DRAFT 5 This draft is intended to stimulate discussion and debate - it is not a final version and is not in operation – the figures quoted are examples only.

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Special Educational Needs and Disability Support through a Personal Budget



Information for Parents and Carers of Children with Special Needs and Disabilities in Middlesbrough and Redcar and Cleveland April 2014









Welcome

Being a parent/carer is the most rewarding experience but it can also be tough, especially if your child has a special educational need or disability.

Sometimes families need to access additional support for their child - this extra support might include:

- Additional support from education to ensure that a child's learning needs are met
- Additional support from Health where a child has a complex, long-term and/or life limiting condition
- Additional support from social care where a child needs additional and individual support at home, or where the family need a short break from caring, or where support is needed so that the child and the family can have the same experiences as other families.

Personal budgets change the way services work with families.

Instead of a family being provided with a service, a budget is identified and work takes place to plan how this can best be used to meet the child or family's needs.

This can be by purchasing existing services or by developing new and imaginative ways of using the money. The money might be held by the Council or Health and used in agreement with the family, held by a third party, or paid directly into a bank account set up by the family for this purpose.

This booklet has been put together to explain what a Personal Budget is and what you need to think about if you would like some of the support provided to your child and family to be delivered in this way. We hope you find it useful and that it answers some of your questions.

Other information that you might find helpful is available at (website address)

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1. What is an Education Health and Care Plan (EHC)

The government has changed the way in which support is to be provided where a child has a special educational need. The intention is to focus more on support and people working together, to allow children, young people and their families to be more involved in the support and services which are provided to their family.



These changes are included in the new Children and Families Bill and implementation needs to start by September 2014.

There are many children and young people who have a special need or a disability but who do not need additional support as their needs are met by existing services.

However there are some children and young people who do need additional support. Some of those children and young people have had in the past, or may have now, a Statement of Educational Need. This will now be replaced by an Education, Health and Care Plan (EHCP) and the main difference will be that this will include information about health and social care support.

The plans should be agreed by families and all those who work with the child. This should mean that in the future instead of a child having separate plans from all the different services involved there will be one plan.

Services and families have been working together to find a way to make this work. In some areas of the country Local Authorities have been given extra money over the last two years to try to find a way to do this. These Local Authorities are referred to as "Path Finders". If you would like more information about them, and about the work that they have done, this can be accessed through the website www.sendpathfinder.co.uk

Middlesbrough and Redcar and Cleveland are not Path Finders, they have to now work out how to put this in place. They can learn from the Path Finders, and are also consulting with children and their families. This may mean that staff might not be able to answer all questions immediately because we are still working this out together and need to be patient with each other.

The intention is to improve services and the EHC Plan will still be a legal document which everyone will have to follow,

If a child or young person is under compulsory school leaving age parents or guardians have the final decision about the EHC plan. Once a young person is over compulsory school leaving age the final decision is theirs. Families still need to be involved in discussion but only if the young person agrees to this. For those young people who are not able to do this, parents, next of kin or guardians will be the ones to make the final decision.



2. What is a Personal Budget?

The new legislation about EHC Plans says that the EHC Plan should be clear about the amount of money to be spent, and the family should be able to see how much everything costs. This is called a costed plan.

Children's services will, as part of setting out what support and provision may be available for a child or young person, make it clear what funding may be available as a personal budget. A family can then decide whether to ask for the personal budget, which means they can have more control over how it is used to support their son or daughter. If a Personal Budget is agreed for parts of the plan then these can be put together into one budget, so if a budget is not agreed from Health, but is agreed from education and social care, these amounts can be put together into one Personal Budget.

Usually the family will discuss this with the person helping them with their EHC plan while it is being written. That person will be able to tell them roughly how much money would be involved, for example:

- A family can chose to use some of their money to pay for a personal
 assistant. If a family decide to employ a personal assistant to provide their
 social care support they will usually receive in the region of £10 per hour to
 do this (this does not mean they will be able to pay their worker £10 per
 hour as some of the money needs to be used to pay tax etc).
- If a family decide to have a Personal Budget for transport, rather than use the Education transport service then usually they will receive 40p per mile.

A family can decide to only use a small amount of the funding available as a personal budget, they can, in discussion with the person helping them decide to maintain many of the services which are currently working well for their child and only use a small amount of funding as a direct payment. (See later in this booklet for an example of this).

The family might discuss a Personal Budget at any time, but there will need to be an agreement about when this can be arranged. This would usually be when the EHC Plan is being drawn up, or at the review.

There are three ways in which a Personal Budget can be provided to a family:

- A Direct Payment the family are given the money directly and use the money to purchase the support that is agreed in the plan (see section 6 "How will a Direct Payment Work?")
- A Third Party Managed arrangement sometimes called a TPSA which means third party serviced account. A charity or other organisation is given the money and helps the family spend it. The third party organisation takes responsibility for all financial arrangements.
- An organisational arrangement this means that the money remains with Health or with the Council, but the family are told how much money is available and identify how the money is to be spent.



3. Personal Budgets and Social Care

Most children with a special need do not receive support from social care, either because they do not meet the criteria for this support, or because they choose not to use it.

Some children with special needs or a disability do access support from social care. This might be for:

- Support in the home this may be additional help with bathing or personal care
- Support to access social or family activities help to do the things that other children their age can do and to take part in activities other families can access
- Short break support help so that parent/carers can have a break



Many families in Middlesbrough who have this type of support in place now have this provided through a Personal Budget or a Direct Payment. Redcar are also delivering support through Direct Payments and exploring how Personal Budgets can be used.

For example, a family who have an assessed need for four hours of support each week to support a young person to access social activities might have this provided by the Council, or might be given the money to provide this for themselves. Some families who do this employ a worker directly or some families employ an agency (this must be an agency approved by the Council).

When families who have this support in place have an EHC Plan then the support provided will be included in the plan, and the budget agreed will also be included.

If you have support from social care in place make sure that the person helping you organise your EHC plan is aware of this.

If you do not receive one of the new EHC Plans your support from social care will not be affected and will continue.



If you feel that you may be entitled to support from social care, and this is not currently in place this will be discussed with you when your EHC Plan is completed, or you can contact Middlesbrough Council or Redcar and Cleveland Council and ask for an assessment in connection with support for a child who has a disability.

If you are not sure and just want to talk to someone about this, contact the Middlesbrough Children with Disabilities Team on 01642 579176 or the Redcar and Cleveland Children with Disabilities Team on 01642 304500.



4. Personal Budgets and Health

Most children with special needs or a disability do not require any more support from Health than any other child. They access health and dental care as and when needed, and they receive support in emergencies.

However there are a small number of children and young people who do need additional support from Health because they have a complex, long-term and/or life limiting condition. This might include children who can not breathe without support or who have severe epilepsy which is not controlled by medication, or who have a significant health need which means that someone has to be with them all the time to keep them as healthy as they can be.

Children in this situation are referred to as having "continuing care needs" and may have had a "continuing care assessment". This assessment helps decide which additional services they need. Where such services and additional needs are in place these should be included in the EHC Plan and the family should know how much money is available from Health to meet the needs identified.

Children who have a service provided because they have a continuing care need have the right to have this provided as a Personal Budget from October 2014.

Some families might prefer to allow the service to be provided to their child, but some might prefer to manage the money themselves and take responsibility for the provision of support.

For example, a family who have an assessed need for ten hours of support each day to help with meeting health care needs might have this provided by Health or might be given the money to provide this for themselves. Some families who do this employ a worker directly (this must be a worker approved by Health as being competent to undertake the required tasks) or some families employ an agency (this must be an agency approved by Health).

When families like this have an EHC Plan then the support provided will be included in the plan, and the budget agreed will also be included. Remember this is not about services, which are available to all families, such as access to a doctor, to a hospital or to emergency services such as out of hours support.

5. Personal Budgets and Education

Many children with special educational needs or a disability attend school or college and are supported by the resources available there and do not need any additional support. The school or college make it clear what additional support they provide. This information is also available in the "Local Offer" a statement which makes it clear which support and services are provided by your local authority.

However there are some children who do need additional support. Where this has previously been agreed in their Educational Statement, and where it is now part of an EHC Plan, then this support is usually paid for be the Local Authority.

The money used to pay for this is referred to as "High Needs Block" funding and is usually paid by the Council to the school or college.

This additional funding might be used instead to provide a budget to a family so that the family might organise this support themselves.

For example, where an EHC Plan includes transport to and from school, then the family may decide not to have this service provided by the Local Authority Transport Service but may decide to have a small budget and organise the transport themselves.

It is also possible for the school or college to agree to release some funding to contribute towards the family having a budget where it is clear that this will help to meet the needs of the child and achieve the desired outcomes.

For example, where part of the plan for the young person is that they will access work experience, the school could agree to release some of the funding into the budget, so that the family could employ a direct payment worker to support this.

Families need to remember that they will not be able to access a budget to pay for something the school or college already provides. This may mean that the support available through a Personal Budget will change if their child moves

from a mainstream school to a special school as the special school will be providing a higher level of support.

Where the support or service is to be used in a school the Headtacher of the school must agree. If they do not the Local Authority cannot make the payment.



6. How will a Direct Payment Work?

You may choose to have responsibility for the financial management of the budget by receiving a 'Direct Payment' to buy all or some of the services outlined in your child's plan. This means that the money will be given to you. Usually you will receive a monthly payment, but occasionally additional sums may be given to you for any extra amounts that are agreed.

You will have to open a separate bank account to do this, and you will have to keep all the receipts. The account will be audited periodically by the Local Authority, and any unspent money has to be returned to the Council.

Receiving a Direct Payment can mean more flexibility around how services are provided. However, it also entails more responsibility. There is support in place to help with this. Middlesbrough and Redcar and Cleveland both pay an independent support agency to help families with a Direct Payment. At the moment this is Penderels in Middlesbrough and in Redcar and Cleveland it is A4E. These organisations can help manage the money, provide advice and support with paying staff and also help with the recruitment of a personal assistant.

If you choose to receive a Direct Payment to buy some of the items or services identified in the plan yourself the Council will ask you to sign a written agreement. The purpose of the agreement is to confirm that you understand how the Direct Payment is to be spent. It will explain what your responsibilities are as the person receiving the money and what responsibilities the Council holds in providing the Direct Payment to you.

You must make sure that you have read and understood the agreement before you sign it. You will need to understand that if you spend the money on anything which has not been agreed then you can be asked to pay it back.

You also need to understand that any money not spent must be returned at the end of the financial year. You should take time to read the agreement carefully.

7. Examples

Example 1. Ann

Ann is fifteen years old and she has a learning and physical disability. She attends a special school.

Ann has an EHC Plan. The plan does not include any additional support from Health as Ann is fit and well. The plan does not include any additional support in school as the special school meets all her needs. The plan does include transport from home. The plan also includes support from social care so that Ann can go out and have a good time like other young people of her age, and so that her family can have a break. The family and Ann decide that they would rather have a budget for the transport and the social care so that they can arrange this themselves.

Their house is five miles from the school, so they receive a budget to cover the 100 miles during term time (4 journeys each day). At 40p per mile this is £40 per week for 39 weeks of the school year. The total is £1560.

Their social worker completes a resource allocation tool with the family and agree a budget of £4,885.44 per year to meet her social needs.

Their total budget is £6,445.44 per year. They set up a bank account and every four weeks £495.80 is paid into it. They plan as follows:

- They take Ann to school, themselves. They do not take anything from the budget for this, deciding to use the money in other ways
- They employ Ann's cousin who is nineteen for 9 hours per week during term time. She picks up Ann every day from school and three days per week she takes her home. Two days per week she takes her out for something to eat or swimming/shopping etc. Ann's parents cover any costs and Ann gets home at about 7pm.
- They employ Ann's cousin for 12 hours per week during school holidays.
 Ann and her cousin use this time flexibly to go out about and attend activities and events. The family cover any additional costs.

- Twice a year Ann and her cousin go on a coach holiday. The payment for this comes from the budget and this year they are going to Cadbury's World and to Blackpool.
- They retain a "contingency fund" some additional funding which can be
 used if they need extra support because there is a family emergency or
 because Ann is unwell and to cover additional hours used during the coach
 trip.

Ann is happy because she did not like the school bus and is enjoying many different activities.

The budget works as follows:

Direct Payment of 9 hours per week during term time = £3510

Direct Payment of 12 hours per week during school holidays =£1560

2 coach trips for two people = £800

Contingency fund £575.44

Total is £6,445.44

Example 2. John

John is eight years old and has a learning disability and autism. He attends his local primary school.

John has an EHC Plan. The plan does not include any additional support from Health as John is fit and well. The plan does include 20 hours additional support in school as his primary school cannot meet all his needs. The plan includes transport from home. The plan also includes 10 hours support from social care as his mother is a single carer and has three other children. His mother decides that she would like to keep the transport in place and does not want the responsibility of having a Direct Payment.

She asks for the money from the support provided into school and from social care to be "pooled" and for one agency to be asked to provide both so that there is consistency for John. This also means that if John is unwell and cannot attend school the support worker can be with him at home.

Example 3. David

David is a 10 years old and affected by complex epilepsy and global developmental delay - he attends a local special school

David has an EHC Plan. He lives at home with both his parents and 3 younger brothers and sisters. His father works full time and his mother stays at home to care for David and the younger children. The plan includes additional support paid for by both social care and health. The plan includes 38 hours additional support at home including some overnight provision to enable David to get ready for school and access social activities whilst his health and care needs are also met.

The family chose to take a personal budget and they ask for the money to be paid as a direct payment into a Bank account, which they set up for this. They employ a team of 2 personal assistants. David and the family are able to take control of the people coming to their home and build strong trusting relationships with the personal assistants they have employed.

8. Frequently Asked Questions?

Q1: I have decided that I want to request a Personal Budget and a Direct Payment. Must the local authority agree to this?

A: No, the Local Authority can only agree to this if they are sure that:

- You plan to use the Direct Payment in an appropriate way
- You will act in the best interests of the child
- Making the Direct Payment will not adversely impact upon other services provided to other children who an EHC Plan
- It is an efficient use of the Local Authorities resources.

Where the support or service is to be used in a school the Head Teacher of the school must agree. If they do not the Local Authority cannot make the payment.

If the Local Authority refuses a Direct Payment they must explain their decision in writing and also explain to you how you can challenge this decision.

If the refusal concerns the personal health part of the plan, then the explanation concerning the refusal must be sent out be the Clinical Commissioning Group who are the health organisation responsible for the decision.

Q2: I have decided that I want to request a Personal Budget and a Direct Payment - but my Child's Statement was completed recently and may not be updated to an Education Health and Care Plan for two years. Must the local authority agree to my request now?

A: No - your request will usually be considered when your child receives an Education Health and Care Plan. However, it may be possible to consider some parts of your request, or to bring forward the date for the Education Health and Care Plan. Talk to the professionals working with you and they will try to help find to find a way forward.

Q3: How much money will I get?

A: This will depend on the plan, and will vary from child to child. The Local Authority must make sure that the amount they pay you is enough to meet the need identified and to purchase the support and services agreed in the plan.

The budget is "personal" to the child and based on an assessment of their needs, so each child will have different plan and a different budget. However, if a Personal Budget is used instead of transport the amount will usually be around 40p per mile. If a Personal Assistant(PA) is employed the family will usually receive around £10 per hour to do this. This amount must cover the payment to the PA and also tax etc. If a worker with health/nursing skills is required the amount may be higher.

Q4: We both work - does this mean we will not be able to have a Personal Budget?

A: No. Personal Budgets are not means tested. However if your child/young person is over 18, and part of the budget comes from Social Care then the family may have to make a financial contribution - you should talk to your social worker about this.

Q5: I do not really want a social worker to be involved - I feel uncomfortable about my family being discussed with a social worker. My child has an Education Statement now - why do I have to have social service involved to get an EHC Plan?

A: When the Education Statement was written Social Services would have been informed and asked to provide any relevant information they had - you would have been asked to consent to this when you agreed to an assessment taking place. This always happens and is not something to worry about - consulting with other services helps to ensure that the best service is provided for your child. If you are worried about this talk to the person who is working with you on your plan.

Q6: I do not really understand the difference between a Personal Budget and a Direct Payment. Can you explain?

A: A Personal Budget is the agreed amount you can use to meet the needs of your child. The budget can be used to purchase a range of services including council services. You do not have to handle the money, the budget can be held for you and you can control how it is spent.

Some families do not want to manage the money themselves and are happy for the budget to be held for them.

However some families do want all or some of the money to be given to them so they can purchase services themselves. This is a Direct Payment. The money is paid to you and you open a separate bank account for it to be paid into. Any money not used is returned to the Council.

Q7: If I choose to include a one-off item such as annual membership of a gym or a piece of equipment in the plan how will this be paid for?

A: If you choose to buy a 'one off item' as part of the plan then this can be purchased directly by the Council on your behalf or you can choose to receive a Direct Payment to buy this yourself. The money would be available soon after the plan was agreed.

Q8: Once the budget plan is written can it be changed during the year?

A: Yes, as long as there is money left in the budget to make the changes and the changes meet the needs of your child and the outcomes identified in the assessment. Any small changes will be looked at by the worker who completed the plan with you to make sure that the change is in the best interests of your child.

Q9: My child has a statement of Educational Need, does this mean I will have a EHC Plan and a Personal Budget by September 2014?

A: Implementation of the new guidance starts in September 2014, however it is not possible for all children to have a new EHC plan by that date. EHC Plans need to meet the individual needs of the child and take time to put in place. They will be introduced from September 2014 but it may be up to three years before everyone has one in place.

Q10: My child does not have a Statement of Educational Need and is unlikely to have an EHC Plan. Does this mean that I cannot have a Personal Budget?

A: No, you might still be entitled to a budget from social care or from Health.

Q11: My child is on "School Action Plus" does this mean I cannot have a Personal Budget?

A: "School Action" and "School Action Plus" are being replaced by "SEN Support" so your child may not have one of the new EHC plans and may not have a Personal Budget provided through this. However if your child has social care needs you still might be able to access a Personal Budget to meet those needs. If you live in Middlesbrough contact the Children with Disabilities Team on 01642 579176. If you live in Redcar and Cleveland the contact number is 01642 304500.

If you are receiving support because your child has a complex health need or a life limiting condition then you should talk to the health professional who organises your support and ask them about a health budget.

Q12: My child is to have one of the new EHC Plans but I do not want the stress of a Personal Budget, do I have to have one?

A: No, you can continue to have support and services provided in the same way as previously, however if you ever want to think about this again remember that there is a lot of support available, and it is not as difficult as it might first seem.

Q13: Is a Personal Budget just a way of the Council getting out of providing services and making a parent sort it out for themselves?

A: No, it is put in place so that families who want to organise their own support can do so. Many families have a Personal Budget or a Direct Payment already in place for the support they receive from social care and they find this very useful, but it is optional. You can continue to use traditional support if this is what you want.

Q14: When can I request a Personal Budget?

A: You can talk to those working with you about this at any time, but usually a budget is put in place when the EHC Plan is being drawn up or at the review.

Q14: My child has a Personal Budget from social care and I think may get a Personal Budget from Health and Education, do I need three separate bank accounts?

A: No, just one! The money will be put together into one budget and paid to you by the Local Authority who will also audit the account. Health will give their share of the money to the Local Authority.

Q15: My child needs speech and language therapy and physiotherapy. He also has support from Mental Health Services. I have never been

happy with the service provided; can I have a budget and employ my own support?

A: Nothing is impossible and you should talk to the people helping you with your EHC plan. However currently these services are provided through a contract which is in place and it may not be possible to provide these through a budget at this time. This might be something which we have to work on in the future.