



think local
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National Voices

People shaping health and social care

MY LIFE,

MY SUPPORT,

MY CHOICE.

A Narrative for person centred coordinated care and support for children and young people with complex lives.



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FOREWORD

‘Person centred, coordinated care’ is the gold standard which we are all working to achieve. But there are still too many children, young people and their families and carers who have to navigate fragmented systems; repeat the same conversations with multiple people and coordinate the services provided by different professionals and organisations.

Our ambitions go beyond the aim of designing more joined up services – support should be shaped around the needs, aspirations and preferences of children, young people and those around them. In the words of one young person who contributed to this work:

“We want services to realise we are a person who has needs, hopes and dreams. Services cannot be one size fit all, we are all different and we should be treated as an individual”.

We do not need to re-hash the argument that more coordinated health and care systems can deliver better outcomes and make better use of resources. But we do need to take a step back and think about what coordinated care should look like and how it could be structured to produce the best outcomes for people who use services. To our minds, the most logical place to start is to understand what people want from their care and support, and how they think organisations need to act to facilitate this.

This narrative is a tool to build that understanding. It is a series of statements which express what children and young people with complex lives think coordinated care should look like: what the key outcomes should be; and how these could be achieved. The central theme – the ultimate outcome from coordinated care – is that every child and young person with complex needs should be able to say:

“I am respected and listened to; I have choice and control; and at every stage I am supported to live a full independent life”.

What is particularly powerful about these statements is that they specify what children and young people want from their lives; not just what they want from the immediate function of the services they receive or how they want to receive them. It is a strong reminder that children and young people engaging with health and social services are much more than their disease, condition or other need. They want services to see and respect the wider picture of their individual strengths and preferences, relationships, responsibilities, goals and dreams; as well as those of the people close to them.

This narrative complements the work which has been done to develop a generic [Narrative for Person Centred Coordinated Care](#), which was – like this narrative – developed with people who use services and carers, and places the individual at the centre, around whom services are coordinated:

“I can plan my care with people who work together to understand me and my carer(s), allow me control, and bring together services to achieve the outcomes important to me.”

This work also supports the document Integrated Care and Support: Our Shared Commitment. The definition and the plans set out in the Shared Commitment are relevant for the care and support of children and young people, particularly those with complex lives and needs. However, in publishing this additional document we seek to capture and build understanding of the specific desires and needs of children and young people. Services designed for adults cannot simply be transposed onto those used by children and young people. Children and young people have different clinical, developmental and social requirements and services must operate within different legal, regulatory and policy frameworks. We therefore have a clear opportunity to firmly extend the coordinated care agenda to include children and young people's services.

The narrative is not a new requirement or prescribed way of engaging or delivering integrated care, rather it is a tool to help you understand what children and young people with complex lives want from their care and support and offer ideas for how this could be delivered. We urge you to think imaginatively and collaboratively about how you could use the narrative in policy making, commissioning and day to day professional practice. It is a platform to engage children, young people and those close to them in the design and measurement of coordinated care: a prompt to ask what they want from their care and support. This could be done at population level to consult on commissioning arrangements or service structures, and on an individual level to plan and monitor an individual's care. Similarly, the narrative could form part of the evaluation of children and young people's experiences, in particular the extent to which support has been coordinated around their needs and wants.

As co-chairs of the Children's Health and Wellbeing Partnership – a space where leaders within the health and social care system collaborate to improve the health outcomes of children and young people – we are very proud of the Pledge the Partnership has made to improve health outcomes by working towards shared goals including putting children, young people and their families at the heart of decision making and coordinating care and services around the needs of the individual. The Partnership has taken a particular interest in coordination this year, including hosting a workshop for system leaders to discuss the barriers to coordination and the important role of financial incentives, and hearing about a young person's perspective on coordinated care at our Children's Commissioner's Takeover Day event. This narrative brings a much needed common language and definition to focus these efforts. We are already starting to use the narrative, for example, by using it to inform the development of an indicator of integration for children and young people, and are excited about exploring other uses and hearing about how others are using it.



Jon Rouse

Director General, Social Care, Local Government and Care Partnerships, Department of Health, Co-chair of Children's Health and Wellbeing Partnership



Mark Rogers

President of SOLACE and Chief Executive of Birmingham Council, Co-chair of Children's Health and Wellbeing Partnership

INTRODUCTION

In this document, National Voices and Think Local Act Personal (TLAP) set out to describe some critical outcomes and success factors in the care and support of children and young people with complex lives, from their perspective and that of the people who are important to them.

In doing so we have been supported by a range of partners, and the final document is endorsed by the national Children's Health and Wellbeing Partnership, which provides system leadership for the improvement of health outcomes for children and young people.

When we talk about children and young people with complex lives, we include the many different children and young people who are likely to need support from multiple services in their life. These services may include, for example, child and adolescent mental health services (CAMHS), Disabled Children Teams, Looked After Children's teams, Child Protection Services, probation, health services, palliative care support, or specialist education support. Other people around the child or young person may also have their own support needs.

What brings this group of children and young people together is that their lives have been made even more complicated by all the different professionals, agencies, funding streams, policy and legislation involved. This puts their care and support squarely in the context of 'integrated care', which is defined for England as 'person centred coordinated care' in the [Narrative](#) coproduced by National Voices and TLAP and adopted by all system leading organisations in health and care.

This additional document draws on the direct experience of children and young people, and those who love and care for them, to establish a simple set of principles and outcomes that commissioners and service providers should be working towards in organising person centred coordinated care specifically for children and young people, and to know when they are achieving it. It covers children and young people up to the age of 25 and takes account of the transition into adulthood, including the use of adult services.

The document supports implementation of a range of other key policy initiatives and legislation that are currently shaping services and support for children and young people, including:

- The Care Act 2014, in particular provisions relating to information and advice; prevention and promotion of wellbeing; assessment and planning; joint commissioning and personal budgets; and support for carers.
- The Children and Families Act 2014, including the duty to develop joint commissioning across education, health and care for children and young people with special educational needs and disabilities; as well as other key provisions relating to the local offer and information; advice and support; outcome focused, person-centred assessment and planning; and involvement of children, young people and families in assessment, planning, service design and delivery.

- The Integrated Personal Commissioning programme, which will include children with complex needs in a first wave of individuals to be offered the option of controlling their own blended health and social care funding.
- The final report of the children and young people's mental health and well-being taskforce.
- An increased focus on outcomes for children and young people in the reformed health system, as set out in the NHS Outcomes Framework and Better Outcomes Pledge, in line with recommendations made by the Children and Young People's Health Outcomes Forum.

However, this document is not pinned to any one policy or programme. Rather it tries to capture the views and perspectives of children and young people, and to build a shared understanding of these among professionals, regardless of organisational structures or mandates.

In preparing the document we found that children and young people are less concerned to talk about specific services or care settings, and more to emphasise their claims and rights to live their lives the way they want to live. They expect care and support services and the people who work in them to respond in the same spirit.

Therefore we urge commissioners and providers to use this document as a tool to have their own conversations with children and young people about their lives, their dreams and goals, and the way they want to be supported.

We also hope that it may empower children and young people and those around them to challenge their local services, to start conversations with them, and to get involved in designing services and support.

Finally, these statements are intended to be used alongside the existing Narrative for Person Centred Coordinated Care, published in May 2013. All the statements in that Narrative apply equally to these children and young people, such as 'I tell my story once'. The document also follows TLAP's work on personalisation, Making it Real, and providers may wish to consider the 'three step approach' to implementing Making it Real.



OVERVIEW

In developing this document we looked at what children and young people want to do in their lives now, and what is important for them in planning for the future and preparing for adulthood. We also looked at how children, young people, and the people who are important to them, want services to work with them.

A strong message emerged that children and young people want to be treated with respect, to exercise choice and control and to live a full, independent life.

DEFINITION OF AN INDEPENDENT LIFE

Independence is a central value in everything we have heard from children and young people about their aspirations and preferences. When we talk in this document about a full, independent life, we do not seek to define the way that life is lived. Every child or young person is unique in their goals, dreams and preferences and in the challenges and barriers they may experience. However, what we mean is that at every stage, and whatever their situation:

The child or young person experiences their life as one where they are provided with the right level of support to achieve their rights and work towards their individual goals, and the notion of choice and control is firmly embedded within all aspects of their life.

See Appendix one for further background to our thinking around the concept of independence.



A number of themes then emerged about what was important to make this possible.

This overarching summary and key themes are shown in the graphic below. Subsequent sections of the document include more detailed 'I statements' capturing key outcomes and aspects of experience relating to each theme. These are supported by case studies illustrating how they can be delivered in practice.



THE "I" STATEMENTS

RESPECT AND BEING LISTENED TO

- I am respected and valued for who I am.
- I am always listened to.
- I am confident that my voice is clearly heard, as distinct from those of the adults around me.
- I trust professionals to tell me how my information will be used and who it will be shared with.
- I can make choices about different levels of information that is to be shared with people around me, including members of my family, my school or college and other services.
- I feel safe in and around where I live and am not in fear of bullying or being treated differently.
- I am educated and supported to recognise bullying, discrimination and hate crime, and to know what to do about it.
- My family and/or supporters are respected and do not experience discrimination or bullying. People understand how their lives may be different to other people's.

CHOICE AND CONTROL

- I have as much choice and control as possible in my life.
- I have support to communicate and make my voice heard if I need it.
- My choice, control and independence develop over time. I am supported to build my skills and confidence at every stage.
- I am helped to prepare and to make plans because the people supporting me anticipate new stages and work with me in advance.
- I receive information as and when I need it and in the best way(s) for me. This means I can make informed decisions at all stages of my life.
- I am given information about my rights and choices without having to ask for it (because I don't know what I don't know).
- If I want to do things, I am supported to understand what might go wrong, but also to try, even if it might not always work out well.

SUPPORTING MY DREAMS AND GOALS

- I am supported to feel confident and to develop my own dreams and goals.
- Adults around me do not make assumptions about what I can and cannot do.
- I am supported to make progress with my studies and get the fullest education possible in a way that does not limit my later options.
- I can meet and learn about other people I relate to, whose experiences may have been similar to mine, and who I can share my experiences with.
- People, professionals and services recognise that, when help is required, it must be timely so as not to disrupt my progress. They act accordingly.

FRIENDS, RELATIONSHIPS, PEOPLE AND THINGS AROUND ME

- I have the right to interact with others in my own space and time.
- I have fun things to do and enjoy, such as activities, breaks, a change of scene and going on holiday.
- I have friends and other positive relationships, and a social life.
- I have a place I can call home, that meets my needs and where there is independent space for me.
- I can get support in a place where I am close to the people and things that are important to me. If there are times when I cannot be close to them, I am supported to stay in contact.
- I can go to the same places and do the same things as other people. If I need support to do this it is available to me.
- I can take part in discussions with others and have my voice heard in society and in public.
- As I grow up I get the same choices of where to live and who to live with as other people.
- When I am old enough and feel ready I can have legal healthy, consensual, sexual relationships. I am supported to think about being a parent if this is important to me.



SUPPORT THAT IS PERSONAL TO ME

- My support is designed to help me to do the things I want to in life.
- My support is appropriate to my age and development.
- The choices I have about services are flexible and creative
- I am aware of the different types of support that are around me and how I can access them.
- Services and support are provided in a way that doesn't get in the way of having a full, independent life.
- I have important adults in my life who I can trust and turn to when things are difficult, and who help me when I ask.
- I consistently see the same team of people who work with me and get to know me.
- When there is a need for meetings, these are organised so as to minimise disruption to my education.
- I can choose to get some support from people my age and/or like me. People understand that this is important to me.
- If I move to another area my support plan and package move with me.

SUPPORT FOR THE PEOPLE WHO ARE IMPORTANT TO ME

- The people who are important to me feel the system is working with them. They don't have to fight for everything we need.
- The people who are important to me are supported too so we can all do the things that are important to us. This means things we do together as well as things we do on our own.
- I and the people who are important to me have:
 - a named professional, who coordinates all the support we need. We are not left to navigate the system on our own
 - the information and support they need
 - help to build skills, knowledge and confidence to help me
 - early support, not just when they reach breaking point
 - confidence that they are listened to and taken seriously when they raise concerns.
- I am supported to maintain relationships with people who are important to me.



MAKING CHANGES AND GROWING UP

At all stages of my life:

- I experience support and early planning for big changes such as:
 - from primary to secondary school
 - from one setting to another, such as returning to school after a hospital stay or moving between care settings
 - when there is a change in the team that works with me
 - starting college, university or work.
- I and the people who are important to me are supported to understand the changes in our roles and relationships as I get older or there are changes in my life.
- As I get older I may want to be supported by different people, or in a different way. My support changes to take account of this.
- I am supported to prepare for adulthood throughout my life.

As I move towards adulthood:

- Because we have been helped to plan ahead, I and the people important to me know what is going to happen when I reach adulthood, and how I will be supported.
- I am confident that I will be able to:
 - be happy
 - be respected
 - live a full, independent life
 - stay as healthy as possible
 - have a job, or other meaningful activity, which uses my full potential
 - have friends, and play a part in social groups and networks
 - still be able to access services if I need them.
- My preparation for adulthood includes thinking about new types of support that I might need, like support with housing and work, or support if my health gets worse.
- I am prepared for moving into adult services and I am supported to transfer when I am ready, taking into account other things that are happening in my life.

When I reach adulthood:

- I feel comfortable using adult services.
- Even though the services aren't the same, the level of coordination is.

IN PRACTICE

In the following sections we set out some real case studies to support the “I” statements and show what they look like in practice...

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- My family and/or supporters are respected and do not experience discrimination or bullying. People understand how their lives may be different to other people's.



TOTAL RESPECT TRAINING, LONDON BOROUGH OF RICHMOND

Young people in the London Borough of Richmond deliver Total Respect training to its staff. Total Respect aims to encourage participants to understand better the experiences of young people in care, to think about young people as individuals, challenge assumptions, support participation of young people in their care planning and to provide further knowledge of children's rights and advocacy. It was developed by children and young people who had experience of being in care and is designed to be delivered by young people themselves.

“Children in care and leaving care have had both positive and negative experiences, so who better to train workers and share their views on how services could be improved. Overall I think Total Respect training proves how well professionals and young people can work together...”

– Young person from Richmond who delivers Total Respect training.

Example of innovative practice from All Party Parliamentary Group (APPG) for Looked After Children and Care Leavers' entitlements inquiry report.





SHANE'S WIKI, LONDON BOROUGH OF GREENWICH

A wiki is a multi-media mini website which can be easily accessed and updated. Sam, from Greenwich Parent Voice, describes how her family uses a wiki to make sure that everyone working with her son Shane understands him and values him for who he is.

"I initially developed a wiki for my son Shane as it was very important to me for everyone involved with Shane to get an insight into him as a person and not just his disabilities and difficulties. The wiki gives information about our family, Shane's communication, mobility and care needs, the things Shane likes to do, his spiritual life and school life.

"Shane's Individual Education Plans (IEPs), annual review reports, education health and care plan, speech and language reports, physio program, medical letters etc. are all on the wiki. Everything is in one place and I no longer have to hold onto lots of papers. Shane's brother Daniel who was 11 at the time helped create the whole wiki. Siblings of disabled children can sometimes feel left out and by involving Daniel in this process he felt very important. Daniel has subsequently supported his brother at annual reviews helping him showcase his wiki especially highlighting the progress Shane has made towards his outcomes and life aspirations.

"The wiki has been fundamental with Shane's transition into Post 16 enabling new staff to get a really good understanding of Shane and providing valuable information about how best to support him which resulted in a smooth transition."

To hear Shane's mother talk about his wiki go to <http://youtu.be/wOK84qsB4BA>





MAKING OUR VOICES HEARD: THE FLYING HIGH GROUP, NORTH YORKSHIRE

The Flying High project, supported by Barnardo's, is a group of young people, aged 16-25, who have disabilities and additional needs. The group represents and supports young people to get the lives they want.

Members of the group are regularly involved in consultations and other initiatives to improve children and young people's services. They attend and present at meetings and events, including awareness-raising sessions for professionals, and have been involved in recruitment processes for staff.

As well as giving their own views, members of the group also go into schools and other forums to find out what other young people think and make sure their voices are heard. Students have said that they like other young people with disabilities visiting them at school, and the visits have also provided an opportunity to inform children and young people about new service developments such as education, health and care plans and the local offer.

One young person who has been a long standing member of the Group says:

"I got an opportunity to be involved with an amazing wonderful project that empowers young people – the Flying High Group. I have watched the group grow from five young people to 18 and seen group members come out of their shell and develop confidence and feel empowered. I've always had to stand on my own two feet within the care system and take what's thrown at me as a disabled person – I feel proud that the Flying High Group is still running after six years and is still making a difference for disabled people."

The Principle Disabled Children's Services Officer for North Yorkshire County Council says:

"The Flying High Group is the place that people go to for advice and to receive feedback about their work with disabled young people. In the last couple of years the Flying High Group has helped us consider how we improve transitions, the moving on pack for people going through transition, the buddying up pilot in Harrogate and making a young people friendly version of the Local Offer. The group continues to work with local schools around short breaks and inclusive activities ... We really couldn't do without the group as we try to improve services for young people."

For further information about the Flying High Group visit:
www.nyss.org/index.aspx?articleid=23868





HELPING CHILDREN AND YOUNG PEOPLE TO UNDERSTAND HOW INFORMATION ABOUT THEM MAY BE USED AND SHARED: MY CAMHS CHOICES

YoungMinds, Off the Record (Bristol) and the Evidence Based Practice Unit at the Anna Freud Centre collaborated on a Department of Health funded project, My CAMHS choices, which ran for three years, finishing in March 2014. The project was steered and developed by young people with experience of Child and Adolescent Mental Health Services (CAMHS). They believed that finding out as much as possible about their treatment options was a really important and helpful step in enabling them to engage with the service and their worker, as it made them feel as though it was something they were involved in rather than something that was happening to them. Because of this, the group decided to create a website, featuring videos answering key questions about CAMHS.

One of the sections of the website focuses on Privacy and Confidentiality. It aims to address young people's concerns around what details of their therapy will be shared and with who. It features videos from the perspectives both of young people who have had first-hand experience of CAMHS and the professionals who work there: answering frequently asked questions such as:

- What is confidentiality?
- Who has access to what a young person says to a worker in CAMHS?
- Will CAMHS liaise with my school?
- Will letters addressed to me be copied to my parents?

Young people also describe their experiences of issues around privacy and confidentiality when accessing CAMHS, and whether their choices about this were respected and listened to. One said:

"I really didn't want my parents involved in any way and they sort of had to be sometimes, which I really struggled with at the time, but then as time went on I sort of realised that everybody was on my side anyway, but in the most part if I had said "I really don't want you to tell my parents that" and if they weren't bound to then they didn't. And if they did have to tell somebody something then they did tell me first".

These videos, and others on the My CAMHS Choices website, are a useful tool for practitioners in supporting children and young people to understand and make choices about how information about them may be used and shared, and to exercise their right to choice and control over their mental health care more broadly.

For further information, visit <http://mycamhschoices.org/>





TACKLING BULLYING OF CHILDREN AND YOUNG PEOPLE WITH SPECIAL EDUCATIONAL NEEDS AND DISABILITIES (SEND): THE ANTI-BULLYING ALLIANCE SEND PROGRAMME

Evidence shows that children and young people with special educational needs and disabilities (SEND) are significantly more likely to be bullied or victimised than those who don't have any SEND. The Anti-Bullying Alliance SEND programme aims to reduce the incidence and impact of bullying of children and young people with SEND.

Between 2013 and 2015 the programme, which is funded by the Department for Education and delivered in partnership with Achievement for All 3As, Contact a Family, Mencap and the Council for Disabled Children, is providing free training for schools, parents and carers and the wider workforce to help them better prevent and respond to bullying of children with SEND. Online training modules have also been developed for professionals to access free on the programme website, as well as a wide range of other resources for young people, parents and carers, school staff and other professionals, which are held in the programme Information Hub.

Children and young people themselves have been involved in advising on the direction of the programme and in developing resources, including three guides for schools on bullying and mental health, bullying and children and young people with autism and cyberbullying and disability.

To find out more about the programme and access the resources and training, visit www.anti-bullyingalliance.org.uk/send-programme



CHOICE AND CONTROL

- I have as much choice and control as possible in my life.
- I have support to communicate and make my voice heard if I need it.
- My choice, control and independence develop over time. I am supported to build my skills and confidence at every stage.
- I am helped to prepare and to make plans because the people supporting me anticipate new stages and work with me in advance.
- I receive information as and when I need it and in the best way(s) for me. This means I can make informed decisions at all stages of my life.
- I am given information about my rights and choices without having to ask for it (because I don't know what I don't know).
- If I want to do things, I am supported to understand what might go wrong, but also to try, even if it might not always work out well.



UR SAY UR PLAY, WARWICKSHIRE

Ur Say Ur Play is a set of playing cards featuring details of support services for Warwickshire's looked after children aged 13-18. The cards were designed by members of the local authority's Children in Care Council – all children and young people with experience of life in care – to replace the 'big suitcase' of information leaflets that they used to be given. They chose the playing card format because it is easy to carry around, as well as being something you can 'have a bit of fun with'.

Each card features a different service – chosen by young people – and a QR code which links directly to the service website when scanned using a smartphone. By accessing information direct from the website, young people can feel confident that it is up-to-date and accurate.

The council is also able to track hits to the different service websites, so they know which cards young people are using most regularly. This helps to identify issues that young people are particularly concerned with, such as mental health, which can inform future service development. Warwickshire is now exploring having an online version of Ur Say Ur Play so the cards can be updated more easily and young people can download them directly onto their smartphones.



Find out more about Children in Care Council at www.warwickshire.gov.uk/cicc, and get an introduction to Ur Say Ur Play from care leavers Matt and Sarah at www.youtube.com/watch?v=A32iowCTT4





CHECKPOINT TORBAY: INDEPENDENT INFORMATION, ADVICE AND ADVOCACY FOR CHILDREN AND YOUNG PEOPLE

CheckPoint Torbay is a programme delivered by The Children's Society which provides a range of free and confidential information, advice and support services to children and young people aged 8-17. The programme's guiding philosophy is to ensure that young people have immediate and straightforward access to independent help. It aims to promote young people's safety, health, values, rights and responsibilities in the community so they are encouraged to reach their own decisions and consider their choices in order to achieve their full potential.

One of the most popular services provided by CheckPoint is the Drop In: a street-level access point for young people where no appointment is necessary and information, advice and initial support is readily available. CheckPoint has also developed additional, more specialist services to meet the needs of different groups of young people. These include:

- A Children's Rights service providing advocacy for children and young people subject to either child protection processes or who are looked after by the local authority
- Independent visiting for children and young people who are Looked After and have little or no contact with their natural family.
- A Disability Council that supports young people with disabilities to have a voice.
- A substance misuse treatment service for young people
- Runaways service providing return home interviews and support for children who go missing
- A Mental Health and Emotional Wellbeing service provides structured counselling, trains professionals in mental health first aid and offers schools the opportunity to participate in the national Good Childhood survey.

You can learn more about CheckPoint Torbay and the full range of services it provides at: www.childrensociety.org.uk/what-we-do/helping-children/our-programmes/children-risk-streets/check-point





MIND OF MY OWN: MOMO

MOMO is a self-advocacy app that helps vulnerable children and young people to express their views more clearly, get more involved in meetings and make better decisions with their social care team.

MOMO gives young people three different scenarios to share their views through. The scenarios focus on preparing for meetings, changing things about your situation and sorting out problems that are bugging you. As young people work through the scenario that is relevant to their situation, the app provides hints and tips to help them get their point across, using links to information on young people's rights and entitlements.

At the end, MOMO puts their views into a structured statement which young people can save, email or download. If a local service has connected to MOMO then the user is offered the option to send their statement to them directly. This makes it easier for young people to communicate with their social worker and to contribute to looked after children (LAC) reviews and other meetings.

Darren, a young person using MOMO says *"It got me what I needed straight away. I sent it and got a response from an advocate and then a meeting with my social worker where we went through what I said. Now I've got a good outcome."*

Professionals using the app with different children and young people have also found it valuable. One professional had used the app to help Andy, a young person with autism and attention deficit hyperactivity disorder (ADHD), who had been getting so anxious about his review that he had trouble managing his behaviour within school. *"I was able to visit early and use the app with Andy to create a statement of his views. He was a lot calmer and less anxious and remained in his review longer than he anticipated and he was very positive about MOMO to his social worker!"*

Another professional used the app with Denise, a young person who does not like meeting with people or answering questions face to face. The computer gives Denise the 'side-by-side' scenario which is more conducive to talking and sharing. Denise likes MOMO because it gives her choice over the answers, whether to print or send and who to send it to. Without this kind of tool it would be difficult to engage such a child and gain their wishes and feelings before their review.

For more information
go to the MOMO
website: [http://mind
ofmyown.org.uk](http://mindofmyown.org.uk)





THE PERSON CENTRED REVIEW PROCESS: ALEX AND SALLY'S STORY

Sally Percival describes how the person centred review process has enabled her son Alex to become really involved in his own future and have choice and control:

"My son Alex is a wonderful young man with a great sense of humour and really good company; he is a fanatical world war two re-enactor and goes around the country taking part in displays, his knowledge about the subject is vast. Alex has autism and a learning disability which to him are a pain in the neck but he doesn't let that get in the way.

"In the past Alex's reviews had been formal, intimidating, focused on "can't do", "won't do", depressing and boring! And they didn't include him! But it doesn't have to be that way.

"When we started preparing for transition, we had person centred reviews which focus on: what we like and admire about Alex; what is important now; what is important for the future; what support and help is needed; what is working and not working; questions to answer/issues we are struggling with, and actions that need to be taken.

"A lot of talking needs to be done prior to the meeting. We just sat with Alex and talked to him about all of the questions that needed to be answered, we asked him what he thought, what he liked and what he didn't. We got a roll of lining paper and tried to capture what he said in words and drawings; Alex joined in too and did some lovely drawings. We did this at home the night before the meeting. Alex really felt involved and enjoyed it.

"For the first time we focused on what was good about Alex, it was so wonderful to hear what people liked and admired about my son, it brought a tear to my eye. We also introduced his circle of friends. I think that one of the most important things about the review is that people all join in, because it is a very visual process that is recorded graphically on paper, people can see that they have been heard. Another really important component is the actions sections, each action is written on paper on the wall and we all take responsibility for each action and sign up to them. This makes sure they get done.

"Alex is now 20 and he has progressed to a local college that specializes in conservation and horticulture. Over the last six years I have witnessed Alex slowly but surely become really involved in his own future, like us all he wants to be in control, when you have choice and control your anxiety levels drop and for Alex that is a must. Alex now wants to be involved and that is because he simply became part of his own life and part of the decision that were being made. It's not rocket science just common sense; it is just what most of us want."

To hear more about Sally and Alex's story go to:
www.thinklocalactpersonal.org.uk/Latest/Resource/?cid=9206





CHOICES AND DECISION MAKING MATTERS: EMILY'S STORY

Disability Matters is a free e-learning resource for the UK workforce. It consists of 57 individual sessions of e-learning plus a range of resources to support face-to-face group learning. Every session in Disability Matters has been coproduced with disabled young people and parent carers, along with other experts in the field, and although the resource is targeted at practitioners, the hope is that they will be just as accessible and useful for disabled children, young people and parents themselves.

The resource includes a session on Choices and Decision-making Matters, designed to help practitioners develop their skills and confidence in supporting disabled children and young people to make their own decisions in all areas of their life. It describes how Emily and her parents were supported to enable her to try something new and go on a school trip to France.

Emily is 14-years-old and has Down's syndrome. She was really excited about going on the trip, but also really anxious, particularly as she has never been away from home overnight before. Her parents Mary and Pete were also really concerned about making the right decision. They did not want to deprive Emily of the chance to go away with her classmates, but were worried it may be 'too much for her'. They were concerned that Emily is too vulnerable, but also said they were afraid they were being over-protective.

Emily's parents were supported to weigh up all of the pros and cons of her going on the trip, talking to Emily about it and answering her questions too. They met with staff and other parents to find out more about the trip, and were able to speak to the host family over the internet. They also met with people who knew Emily in other settings as a young person to get their views on her going on the trip. Arranging a sleepover at a friend's home locally also helped to build their own and Emily's confidence about being away from her parents. They worked with Emily's paediatrician to ensure her Emergency Healthcare Plan was up-to-date and had the right information on it that would be helpful for the trip.

Emily's parents were then able to make a decision to consent to her going on the trip, having considered Emily's best interests, her views and those of everyone who knew her well. She went and had the time of her life! She came back full of confidence and her parents noticed the positive difference for her, which was an important step for her in growing up.

Emily's Story © 2014 Royal College of Paediatrics and Child Health, used with permission.

The full e-learning session, Choices and Decision-making Matters, can be accessed at www.disabilitymatters.org.uk/course/view.php?id=73
To find out more about Disability Matters and see all of the courses and resources available, visit www.disabilitymatters.org.uk



SUPPORTING MY DREAMS AND GOALS

- I am supported to feel confident and to develop my own dreams and goals.
- Adults around me do not make assumptions about what I can and cannot do.
- I am supported to make progress with my studies and get the fullest education possible in a way that does not limit my later options.
- I can meet and learn about other people I relate to, whose experiences may have been similar to mine, and who I can share my experiences with.
- People, professionals and services recognise that, when help is required, it must be timely so as not to disrupt my progress. They act accordingly.



URI'S STORY: USING A PERSONAL BUDGET TO SUPPORT MY DREAMS AND GOALS

Uri lives at home with his mum, dad and sister, Katya. Uri has a personal budget which enables his family to have more control and to choose creative ways to spend the budget and use the support in a way which is far more tailored to Uri's needs. They describe how this is supporting Uri to do the things that matter to him.

"Uri needs lots of encouragement to go out, so his support needs to be so personalised to him... He got this and he did lots of things from dance to baking days at home, things he wanted to do. He had support to learn travel training which is crucial in the rural area we live in, he has also been learning lots of life skills.

"Uri bought an airbed so he could go camping...he went on three trips, one to Thetford forest, one to Ely and once to St Ives...this was a great opportunity for him to spend time with his peers. Uri has learned so many things and this is down to the support he gets when he needs it"

This family story is from a selection of case studies collected from across England by the charity KIDS that describe how some families have used personal budgets in imaginative ways to meet the requirements of their disabled child or children. More examples can be found at <http://kids.ritdns.com/making-it-personal-case-studies>





NO ASSUMPTIONS ABOUT WHAT I CAN AND CANNOT DO: ELEANOR'S STORY

Eleanor is eighteen and her family has always wanted her to have an ordinary life: to have friends and be part of her community. As Eleanor got older they hoped she would be able to make a valuable contribution to her community and maybe one day get paid for her work. However, her family felt that her rare condition, her health needs and the fact that she does not say many words led 'the system' to forget what Eleanor was capable of achieving.

Eleanor went to a mainstream secondary school where her teachers, with the help of the educational psychologist, set up a circle of friends. Her friends have stayed in touch beyond school, and were incredibly helpful when Eleanor started planning for employment. Eleanor's mum Liz says: *"They saw everything so simply and they came up with 70 job ideas for Eleanor. We had always found it really hard to engage people to talk about employment and social life, but Eleanor's friends were so creative."*

When Eleanor and her family started to plan for her post-16 education they continued to have high aspirations. They wanted to put together a week that was like that of any other 16 year old. The local authority agreed to create a personal budget made up of funding from education and social care. This funding provided Eleanor with the support she needed to take part in a level 3 health and social care course at the local sixth form college, a ceramics painting class, an adult education cooking class, music lessons, Girl Guides, swimming and laughter yoga.

Eleanor had a range of work placements, including at a local nursery, where her love of singing made it a particularly successful experience. Eleanor also shares her singing skills by visiting an elderly woman in her community who loves to sing. During the last year Eleanor and her mum, with one of Eleanor's assistants, have established a small cosmetics business, which means Eleanor holds parties and has stalls at various fairs and events. This development was based on Eleanor's interest in cosmetics and her love of being with people.

This case study is taken from *Delivering support and aspiration for disabled young people*, a report from the Preparing for Adulthood programme: www.preparingforadulthood.org.uk/resources/pfa-resources/delivering-support-and-aspiration-for-disabled-young-people You can see Eleanor's mum Liz talking more about their experiences at www.preparingforadulthood.org.uk/videos.

Liz suggests that people use the Pathways to Getting a Life to support young people to prepare for adulthood. She says: 'The Pathways set out what we have done'. You can see the Pathways at: www.gettingalife.org.uk





BU BE AMAZING PROJECT, THE MAYDAY TRUST, NORTHAMPTON

The BU Be Amazing project aims to support young people to recognise and build on their assets – enabling them to thrive, be healthy and motivated, and feel that they have a voice and opportunities in their community. It follows the US ‘Developmental Assets’ model for positive youth development which works on the principle that by increasing a young person’s ‘assets’ they are more likely to succeed in life.

Referrals to BU Be Amazing come through a local partner charity, Blackthorn Good Neighbours, and the work is supported by In Control. Following referral a trained personal mentor engaged by Mayday Trust, will work with the young person to identify their strengths, aspirations and significant networks and local resources and then put together a plan that will aim to build their assets and give them an opportunity to integrate positively within their local community. BU Be Amazing offers a small personal budget of £250.

The success of BU Be Amazing is founded in the focus on both the ‘assets’ of the young people and the ‘assets’ of the community. This focus on assets, allied with a small budget, is unlocking potential and opportunities for young people who could easily remain isolated.

Matt Boylan, Personal Asset Mentor, described a bewildering array of contacts he had made, voluntary agencies, council departments and more importantly people from his own network he has drawn in to benefit the young people he works with. BU Be Amazing uses Twitter to create and sustain these networks, and young people referred to the project also benefit from the wider Mayday Trust offer.

When Matt started working with a young woman called Mary she identified two ‘talents’ to build on: singing and cooking. Mary was easily connected to the Mayday Health hub and brokered some free cooking and singing lessons, as well as access to studio space. Mary says, *“Before I went to my first singing lesson I felt a little bit nervous but after a while, I felt comfortable around the teacher and Matt – I want to achieve how to reach my higher notes and my breathing techniques”*. The lessons have given Mary a space to build on her assets and develop some new relationships. Matt has also supported Mary to develop better relationships with all of the other people in her life, family and school.

The impact of BU Be Amazing on Mary is beginning to be seen. She uses her time more constructively, is meeting new people, has renewed self-confidence and self-belief, and a sense of achievement. Like other young people involved with the project, she has not moved up Northampton’s Vulnerability Matrix.

This information is from: Self Directed Support and Early Intervention
Tim Keilty In Control May 2014: www.in-control.org.uk/what-we-do/children-and-young-people/publications/children's-programme-publications/self-directed-support-and-early-intervention,-may-2014.aspx

Further information about BU Be Amazing can also be found at:
www.in-control.org.uk





EXPLORING JOINT COMMISSIONING OPPORTUNITIES TO ENABLE CHILDREN AND YOUNG PEOPLE TO ACCESS THE CURRICULUM FULLY AND MAXIMISE INDEPENDENCE: KENT AND MEDWAY 0-25 WHEELCHAIR SERVICE

Kent and Medway's 0-25 wheelchair service came about as a result of working with the national advisory group for wheelchairs from a children's commissioning perspective and coproducing an effective local model of delivery with parent carers, disabled young people and a range of professionals from health, education, social care and the voluntary sector. The local Clinical Commissioning Groups (CCGs) wanted to commission a holistic approach to the provision of wheelchairs, repairs and maintenance delivered by a lead provider, working collaboratively with the child/young person and family and other agencies to develop a multi-agency assessment of need and maximise the child's or young person's independence.

As one of its projects the new Kent multi-agency special educational needs and disabilities (SEND) strategy has to look at the joint commissioning opportunities around the provision of wheelchairs on a case by case basis for particular groups of children. For instance a Year 6 child may have been able to maximise his/her independence with a manual chair in primary school, but on transition to secondary school will require either a teaching assistant to support them to go from class to class (because the child does not have the physical strength to travel around the school) or a jointly commissioned powered chair (from £3.5K) that would deliver savings in the school and maintain his/her independence and mobility in all areas of the child's life. Also, there are joint commissioning opportunities linked to the provision of risers (enable a wheelchair user to go up or down). It would be far cheaper to jointly commission a wheelchair with a riser than spend capital funding adapting classrooms etc. to enable a wheelchair user to fully access the curriculum.

The work was important for them to enhance the clinical expertise in the children's and young people's pathway for wheelchair services through creating a 0-25 model. This has in turn enhanced the clinical expertise in the adult pathway (26+).

This case study is taken from the SEND Pathfinder Information Pack Version 5, October 2014 – Joint Commissioning. For further information and examples of joint commissioning for children and young people, visit: www.sendpathfinder.co.uk





MAKE THE GRADE: ENSURING CHILDREN WITH DIABETES GET THE FULLEST EDUCATION POSSIBLE

Without good coordination and joint working between parents, schools and healthcare professionals, children and young people with medical conditions too often miss out in all parts of school life, from lessons to school trips, meaning both their health and education suffers. The Children and Families Act 2014 introduced new legal requirements in England for schools to support children with medical conditions.

As part of its Type 1 diabetes: Make the grade campaign, Diabetes UK has launched a range of resources to help all schools meet these requirements and provide good care across the UK to ensure that all children with diabetes get the support and care they need. The resources include toolkits for schools and for parents; a sample individual healthcare plan (IHP) for a child with diabetes; and a sample medical conditions policy for the whole school. All of these resources and further information about the campaign can be found at www.diabetes.org.uk/schools.

One parent describes how good care at school has enabled her daughter to stay healthy and safe at school and get the fullest education possible:

“When my daughter started school in September, I had a meeting with them before she started to explain about her diabetes. They were great. They watched her and helped her if she needed it. She has a card to show if she needs to leave class no questions asked! The school go and get her at breaks and make sure she is checking her blood glucose levels and they help her with lunch. The school never marks her absent if it is to do with her diabetes.”



FRIENDS, RELATIONSHIPS, PEOPLE AND THINGS AROUND ME

- I have the right to interact with others in my own space and time.
- I have fun things to do and enjoy, such as activities, breaks, a change of scene and going on holiday.
- I have friends and other positive relationships, and a social life.
- I have a place I can call home, that meets my needs and where there is independent space for me.
- I can get support in a place where I am close to the people and things that are important to me. If there are times when I cannot be close to them, I am supported to stay in contact.
- I can go to the same places and do the same things as other people. If I need support to do this it is available to me.
- I can take part in discussions with others and have my voice heard in society and in public.
- As I grow up I get the same choices of where to live and who to live with as other people.
- When I am old enough and feel ready I can have legal healthy, consensual, sexual relationships. I am supported to think about being a parent if this is important to me.





GET CONNECTED

The Get Connected programme was commissioned by Newcastle City Council four and a half years ago to enable children and young people to access a much wider range of mainstream activities in their local community.

The programme combines musicians, dancers, artists and sports coaches who work together to introduce children to activities, support them while they take part and settle in well. The activities are free or at low cost. Young people and families have easy access to the service and can self-refer to meet a Get Connected worker. Following a conversation to understand the child's strengths and support needs, the worker then supports the child to be introduced to a suitable activity. Last year 119 children were connected to a vast, diverse range of activities including; dancing, judo, boxing, photography, music performance, painting and circus skills.

Jakes story: Angela from Get Connected says she first met Jake at an Arts Connect taster day; *"it was clear he knew an awful lot about Photoshop and was very talented. Jake has been coming to Photo Club for several years now and has produced some amazing work; whatever app or technique we show him, he excels at. But for me his achievement is social. Jake is autistic and has always been shy in the group. He made one very good friend though after a few months and they would talk about comics etc. But what thrilled me was on a field trip recently, as we were walking to our destination there was a lot of excited, animated chat about a video game between four lads and I realised that Jake was leading the conversation! Making friends in an inclusive setting was always one of the aims Arts Connect set us and it's great when we see this happen."*

Jake says *"When I first got there I didn't really talk to many people, but a couple of weeks ago I did start a conversation because someone in the group was talking about comic books, and maybe going to Gateshead to a comic book place with Manga. That got me talking, because of my interest in Manga and Anime."*

For more information about Get Connected, visit: www.newcastle.gov.uk/health-and-social-care/disabilities/children-with-disabilities/get-connected-leisure-and-cultural-activities-for-children-and-yo





HAVING A CHANGE OF SCENE: GEORGE'S STORY

George lives at home with his mum, dad, and brother. His cousin also spends lots of time at the family home and is very important to George. George has a personal budget which has given him and his family a way to choose how services can best assist them in supporting George and ensuring he has fun things to do and enjoy.

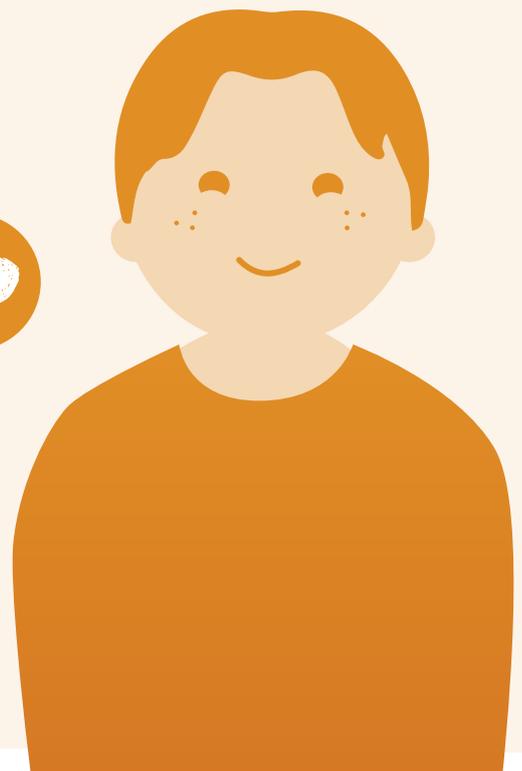
"Having a personal budget provides us with the complete flexibility to cater for and adapt to any change, likes and dislikes, needs and desires within a plan that gives the care we feel best suits George.

"We have been able to incorporate a portion of our annual family costs into the plan. George enjoys and benefits greatly from a warm climate and access to water due to his high tone. For many years we have holidayed in the Canary Islands where we visit a rehabilitation centre. George now enjoys staying overnight at another family environment and isn't restricted to every other Tuesday night; it is at a time that suits us all.

"George enjoys going into town for clothes shopping ... he really likes the latest fashions. He likes going out in the community, likes watching golf and any chance to get into a hot tub or plunge pool.

"Having a budget was like a breath of fresh air... it was like a light coming on. It is the fundamental right of every free living person to be 'in control'. Our children should be no different to any other in that respect. As they may not enjoy the overall control that able-bodied children do, is it not even more important that they be able to enjoy control in other areas of their lives? This just makes things so ordinary. Just because George's body is disabled does not mean his mind and souls is."

This family story is from a selection of case studies collected from across England by the charity KIDS that describe how some families have used personal budgets in imaginative ways to meet the requirements of their disabled child or children. More examples can be found at <http://kids.ritdns.com/making-it-personal-case-studies>





SUPPORT TO STAY CLOSE TO HOME AND DO THE THINGS THAT OTHER YOUNG PEOPLE DO: PETE'S STORY

Pete is 19 years old and has fragile diabetes, autism and a high level of learning needs. Pete has always required lots of support to keep healthy due to his diabetes. Until he was 17 his mother had to come to his school every day to give his insulin injections and she has to sleep in the same room with him at night in case his blood sugar levels drop too low.

When he was about to leave school things came to a head. The college he wanted to attend said they would not give him a place unless he had someone with him at all times. This meant that Pete would have gone to a residential college, something his family did not want for him. The Transition team from the local authority who were supporting Pete and his mother knew that their area was piloting the new personal health budgets. They worked with Pete and his mother to draw up a support plan that identified what his and his family's dreams are for him for the future, along with his talents, what he likes and dislikes and what is important to and for Pete. It was agreed that he was to be given a combined personal health budget and personal budget for social care to support him throughout the week.

Pete now employs three male personal assistants to support him for over 30 hours per week. This has enabled him to stay at home rather than going away to residential college, and also to go to the same places and do the same things as other young people. The assistants are trained to give injections and to read Pete's blood sugar levels.

One personal assistant, who worked in the school Pete attended, goes out with him at weekends; another attends college with him; and the third supports him to go out and do things that other young people do, such as shopping and visiting his sister and her family. The support has also meant that his mother has now been able to establish a life for herself and is able to work more hours.



From An Ordinary Life. Foundation for people with learning disabilities. You can find more information on this project and see more stories at: www.learningdisabilities.org.uk/our-work/changing-service-delivery/an-ordinary-life/





AN INCLUSIVE APPROACH: AMY'S STORY

Amy's mum Tara describes how her daughter has been supported to experience the hustle and bustle of an ordinary life, including attending her year 11 prom, through an education, health and social care combined budget.

"My daughter Amy started mainstream schooling aged nine, and started at the Weald School in Billingshurst when she was eleven. Apart from a few wobbly times, Amy's bubbly personality and a handful of wonderful personal assistants (PAs) and learning support assistants has meant that she has thrived in her mainstream setting.

"For Amy, the main benefits of mainstream schooling, apart from access to many learning opportunities in a language-rich environment alongside children from her local community, is the hustle and bustle of an ordinary life. The whole process of including a wheelchair user with no speech has not been easy, but Amy's inclusion has got better as the years have moved on where everyone has learned.

"Her outcomes have been achieved by a team of wonderful PAs recruited and trained at home and funded by an education, health and social care combined budget, which we hope will support her transition into adulthood. Amy's PAs work alongside staff at school to meet her outcomes which included access to her local pool, switch practice to operate her power chair, and access to school trips. They call themselves The A Team and meet every month to discuss what works well and what could be improved and the best example of an outcome achieved was her trip to her prom."

With the help of her PA, Amy communicated *"a highlight was Mr Pollard pushing my wheelchair up the ramp."*

This story is an abridged version of a case study provided by Independent Lives. For further information, visit www.independentlives.org





SUPPORTING CHILDREN AND YOUNG PEOPLE TO REMAIN AT HOME AND IN LOCAL SCHOOLS: BRISTOL ONE SERVICE ONE PROCESS

Bristol has a pooled budget between health, social care and education to commission bespoke packages for children and young people with learning disabilities and complex needs who are at risk of school or home breakdown. The packages usually take the form of Positive Behaviour Support mostly in school and occasionally at home. These packages of support have enabled the children and young people to remain living at home and in local schools. In addition to seeing improved behaviour in the children there has been an added benefit through parents and school staff learning new skills.

Last year six young people with severe learning disabilities and/or ASD have been in receipt of funded packages and remained in Bristol. All six have been at risk of their special schools no longer being able to support them and risk of families no longer being able to care for them at home. These children had all been in receipt of a range of local services for children with learning disabilities but these had been exhausted and their complex needs were still not being met adequately. School remains the main provider of a break for parents and carers. Once this starts to fail families can very quickly escalate to crisis. Of the six children funded through 151P 2013/14 none have had to leave their homes or school to go into independent out of area provision and there have been no admissions to CAMHS inpatient services for this client group this year

This case study is taken from the SEND Pathfinder Information Pack Version 5, October 2014 – Joint Commissioning. For further information and examples of joint commissioning for children and young people, visit: www.sendpathfinder.co.uk



SUPPORT THAT IS PERSONAL TO ME

- My support is designed to help me to do the things I want to in life.
- My support is appropriate to my age and development.
- The choices I have about services are flexible and creative
- I am aware of the different types of support that are around me and how I can access them.
- Services and support are provided in a way that doesn't get in the way of having a full, independent life.
- I have important adults in my life who I can trust and turn to when things are difficult, and who help me when I ask.
- I consistently see the same team of people who work with me and get to know me.
- When there is a need for meetings, these are organised so as to minimise disruption to my education.
- I can choose to get some support from people my age and/or like me. People understand that this is important to me.
- If I move to another area my support plan and package move with me.





KATIE'S STORY, STREET SAFE IN LANCASHIRE

Street Safe Lancashire is a project run by the Children's Society that works throughout the county to support young people at risk of child sexual exploitation and missing from home.

Katie is 14 years old and was living in residential care when she was referred to Street Safe Lancashire. She had been reported missing from home fifteen times, and was reported missing 32 times in her first four months in care. She was frequently picked up in cars outside the unit by unknown males, and engaged in sexual activities in return for cocaine. Katie was also consuming large amounts of alcohol on a regular basis. This had enormously affected Katie's physical and mental health.

Street Safe Lancashire worked consistently with Katie over a 12 month period to support her, advocate on her behalf and begin to address some of the issues underlying the behaviours and situations linked to her sexual exploitation. The work was individually tailored to Katie and it sensitively considered issues like abusive relationships, images of self and others, grooming, drugs and alcohol.

The Street Safe worker became a consistent figure in Katie's life especially in those times of difficulty. Together they worked on strategies to build up Katie's confidence and to find alternative ways of expressing feelings like fear, anxiety or anger. Katie accepted the support because she found the worker non-threatening, she liked it that she was independent from police and social care and that she listened rather than telling Katie what to do.

The trust that was built became a basis to engage and learn to trust in other professionals too. A particularly good relationship was created with the police's missing from home coordinator. This gradually enabled Katie to participate fully in meetings about herself and to be part of the decisions made.

After spending nearly a year in care, Katie was able and willing to return home to live with her mum and step-dad. She has completed her GCSEs and is looking forward to starting college.

You can learn more about Street Safe at www.childrensociety.org.uk/what-we-do/helping-children/children-risk-streets/childrens-society-lancashire---street-safe





ACCESSING THE SCHOOL NURSING TEAM THROUGH A TEXTING SERVICE, LEEDS COMMUNITY HEALTHCARE NHS TRUST

When young people told the school nursing team in Leeds that they would like to be able to communicate their personal issues by texting, rather than attending a drop in session, the team decided to pilot this approach.

The pilot enabled young people to communicate with their school nurses in a way that suited them. School nurses also found that it was a more flexible way of working that could fit around other work, as opposed to the traditional drop-in session. The team felt it was a good way for pupils to connect with the service after they had met the school nurse once, for example during an assembly. Some cases from young people were more complex and required considerable input and face to face contact with the young person, and in one case contact with parents too (with the consent of the young person). It was felt that these cases would not have come to the school nurses' attention if it had not been for the texting service.

Throughout the pilot there was continuous steady use of the text service, thank you messages after the advice was given, and repeat text messages from same young people. A formal evaluation process with pupils also demonstrated that young people valued the having this flexible service, which they could access in a way that worked for them.

From British Youth Council Our School Nurse www.byc.org.uk/media/75447/byc_school_nurse_report_web.pdf



CIRCLES OF SUPPORT: HANNAH'S STORY

Hannah has all of her life decisions made for her by her circle of support, which consists of friends her own age, with and without a disability, family and professions. This ensures that good, well thought through and appropriate choices are made for Hannah and that it isn't just one person taking responsibility.

One of the important things about Hannah's circle of support is that it includes people of her own age, which keeps everyone mindful that she is a young woman. Getting the best life for Hannah is of paramount importance and by forming a circle of friends it spreads the responsibility and ensures that Hannah's best interests are kept at the focus of everything.

Further information on circles of support: See how to set up a circle and read about more examples of circles in practice at: www.learningdisabilities.org.uk/our-work/family-friends-community/circles-of-support





PROVIDING PERSONALIZED SUPPORT IN HOSPITAL: HARRY'S STORY

Harry is thirteen years old and has epilepsy as well as low functioning classical autism. Harry is non verbal and needs help going to the toilet. His behaviour can be unpredictable and if upset he can become violent. Harry has attended Birmingham children's hospital for many years. His family used to find visiting the hospital extremely difficult, as most of the hospital staff did not understand severe autism and how it affects people.

Their experience of visiting Birmingham Children's Hospital has dramatically improved, with the help of Raj Jhamat, the hospital's learning disability nurse. Raj has got to know the family and provides consistent support when they visit the hospital, as well as helping to make sure that other people involved in Harry's care understand him.

When Raj first started working with the family she visited them in their home to meet and get to know Harry. Now when Harry visits the hospital, Raj meets them at the hospital entrance and accompanies them around the hospital. She liaises in advance with hospital staff to help make Harry's visits go more smoothly. Outpatient appointments are arranged at the beginning of clinic, so Harry does not have to wait long to be seen. Raj understands and is used to working with children with severe autism and spent time getting to know Harry. She sits in with the family when they see the doctor, helps facilitate conversation and at the same time keeps Harry engaged in activities, to prevent him from becoming distressed. If he starts to become agitated she will take Harry outside to play. This helps his parents feel less rushed, and able to have a meaningful conversation with his doctors.

Raj also helped the family to fill out a care plan for Harry as well as a hospital passport. These have been extremely useful. When Harry has a seizure he often has to go to hospital A&E. The 'care plan' lists all his medications and gives information about other medications that need to be avoided as Harry has had a bad reaction to them in the past. The passport includes information for hospital staff on how to avoid upsetting Harry such as not getting too close, not looking him in the face, speaking calmly and trying to divert his *attention*.

Harry's mother says: "The hospital passport is amazing. It is simple, short and sweet and gets everything that needs to be said across in a very simple way. I don't just use it at the hospital – I use it everywhere I go, including school. It is so much easier to use this little book than the realms of notes that I used to carry around before."

To find out more about Birmingham Children's Hospital work to improve the hospital experience for children and young people who have a learning disability – see www.cafamily.org.uk/pcp/success





SUPPORTING HIV POSITIVE YOUNG PEOPLE TO CONNECT WITH THEIR PEERS: THE FREEDOM TO BE SUPPORT CAMP

Since 2010, the Children's HIV Association (CHIVA) has hosted a summer residential camp for around 100 young people aged 13-17 living with HIV. All of the participants who attend are HIV positive, and many of the camp leaders are older young people (18-24 year olds) who have previously attended the camp. Regardless of whether they have previously attended the camp themselves, all camp leaders are also HIV positive.

The camp lasts five days/four nights and includes workshops on issues related to growing up and living well with HIV, creative and outdoor activities which encourage expression and sharing this experience, as well as free time to build friendships.

An evaluation of the camp in 2013 showed it to be an extremely positive experience for participants, enabling them to increase their knowledge and understanding of HIV and thus enhance their ability to live well with HIV. Importantly, the camp also contributed to the formation and continuation of significant peer relationships that for some positive young people are akin to family. These relationships, and the wider camp experience, have facilitated an acceptance of HIV status as one part of participants' lives, rather than a limitation to future aspirations.

Much of the feedback from young people attending the camp related to having a sense of belonging and not feeling alone: *"being part of a family that are in your shoes"*. Other comments from young people included *"I learnt how to talk to people and I felt free"*, *"I have got to meet new people I can be honest with and talk about HIV with"*, *"making friends for life who know who you really are"*, and *"it's awesome to accept my status"*.

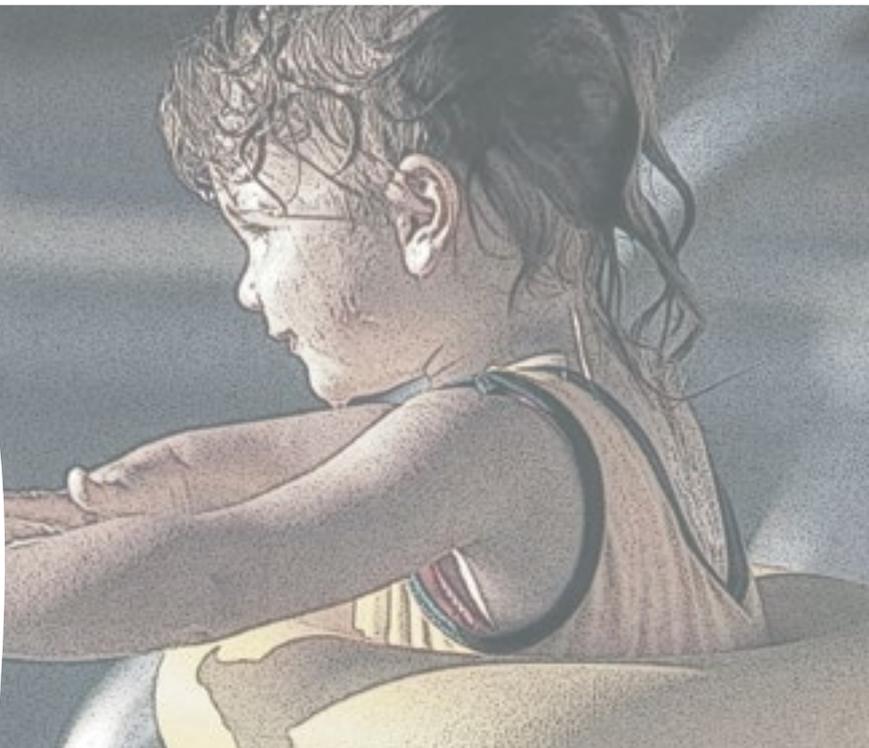
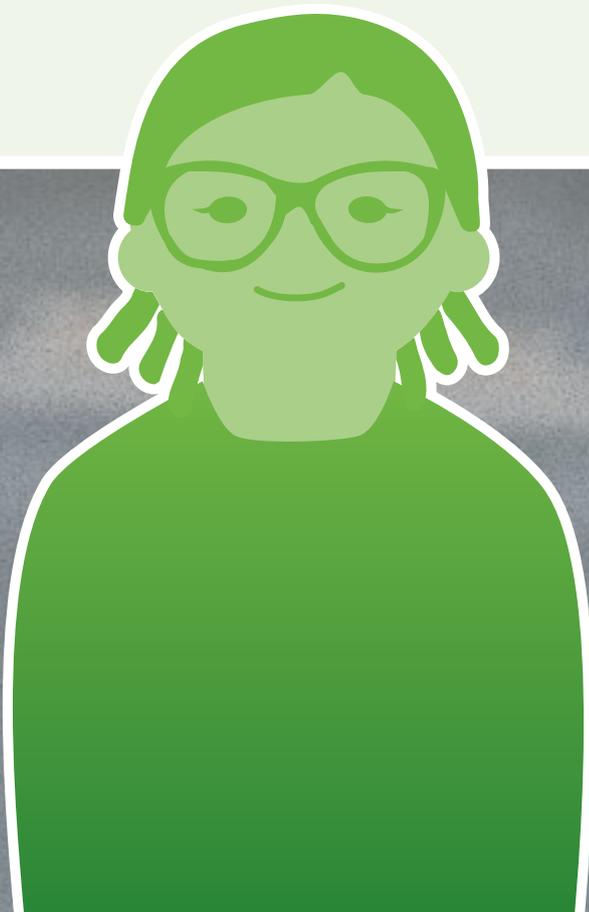
The camp is also a very positive experience for camp leaders and volunteers: *"For me the most thrilling part is taking a small step back and allowing the more experienced young people to take the newbies under their wings. By nurturing and peer supporting one another the young people will become empowered and blossom into adults who own their HIV status."* – Volunteer, Camp 2013.

For more information about the Freedom to Be support camp and plans for 2015, visit www.chiva.org.uk/camp/index.html



SUPPORT FOR THE PEOPLE WHO ARE IMPORTANT TO ME

- The people who are important to me feel the system is working with them. They don't have to fight for everything we need.
- The people who are important to me are supported too so we can all do the things that are important to us. This means things we do together as well as things we do on our own.
- I and the people who are important to me have:
 - a named professional, who coordinates all the support we need. We are not left to navigate the system on our own
 - the information and support they need
 - help to build skills, knowledge and confidence to help me
 - early support, not just when they reach breaking point
 - confidence that they are listened to and taken seriously when they raise concerns.
- I am supported to maintain relationships with people who are important to me.





KEY WORKER SUPPORT FOR THE WHOLE FAMILY TOWARDS THE END OF LIFE, CLIC SARGENT

When Corine was born in February 2009 all appeared well. She was a long-awaited daughter for Tricia and Lamar and they couldn't have been happier. She was a delightful child, with an infectious smile and a gentle temperament. However, when she was just two years old she appeared unwell and not at all herself and, after a long series of tests and interventions, Corine was diagnosed with Medulloblastoma (a kind of brain tumour).

Tricia and Lamar chose to have a series of treatments, which seemed to help Corine, but in 2011, when Corine was three years old, she relapsed. Tricia and Lamar, after long and distressing discussions with the practitioners working with them, chose the option of no further treatment and decided to take her home. With this decision made, a palliative care package was required. To put this into motion, Tricia and Lamar asked their CLIC sargent nurse (key working for the child and family) and consultant oncologist to meet with their GP, children's community nurse and adult district nurse for the area to inform them of diagnosis, treatment already provided and the family's decision to have no further active treatment.

Immediately on discharge from the hospital, the whole family had support from the CLIC sargent nurse on at least a weekly basis, sometimes with joint visits from the local team to enable a relationship to be established.

As Corine's condition deteriorated, further intervention was required. Over the next few weeks the CLIC sargent nurse visited Corine, Tricia and Lamar with the local team. They also set up teleconferencing in the home to allow maximum support to the family and the local practitioners, as the family identified what they wanted. On the occasions that the local team visited they would always talk together afterwards to ensure the support and care options discussed with the family were actioned.

The CLIC Sargent nurse felt that because of the relationship she had built up with the whole family and the local team Corine could remain at home. This was what Tricia and Lamar wanted, at least in part so that they could be with their three sons, Corine's older siblings, as well. Corine died within three months of her relapse and afterwards the whole family were very appreciative of the support they had had.

Following Corine's death, the CLIC Sargent nurse continued to provide key working support and liaising with the local team to ensure the family had support as long as they needed it. Despite the desperately sad situation, the whole family were impressed with the support that had been provided by this joint team, and felt that Corine had been given the best care possible.

Abbreviated from Early Support. (2012). Key working: improving outcomes for all. For more information got to www.councilfordisabledchildren.org.uk/what-we-do/networks-campaigning/early-support/key-working





TAKING A WHOLE FAMILY APPROACH: IMPROVING FUTURES, WORCESTERSHIRE

Improving Futures is a project funded by the National Lottery with some match funding from Worcestershire County Council's children's services. The project aims to work with 100 families from three of the most deprived areas in Worcestershire. It works with families experiencing difficulties and where universal services have failed (or are not being accessed), and where social services are not involved.

The project is built on partnership not only with families but also in its delivery with local voluntary and community organisations including EPIC Community Interest Company, Worcester Community Trust and Onside Advocacy. Each organisation employs two family workers who work alongside families. The project is managed by Vestia Community Trust.

The family workers and the project as a whole focus on family strengths rather than jumping in with solutions – allowing people to build on their assets to find their own solutions. The family workers stick with families and support them to make the most of the resources available in their community. Initially family workers may spend significant time with families, but as people find their own solutions, texting to stay in contact may take the place of more structured support.

Personal budgets are made available to families with a simple upfront allocation of £1,500 for every family. Personal budgets have proved really useful for practical things such as hiring carpet cleaners, washing machines and been most useful for buying 'specialist' support such as counselling. For one family which struggled to think of any positive memories, the budget bought them a trip to a safari park and a memory box to collect good memories as explained by one family worker:

"Following the trip I met with a very happy family who were brimming with smiles and happy memories of their day. Lots of photos were taken and a family trip to the library was made to download the images. The children had saved their wrist bands for the happy memory box. Mum reported that she had seen an improvement in the way in which dad had dealt with the children during the day trip and also in the following weeks."

By offering families early help to reach their own solutions, the hope is that families gain confidence to deal with any problems they face in the future – solving problems before they reach crisis point enabling families to quickly regain control and make lasting changes to benefit their children's futures. The approach works, as one family highlights: *"Usually we just get told what to do and always feel like we are being judged in some kind of way. But this one is completely different. We feel we have a say in what goes on and we get to make decisions, rather than being made to feel about one inch tall."*

Information taken from: Self Directed Support and Early Intervention by Tim Keilty In Control May 2014: www.in-control.org.uk/what-we-do/children-and-young-people/publications/children's-programme-publications/self-directed-support-and-early-intervention,-may-2014.aspx





WORKING TOGETHER TO SUPPORT PARENTS AND CARERS: CALDERDALE COUNCIL AND CALDERDALE PARENTS AND CARERS

In the early days of the Pathfinder, Calderdale Council commissioned the local parent carer forum, Calderdale Parents and Carers, to support young people and families to develop their education health and care (EHC) plans. This means that parents and carers with experience of developing person centred plans with their own children and young people are able to share their experiences and skills with other families, and help them to work out what is important to their young people now and in the future. The importance of this work has been recognised, and a new person centred planning workshop for parents has now been commissioned, which is designed to help parents plan for their child's future whether they have an EHC plan or not.

One parent described her experience on the person centred planning course as follows:

"Pre course my understanding of how we can support Maxwell was limited. In addition, the changes to support that Maxwell is likely to receive in school were, to put it frankly, a complex rubik's cube that was hard to solve! IEP, CAF, SEN, SENCO – all very complicated unless you are engrossed in the educational field.

"In terms of supporting Maxwell with his current day-to-day life, it has been challenging: often with Maxwell being the teacher of what works and what doesn't work. Often it is easy to forget that Maxwell has many qualities and his additional needs need not define him.

"The course was fantastic and left me engaged in terms of how Maxwell is going to be supported at school going forward; and, more importantly, how to support Maxwell in his everyday life and incorporate him within societal boundaries.

"The course unwrapped the educational changes; how support is currently given, and will be given going forward. The course armed us with how to work with school to support Maxwell. The one page profile was a great tool to explore and can be used in many situations to support a child."

Parents and colleagues from the Council also work in partnership to deliver 'Insider Guide Training' for parents. The course helps parents and carers to build skills, strength and confidence, to get relevant help and encourage further learning and achievement opportunities. It is divided into six weekly modules with two additional specialist modules to meet the specific needs of different target groups. The course has been widely praised by parents, carers and facilitators alike.

For further information about Calderdale's implementation of the SEND Reforms please contact AJGoulding@cpandc.org.uk or Julie.Killey@calderdale.gov.uk





CONNECTING CARE FOR CHILDREN, NORTH WEST LONDON

Driven by paediatricians at Imperial College Healthcare NHS Trust, with local GPs, commissioning leads and social care partners, Connecting Care for Children (CC4C) is a new way of working to make the expertise of paediatricians in hospitals much more widely available, and support GPs so that children can access the best possible advice and care within home and community settings.

There are three key components of the programme:

- 1) Public and Patient Engagement:** Young people and their carers are recruited as Practice Champions, volunteering their time to lead patient engagement and coproduction, enabling peer support and self-management, and ensuring GPs, acute clinicians and patients work together. Through training, they are empowered to be equal partners with the primary care team, and become the best advocates for the needs of their community.
- 2) Specialist Outreach:** Hospital paediatricians and GPs run monthly joint outreach clinics, together reviewing children with complex lives who would otherwise have been referred to hospital. A long term management plan is then put in place, to be led by the GP. The outreach clinics have had positive feedback from children and families: *"I hope it will continue like this – it's much easier and more comfortable because I know all the people at the GP"* (young person); *"seeing the doctor twice in outreach clinic meant my previous worries were reassured"* (parent). Cases are also discussed at monthly hub multidisciplinary team (MDT) meetings, and bringing together knowledge of different aspects of the child's health and wider family context means that care provided in both primary and secondary care is greatly improved. Each MDT session concludes with an interactive teaching set and reflections on learning for all involved.
- 3) Open Access:** A telephone hotline and a secure e-mail advice line are available for primary care professionals to contact a consultant paediatrician for advice. This improves communication and allows for supported management of children in the community setting, or a more directed referral, so that the child is seen by the right person in the right place first time. Children are also offered same day telephone consultations with a GP or senior practice nurse and same day appointments if required. One GP using the hotline said: *"It is a great service – the overall result is good and the patient gets advice from a first class specialist"*

Working through GP hubs of three or four practices enables CC4C to put the GP at the heart of the system, while reaching the largest possible population. Pilot hubs have already transferred 53% of new general paediatric hospital appointments to the GP practice setting and through the MDT work and open access delivered an additional 27% overall reduction in specialist appointments. There has also been a 32% reduction in hospital follow-up appointments and a 31% reduction in new sub-specialty paediatric referrals. The original pilot hub also achieved a 20% reduction in paediatric A&E attendances (compared with a 5% reduction in non-hub GPs).

90% of patients and carers said that having been seen in the outreach clinic within their registered practice they are more likely than before to see the GP for future medical issues in their children.

The Connecting Care for Children model is now included within the Commissioning Intentions of five of the eight North West London Clinical Commissioning Groups. For further information about Connecting Care for Children visit www.cc4c.imperial.nhs.uk, or follow CC4C on Twitter: [@CC4CLondon](https://twitter.com/CC4CLondon)





DELIVERING COORDINATED CARE AND SUPPORT FOR CHILDREN, YOUNG PEOPLE AND FAMILIES USING THE EARLY SUPPORT APPROACH IN CORNWALL

Early Support in Cornwall uses an integrated model of multi-agency delivery which involves families accessing a Team Around the Child (TAC) process. Support is available to all children and young people with special educational needs and disabilities (SEND) aged 0-19, although families usually have at least two services already working with them, because the intervention aims to broker a coordinated approach.

Cornwall has invested in a small team of Early Support coordinators and workers to support development of the approach in schools and across services, working closely with other additional support services for families in three local areas.

Children, young people and their families are able to contact the Early Support team for advice and guidance relating to a child's disability. Coordinators are able to support families in identifying and accessing appropriate services which the families can take control of coordinating, rather than following a TAC process, if the family chooses to do so.

Once a Team Around the Child process is initiated, which can be either by a parent or a professional, all professionals that are working with a child or young person are invited to attend a TAC meeting. This provides an opportunity for parents to have as many professionals working with their child in one place: reducing the need to repeat answers to questions and keeping everybody informed as to what is happening for that child and family. An Early Support Plan is then developed, based on the parents' and young person's priorities, with clear actions, including who is responsible and by what date they will be completed.

Families are also asked to choose someone that works directly with the child or young person and has regular contact with the family to act as their lead professional. This person will act as a single point of contact; and will liaise with other professionals on the family's behalf, help find out information for them, and review their Early Support Plan in between meetings to ensure all actions are being met. The lead professional should always be the choice of the family or young person: someone they feel comfortable with and trust.

Cornwall's approach enables a flexible response to children and families' changing needs, as Early Support Workers can work directly with families during key periods of transition or when there's a crisis, until they no longer need this support and can be handed back to their lead professional.

Managers are able to demonstrate that the Early Support approach taken in Cornwall reduces duplication by improving coordination and communication between professionals and agencies; targets service provision more effectively; and maintains a focus on outcomes. The Early Support team also support development of lead professional practice across the system, bringing about positive change in schools and other services. Early Support is perceived as cost effective, because the team developing the approach is very small, but the system as a whole prevents an escalation of additional need that would be significantly more expensive.

More in-depth case study information about the difference that Early Support is making in Cornwall is available on the Council for Disabled Children's website: www.councilfordisabledchildren.org.uk/what-we-do/networks-campaigning/early-support/case-studies. To find out more or contact the team, visit <http://cornwall.childrenguidancedirectory.org.uk/kb5/cornwall/fsd/site.page?id=pQWS3vQE5Zk>



MAKING CHANGES AND GROWING UP

At all stages of my life:

- I experience support and early planning for big changes such as:
 - from primary to secondary school
 - from one setting to another, such as returning to school after a hospital stay or moving between care settings
 - when there is a change in the team that works with me
 - starting college, university or work.
- I and the people who are important to me are supported to understand the changes in our roles and relationships as I get older or there are changes in my life.
- As I get older I may want to be supported by different people, or in a different way. My support changes to take account of this.
- I am supported to prepare for adulthood throughout my life.

As I move towards adulthood:

- Because we have been helped to plan ahead, I and the people important to me know what is going to happen when I reach adulthood, and how I will be supported.
- I am confident that I will be able to:
 - be happy
 - be respected
 - live a full, independent life
 - stay as healthy as possible
 - have a job, or other meaningful activity, which uses my full potential
 - have friends, and play a part in social groups and networks
 - still be able to access services if I need them.
- My preparation for adulthood includes thinking about new types of support that I might need, like support with housing and work, or support if my health gets worse.
- I am prepared for moving into adult services and I am supported to transfer when I am ready, taking into account other things that are happening in my life.

When I reach adulthood:

- I feel comfortable using adult services.
- Even though the services aren't the same, the level of coordination is.





EXTRACT FROM AN ACCOUNT GIVEN TO MPS BY A TWENTY YEAR OLD WITH A LIFE LIMITING ILLNESS ABOUT THE TRANSITION FROM CHILDREN'S TO ADULTS' CARE

Lucy became ill at the age of fourteen, and was diagnosed with Ehlers-Danlos Syndrome, or EDS, a few days after her fifteenth birthday. This is an extract of the speech she gave when she represented young adults with life-limiting illnesses at the Together for Short Lives parliamentary reception at Westminster on 19 November 2013, which describes her experience of preparing for transition to adult services:

"There is very little support for the life limited young adults. Decades previously many of us would not have survived childhood. We are no longer children in the medical and social definition, we are young adults, but adult services aren't equipped to deal with the wants and needs of young adults. Being ill at fourteen meant I started out on children's wards. Then I turned sixteen and my transition into adult services began.

"I am fortunate my transition into adult social care was a smooth procedure. About six months prior to my 18th birthday, I was introduced to the team that would take over my care, including my adult social worker and the transition social worker. They explained everything that was going to happen, how the change would affect us, and what would be expected of me as an adult. I felt comfortable and was encouraged to speak up and input what I wanted and how I felt about things. My views were of paramount importance and everyone was working hard to make my life as I wanted it to be. I got to know the people who would take over from the children's team in advance and as I got to know them and trust them it made the whole thing much easier. One of the things I struggle with is the lack of control in my life, so the things I can control are precious to me.

"I am supported by two young adult hospices; The J's Hospice, who are local to me, and Jacks place, which is a two hour drive away in Hampshire. Hospices look at you as a whole person, and my hospice team from The J's draw my care together, as I see a lot of specialists who only look at the particular area they're treating. Quality of life is of the utmost importance when you have a life limiting illness, as you want to be able to enjoy the time you have left.

"Although our bodies might be dying, our minds and spirits are fighting to live. I'm still a young person with wants, needs, hopes and dreams. I want to have fun and enjoy myself, do things people my age normally do, and I have plans and goals for the future. I have short and long term goals, so that I can achieve things in the short term and if I am lucky enough to live that long, achieve goals that will take time and patience. I like to plan things, but one thing I've learnt through my illness is to take one day at a time."

Lucy is one of Together for Short Lives' Young Avengers – helping to raise awareness about what young people need when they have a life-limiting or life-threatening condition. Together for Short Lives also lead the Transition Taskforce which works to break down barriers to good transition and build bridges between adult and children's services. To find out more, visit www.togetherforshortlives.org.uk/professionals/projects/transition_taskforce





HELPING YOUNG PEOPLE WITH ADDITIONAL OR COMPLEX NEEDS INTO EMPLOYMENT: SUPPORTED INTERNSHIPS IN HERTFORDSHIRE

Young people with additional or complex needs require alternative methods to help them find a job. Hertfordshire realised that work experience in a real employment setting is often not always available for young people in the county and that young people and their families don't always know that work is a possibility. They want to create more opportunities for employment, with good support, from much earlier and are using person-centred transition planning, with a focus on preparing for adulthood life outcomes, including employment, from year 9 while young people are in school to help raise aspirations.

In response to this, Hertfordshire created a small dedicated team of supported employment advisors (SEAs) to work with young people aged between 16 and 25. The SEAs are:

- Each working with a caseload of young people to support them to move into paid work.
- Linked to schools and colleges to get to know young people who need to be supported to get work experience in a real work setting whilst at school, or who are preparing to finish their college course.
- Working with young people to complete vocational profiles and to identify work experience opportunities to find out the areas of work they are interested in.
- Engaging with young people who have left college but have not yet found work and would benefit from support to access employment.
- Working with employers to raise awareness of the support they can provide and to identify job vacancies. They have been successful through using working interviews, rather than traditional interviews, to demonstrate what young people can do, to create real work opportunities.

Hertfordshire has also worked with colleges to develop a structured study programme that includes on-the-job training provided by experienced job coaches. The majority of the young person's time will be spent at the employer's premises and young people will be expected to comply with real job conditions. There will also be support for employers to increase their confidence in working with young people with additional needs to help them understand what young people can achieve and help them employ a diverse workforce.

This case study is taken from the SEND Pathfinder Information Pack Version 3, April 2014 – Preparing for Adulthood. May 2014. For further information and examples, visit: www.sendpathfinder.co.uk





FOCUSING ON LIFE OUTCOMES IN THE EDUCATION HEALTH AND CARE PLANNING (EHC) PLANNING PROCESS, LONDON BOROUGH OF GREENWICH

There has been a lot of thinking about life outcomes in Greenwich's Preparing for Adulthood work. All education health and care (EHC) plans include clear long-term outcomes such as 'When I leave education I want a job' or 'I would like to be friends with more people and when I am older to have a special friend or partner'. This has helped people develop medium and short-term outcomes as steps on the way to the long-term goals. It has also allowed planners to set educational targets in the context of young people's wider aspirations and to identify and allocate funding.

In Greenwich, professionals who wanted to take on the EHC Plan coordination role did more intensive training on planning for positive outcomes, identifying support needs and allocating resources, in addition to their key working and person centred planning training. These professionals then worked with young people and their families to complete the EHC Plans, and worked with the local authority to allocate and agree funding.

Regan, the brother of Cody, one of the young men involved, says *"Just because Cody is disabled, it doesn't mean he is different"*. Kelly, Cody's mum, says that developing the EHC Plan has given Cody a voice. She says *"Cody has been central to the planning. He has surprised us all with some of the things he has said he wants. This has not happened before. We have now been able to say clearly that we are planning for Cody to get a job, to live independently and to have friends. We are developing a vocational profile, planning work experience and looking at how his budgets can pay for this."*

Sourced from The Preparing for Adulthood programme, delivered by a partnership between the National Development Team for Inclusion and the Council for Disabled Children. www.preparingforadulthood.org.uk.

You can view film clips of the families talking about their experiences of the EHC planning process at: www.preparingforadulthood.org.uk/greenwich





WORKING ACROSS ADULT AND CHILDREN'S SERVICES TO SUPPORT THE FAMILY AS A WHOLE: JOSH'S STORY

Josh is 20 and lives with his mum, step-dad and two sisters. He has cerebral palsy and his youngest sister has Rett syndrome. The family has had direct payments for many years, but problems arose when Josh reached 18 because his funding became the responsibility of adult services, whilst his sister was still a child. This meant that his mother would have had to administer two different accounts and organise separate personal assistants to care for Josh and his sister at the same time. His mother said: *"Adult and children's services were not working together, not seeing the family as a whole"*.

Through taking a different approach and adult and children's services working together Josh and his sister now have a joint personal budget, which means that their mother only has one account to administer. Josh has a budget made up of funding from the NHS, social care and the Independent Living Fund and his sister receives direct payments. He attends a day service for young people three days a week and has a team of personal assistants supporting him on the other two days. Between them they have a team of seven personal assistants who provide flexible support to the family. Many of the team have known and worked with the family for many years. Having a coordinated personalised budget has given the family choice and put them in control, as Josh's mother said: *"It means I've got an ordinary life – I've gone to work and been successful in my job. At 20 Josh is still living at home. It means our own physical and emotional health is protected"*.

From An Ordinary Life. Foundation for people with learning disabilities. You can find more information on this project and see more stories at: www.learningdisabilities.org.uk/our-work/changing-service-delivery/an-ordinary-life/





THE ROLE OF KEY WORKING SUPPORT AT TRANSITION: GRETA'S STORY

Greta is 18 years old and she is very keen to be independent. She loves animals and has aspirations to work with them in some capacity.

Greta was identified by a voluntary agency for support around independent living and further education, to help her to achieve her aspirations to work with animals. She had issues with family relationships breaking down and was becoming increasingly isolated. She has cerebral palsy and some issues with learning. When she was referred to the key working service she was residing with her stepfather, but this placement broke down. Greta moved regularly between short break and supported lodgings placements until a place was found at a supported living establishment for people with learning disabilities.

The key working service provided Greta with emotional and practical support, and helped to build her confidence and self esteem. It was important for Greta to have support from practitioners whose goal was to support her to become confident and independent – she had many strengths that could be utilised.

Greta was given a wide range of information to enable her to make informed decisions and achieve her goals, and was able to access advocacy for herself at meetings wherever she requested this. The service made referrals to other services and support to help with health and social care needs, including the adult care management team, the Community Matron for Transition and the Community Team for Learning Disabilities. They also introduced Greta to a local college that offered the qualification she was looking for together with additional support to help her achieve it.

Greta now lives independently and manages her own health care and appointments. She has the confidence to advocate for herself and knows who to go to when she does need extra advice. She is in college, with additional support from a Learning Support Assistant, to study for a level 2 National Vocational Qualification (NVQ) in animal care.

Abbreviated from Early Support. (2012). Key working: improving outcomes for all: www.ncb.org.uk/media/847692/key_working_position_paper_final_november_2012comp.pdf. For more information about key working, visit www.councilfordisabledchildren.org.uk/what-we-do/networks-campaigning/early-support/key-working





HOLISTIC SUPPORT FOR YOUNG PEOPLE: THE MANCROFT ADVICE PROJECT (MAP), NORWICH

MAP opened in 1991 and delivers a range of direct services to around 1,000 young people in Norfolk every month. The service is specifically targeted at young people aged 11 to 25, and can offer support with a wide range of issues that they may experience as they prepare for adulthood, including housing, employment, money, sexual health and relationships.

The key entry route to MAP is through its daily Drop-in service. Its main premises in Norwich and Great Yarmouth provide a space where young people can simply hang out with internet access, refreshments and telephone access to contact other services. Should they want to speak to someone at the project or have a need for professional support, young people have ready access to trained MAP staff and a range of specialist services, including:

- A Therapeutic service, staffed by a team of qualified and experienced counsellors, Wellbeing Advisers and Youth Mental Health Workers offering interventions from one-off 'crisis' sessions and brief guided and supported self-help work to group and one to one therapy.
- An Advice service providing expert help on rights-based issues, such as welfare benefits and housing
- A specialist Money Advice service offering money 'health checks', help with opening bank accounts, budgeting and dealing with debt
- A Housing Team that provides specialist advocacy, mediation and support and undertakes homelessness prevention work
- A Social Work practice working specifically with 16/17 year olds who are either homeless or in danger of becoming homeless
- A Youth Work service offering positive activities and participation opportunities – all aimed at enabling personal and social development, helping young people to lead safe and healthy lives, and building positive relationships in their communities
- A comprehensive Sexual Health service, including C-Cards, Chlamydia and gonorrhoea screening, pregnancy testing, pregnancy support and an accredited 12-week sex and relationships course
- Professional help around a wide variety of other issues, including drugs and alcohol, relationships and writing CVs
- Group-work with specific groups of young people needing support, including young parents and transgender young people.

For further information about MAP, visit www.map.uk.net

This case study was adapted from the Youth Access and Young People's Health Partnership briefing, 'Making Integration a Reality Part 2: Developing effective holistic services for young people in transition'.

For further details visit www.youthaccess.org.uk/uploads/documents/Making_Integration_a_Reality_Part_2_FINAL.pdf



APPENDIX ONE: CONTEXT TO OUR DEFINITION OF AN INDEPENDENT LIFE

In developing our definition of 'an independent life' we drew on the concept of 'Independent Living' which sets out principles of equality, dignity and freedom.

In the context of disabled people's rights, the Independent Living Movement has identified 'twelve pillars of independent living', which outline some of the kinds of support that may be required to achieve it.

THE TWELVE PILLARS OF INDEPENDENT LIVING

- 1) Full access to the environment
- 2) A fully accessible transport system
- 3) Technical aids – equipment
- 4) Accessible/adapted housing
- 5) Personal assistance
- 6) Inclusive education and training
- 7) An adequate income
- 8) Equal opportunities for employment
- 9) Appropriate and accessible information
- 10) Advocacy (towards self-advocacy)
- 11) Peer counselling
- 12) Appropriate and accessible health care provision



APPENDIX TWO: WHO WROTE THIS WORK AND WHAT INFORMATION AND MATERIALS DID WE USE TO HELP

WHO WROTE THIS WORK

National Voices and Think Local Act Personal (TLAP) wrote this work with members of TLAP's National Coproduction Advisory Group who have personal experience of issues affecting children, and young people with complex needs and their families, and the Council for Disabled Children. Other organisations have also been involved, including ADCS, Contact a Family, Diabetes UK, In Control, LUPUS UK, NCB, the Young People's Health Partnership, NDTi, the National Network of Parent Carer Forums, and Together for Short Lives.

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- Personal stories from children, young people and families (both written and filmed)
- What Good Integrated Care Looks Like in Transition, NNPCF Steering Group, August 2013
- Disabled Children's Manifesto for Change, EDCM/Making Ourselves Heard, 2009
- Outcomes – young people's perspectives from the POET project, In Control
- Preparing for Adulthood resources www.preparingforadulthood.org.uk
- Trendsetters Guide to Life, Scope
- 'If I could change one thing...' Children and young people's views, EDCM, 2007
- 'What we say we need' A report on the important items, opportunities and aspirations for children and young people, Office of the Children's Commissioner, November 2013
- The Entitlements Inquiry: report with recommendations, APPG for Looked After Children and Care Leavers, November 2013
- The YoungMinds Children and Young People's Manifesto for Change, YoungMinds
- Young Campaigners' Charter for child and adolescent mental health services, National Autistic Society, 2011
- Report on consultation workshops on how to improve health and care services for children and young people, NCB, September 2013
- Don't let me down: ensuring a good transition for young people with palliative care needs, Together for Short Lives/Marie Curie
- Reach: Support for living an ordinary life standards, Paradigm
- UN Convention on the Rights of Children and Young People
- UN Convention on the Rights of Persons with Disabilities



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