including outcomes for adult life and arrangements for shorter term targets or milestones
- F** The SEN provision required by the child
- G** Any health provision reasonably required by the learning difficulties or disabilities that result in the child having SEN. Where there is an Individual Health Care Plan, this should be included
- H1** Any social care which must be made for a child under Section 2 of the Chronically Sick and Disabled Persons Act 1970



- H2** Any other social care provision reasonably required by the learning difficulties or disabilities which result in the child or young person having SEN, including any adult social care provision being provided to meet a young person's eligible needs through a statutory care and support plan under the Care Act 2014
- I** The name and type of school to be attended
- J** Where there is a personal budget, details of how the personal budget will support particular outcomes, what it will be used for, including any flexibility in how it's used and arrangements for any direct payments for education health and social care. The SEN needs and outcomes that are to be met by any direct payment must be specified.
- K** The advice and information gathered during the assessment must be attached as appendices.

### Notes:

If your child is in or beyond Year 9, the plan must include the support required to prepare him for adulthood and independent living; this means support with finding employment, housing or for participation in society (sections F, G, H1, H2).

Health or social care provision that educates a child must be treated as special educational provision and included in section F of the EHC plan. Speech and language therapy and other therapy provision can be treated as either education or health care provision, or both. However, because communication is so fundamental in education, speech and language therapy should normally be regarded as special education provision.

When health or social care provision is treated as special education provision, the Local Authority is ultimately responsible for making sure it is delivered.

Children with EHC plans can go to more than one school. For example, a child could spend three days in a special school and two days in a mainstream school to help him prepare for fulltime mainstream education. This sort of arrangement can also help special and mainstream schools to share their expertise in teaching and supporting individual children with special educational needs.

## Agreeing the final EHC plan

Remember, good practice in planning will mean setting out to develop a plan that will be agreed by all parties, but given this, your Local Authority must send you the draft plan and give you 15 days to respond. You can comment on it, say which school you prefer, and confirm that you want a personal budget. During this time, your Local Authority must be available to meet with you to talk about anything in the draft plan.

If you suggest any changes to the draft plan, your Local Authority should agree the changes and then issue the finalised plan as quickly as possible. The only other change a Local Authority can make is to alter the name of the school. If your Local Authority doesn't agree with your suggested changes, they can still issue the final EHC plan. Whatever happens, the Local Authority has to tell you about your right to appeal and the time limit for doing this. They should also tell you how to appeal against the health and social care provision in the plan and about the local information, advice and mediation services.

## Reviews

EHC plans have to be reviewed at least once a year and must focus on your child's progress towards achieving the outcomes specified in the EHC plan. Reviews should also:

- Be combined with social care plan reviews
- Gather information that will support your child's learning and progress
- Review any interim targets set by the school
- Make sure that the support being provided is effective across all services
- Look at whether any changes are needed to the outcomes or the support being provided
- Agree new outcomes for the coming year

It will usually be the school that arranges the annual review. They have to gather advice and information beforehand from everyone who will be invited to the review. The following people must be invited, with at least two weeks' notice: you and your child, a representative from the school, a Local Authority special educational needs officer, and representatives from both the health service and social care. Other relevant people should also be invited, depending on your circumstances. The advice and information that's been gathered before the review must be circulated to everyone at least two weeks before the meeting.

A report of the review must be issued within two weeks, setting out any proposed changes to the EHC plan and pointing out any areas of disagreement.

Your Local Authority must decide within four weeks whether to keep the EHC plan as it is, amend it or say it's no longer needed. If they decide to amend the plan, they must send you a copy of the existing plan, with a notice of the proposed changes and any supporting evidence. You have 15 days to respond and can request a meeting with the Local Authority if you want. If your Local Authority decides to amend the plan, they have eight weeks from the original amendment notice to issue the amended plan. If they decide not to make any changes, they must tell you, with their reasons, also within eight weeks.

If your child is under five, your Local Authority should consider reviewing his EHC plan every three to six months to make sure that the support he is getting continues to be right for him.

There is no right for a young person with an EHC plan to stay in education or training once she is 19. However, a Local Authority should maintain an EHC plan if:

- The learning outcomes in the plan have not yet been achieved, and;
- The young person wants to continue in education or training, including provision to help them prepare for adulthood, and;
- The young person still needs special educational provision, and;
- Continuing in education or training will enable the young person to progress and achieve those outcomes

# Resolving disagreements

## Principles for resolving disagreements

- Decisions about provision should be made jointly with the views of parents, children and young people, taken into account
- The relationship between all services and families, children and young people should be open so that everyone knows what's happening and why, and family knowledge and experience can be used to support good decision-making
- Parents and young people should be given information and support to be part of the decision-making. Support can come from statutory or voluntary organisations
- Local Authorities must tell parents and young people about their disagreement resolution and mediation procedures as well as information about appealing to the Special Educational Needs and Disability (SEND) Tribunal

Your Local Authority will have two distinct services, which must be independent: a disagreement resolution service and a mediation service. The mediation service is specifically for parents or young people who are considering an appeal to the SEND Tribunal or who want mediation on the health and social care elements of their EHC plan.

The disagreement resolution service can be used earlier on. You can choose to use it but don't have to. However, if you do choose to use it, all the parties involved have to agree. If you choose not to use this service, it doesn't affect your right to appeal to the SEND Tribunal. The Tribunal will not make any assumptions about your choice and, if your disagreement goes to Tribunal, they will disregard any comments or offers made in disagreement resolution meetings.

## The disagreement resolution service can help resolve four types of disagreement:

- Between parents or young people and Local Authorities or schools about how they are carrying out their education, health and care duties for children with special educational needs, whether they have an EHC plan or not.
- Between parents or young people and schools about the special educational provision for their child, whether he has an EHC plan or not.
- Between parents or young people and Clinical Commissioning Groups or Local Authorities about education, health or social care provision during an EHC assessment, while an EHC plan is being drafted or reviewed or when a child's needs are being reassessed. For education provision, the service can also be used while waiting for a Tribunal appeal hearing or after a hearing.
- Between Local Authorities and health services during the EHC assessment, the drafting of the EHC plan or reviews. These disagreements don't involve the parent or young person.

If you are thinking about appealing to the SEND Tribunal about your child's assessment or the educational element of his EHC plan you must contact a mediation advisor before registering your appeal. You can also go to the mediation service about the social care or health elements of your child or young person's EHC plan, and your Local Authority or Clinical Commissioning Group must attend, but you can't appeal to the SEND Tribunal about them.

The mediation advisor will tell you about their service and answer any questions you have. Whether or not you decide to use the mediation service to try to resolve your disagreement, they

must give you a certificate that will enable you to register an appeal with the SEND Tribunal. You must do this within two months of the original decision being sent to you by your Local Authority.

If you want to use mediation, the first session must take place within 30 days of the mediation advisor telling your Local Authority that you want to do so. Your Local Authority and/or Clinical Commissioning Group must take part. Mediation won't always result in complete agreement between all the parties and you may still decide to appeal to the SEND Tribunal. The Tribunal will disregard any comments or offers made during mediation sessions and reach its own, independent conclusion, based on the facts presented to it.

**If your child is in one of the following groups, we suggest you look at the Code of Practice for information specific to them:**

- Looked after children
- Care leavers
- Children educated out of area
- Children educated at home
- Children in hospital
- Children in youth custody
- Children of service personnel

## **Appealing to the SEND Tribunal**

### **You can appeal about:**

- A decision by your Local Authority not to carry out an EHC assessment or reassessment
- A decision by your Local Authority that, having made an assessment, they won't issue an EHC plan
- The description of your child's special educational needs in the EHC plan or an amendment to the description
- The educational provision specified, or the school that's been named, or that no school has been named
- A decision by your Local Authority not to amend your child's EHC plan following a review or reassessment
- A decision by your Local Authority to cease your child's EHC plan

The Tribunal does not hear appeals about personal budgets, but will hear appeals about the educational provision to which a personal budget may apply.

The Tribunal can decide to dismiss your appeal, order your Local Authority to carry out an assessment, to write and implement an EHC plan, or to make amendments.

### **A note about timescales**

The timescales set out in the Code of Practice are the maximum time allowed. Local Authorities must complete each step in the process as soon as practicable. They should also plan the process so that there is time to deal with any issues and resolve any disagreements while staying within the time limits.

The time for the whole process, from the request for an assessment to the issue of the final EHC plan is 20 weeks. A delay in one part of the process does not affect the timescales for the other parts of the process.

Local authorities have six weeks to respond to a request for an EHC needs assessment.

When local authorities request information or advice as part of the assessment process, those supplying it must respond within six weeks.

If a Local Authority decides not to issue an EHC plan, they have to inform the parent or young person within 16 weeks from the request for an assessment.

A parent or young person has 15 calendar days to consider and provide views on a draft EHC plan, to ask for a particular school, and/or to request a personal budget.

### **Exceptions to the timescales:**

- School is on holiday for four weeks or more (may delay the submission of information from the school, but not from other partners)
- The child or parent misses appointments with people from whom the Local Authority has requested information – only relates to the duty on partners to comply with a request within six weeks
- The child or young person is away from the area for at least four weeks
- There are exceptional circumstances affecting the child or parent

The graphic below shows a summary of the statutory timescales for the EHC assessment and planning process.

### Statutory timescales for EHC needs assessment and EHC plan development

