

Y&H Children's and Maternity Strategic Clinical Network

Transition of children and young people (C&YP) to adult services

Contents

1. Introduction
2. Key National Documents
3. Y&H SCN Themes and Key Principles of Transition Review
4. National Drivers
5. National Transition Work and Groups
6. Local Transition Work
7. Y&H SCN Provider and CCG transition stocktake
8. Y&H SCN Recommendations and Next Steps for Transition.

Appendices 1 Lucy's Story

1. Introduction

In 2010 Sir Ian Kennedy shared his concerns that transition, 'long the cause of complaint and unhappiness'¹ was a critical area for service improvement, as services were failing to meet the needs of young people.

Advances in health care and improved quality of services means that children and young people are living longer with serious illness, chronic conditions and disabilities and will require ongoing care and support into adulthood. Children and young people need to be prepared and supported to live healthy and fulfilling lives.

The recent CQC report (2014) calls for changes in the commissioning of services and 'describes a health and social care system that is not working, that is letting down many desperately ill youngsters at a critical time in their lives.'² (Professor Steve Field, Chief Inspector of Primary Medical Services and Integrated Care)

Transition for children and young people can often be abrupt, fragmented and in some cases doesn't take place at all.

Poor transition may result in CHYP missing vital appointments, non-compliance with treatment, medication and less successful self-management, leading to potential crisis in their condition.

This has implications for the long term health and wellbeing of CHYP and their future aspirations and overall quality of life.

'Poor health makes it harder for young people to remain in education and training, play a full part in their communities and realise their potential.'

What is Transition?

Transition is a coordinated, planned and supportive process that enables young people to gradually move from Children's Services to Adult services.

Supporting young people during transition can be a challenge to commissions and providers. This is because the process must be person centred and focus on the individual needs and aspirations of each young person.³

Effective transition will empower children and young people to take ownership of their health and understand their condition, feel confident to seek help, advice and understand any changes in their care.

¹Getting it right for children and young people, overcoming cultural barriers in the NHS so as to meet their needs (2010)

²From the Pond into the Sea (2014) CQC

³A Transition Guide for all Service (Department for Children, schools and Families/DH 2007)

The needs of Parents and Carers must also be assessed and taken into account during the transition process.⁴ Parents and families must feel supported and confident to understand the transition journey and the implications this has for their child's future.

Therefore transition must be undertaken with an all-inclusive, integrated family approach, delivering support that focuses on the young person and their family rather than services, policy and structures.

Successful transition for CHYP and their families is crucially dependent on collaboration between children's and adult services⁵ and health and social care.

Transition can often be very challenging, complex and difficult to navigate and often 'compounded by young people's moves from one service to another at different ages. For example, a young person may move from paediatric to adult health services at 16, then at 18 moves from children's to adult social care. This is alongside the transition stages in their education. Each of these transitions is likely to occur independently of each other, which means that young people and their families may repeatedly have to deal with new agencies and professionals, re-telling their story each time.'⁶

Throughout the transition process, all agencies have a responsibility to work together⁷ and must develop a joined up approach which includes CHYP and their families to plan transition and enable CHYP to reach their potential in all aspects of their lives.

Commissioners and organisations across the whole health and social care system must work together to respond and meet the needs of these children and young people as they transition from children's to adult services.

Transition of children and young people (C&YP) to adult services was identified at the engagement event for the Children's and Maternity Strategic Clinical Network (SCN) in September 2013 as a priority for stakeholders across Yorkshire and the Humber (Y&H). This priority was endorsed by all 24 CCG's across Y&H and has therefore been included on the Y&H Children's and Maternity SCN's work programme.

This report will provide an overview of transition.....

⁴From the Pond into the Sea (2014) CQC

⁵ Transition: getting it right for young people - Improving the transition of young people with long term conditions from children's to adult health services (DH 2006)

⁶ A Transition Guide for all Service (Department for Children, schools and Families/DH 2007)

⁷ Moving on Well (DH 2008)

2. National Documents

Date	Author	Title	Description	Link
2014	CQC	From the Pond into the Sea	The findings from the CQC recent review show that young people with complex health needs do not always receive the necessary care and support when they move on to adult care services.	http://www.cqc.org.uk/content/teenagers-disabilities-and-long-term-health-needs-lack-appropriate-support-they-approach
2014	NHS England (Still in Draft)	Generic Specification for Transition	Specification insert; Generic Specification for Transition. Generic specification to support young people in the transition process from paediatric to adult specialist health care services	Not available on line
2014	NICE	SCOPE ONLY - Draft Guidance	The draft scope is out for consultation with stakeholders.	http://www.nice.org.uk/Guidance/InDevelopment/GID-TRANSITIONCHILDRENSADULTSERVICES
2014	University Hospital Southampton	Read, Steady, Go	Ready Steady Go transition programme for parents and children over 11years old with a long-term medical condition. A programme to help CHYP get ready and feel confident to move to adult services around 18 years of age.	http://www.uhs.nhs.uk/OurServices/Childhealth/TransitiontoadultcareReadySteadyGo/Transitiontoadultcare.aspx
2013	RCN	Lost in Transition	Guidance from the Royal College of Nursing about managing young people's transition to adult services.	http://www.rcn.org.uk/_data/assets/pdf_file/0010/157879/003227_WEB.pdf
2011	DH	You're Welcome. Quality Criteria for Young Persons Friendly Services	'You're Welcome', sets out principles to help commissioners and service providers to improve the suitability of NHS and non-NHS health services for young people.	https://www.gov.uk/government/publications/quality-criteria-for-young-people-friendly-health-services

Date	Author	Title	Description	Link
2010	Professor Sir Ian Kennedy	Getting it right for children and young people. Overcoming cultural barriers in the NHS so as to meet their needs	The review concentrates on understanding the role of culture in the NHS. It focuses on those areas where there are cultural barriers to change and improvement. It examines the NHS's position in a wider system of care and support, so as to understand and improve the NHS's provision of services to children and young people.	https://www.gov.uk/government/publications/getting-it-right-for-children-and-young-people-overcoming-cultural-barriers-in-the-nhs-so-as-to-meet-their-needs
2008	DH	Moving on Well	A good practice guide for health professionals and their partners on transition planning for young people with complex health needs or a disability.	http://www.bacdis.org.uk/policy/documents/transition_moving-on-well.pdf
2006	DH	Transition: getting it right for young people - Improving the transition of young people with long term conditions from children's to adult health services	This good practice guide aims to bring together current understanding and knowledge on the subject of transition between paediatrics and adult services.	https://www.bspar.org.uk/DocStore/FileLibrary/PDFs/Transition-%20getting%20it%20right%20for%20young%20people%20-%2023rd%20March%202006.pdf
2003	DH	National Service Framework hospital standards	This document sets a standard for the care of children and young people when they are in hospital.	http://www.nhs.uk/nhsengland/aboutnhsservices/documents/nsf%20children%20in%20hospitalldh_4067251%5B1%5D.pdf

3. Key Principles and Themes of Transition.

Y & H SCN at the request of the National SCN Forum to reviewed all key national reports and documents in order to develop a set of ‘common themes and principles’ from the evidence.

As a result two documents have been produced identifying the Key Themes and Principles of Transition.

The Key Themes and Principles are:

1. Commissioning (including Funding/Budget)
2. Integration & Multi Agency Working (including Local Authority, Social Care and Mental Health Services)
3. Transition Process and Transition Plan
4. Involvement of CHYP, Parent & Carers, including Self-care, Social Media and other methods
5. Professional and Workforce Development
6. Health Settings and Services, including primary care.
7. Guidance and Protocols
8. Quality, Data, Performance and outcomes (including CHYP Service experience measures)
9. Communication and Information

4. National Drivers

NHS Outcome Framework Domains	<ul style="list-style-type: none"> • NHS Outcomes Framework* • NHS 2.3.ii - Unplanned hospitalisation for asthma, diabetes and epilepsy (under 19s). • NHS 4 - Improving Children and Young People’s Experience of healthcare
CCG Outcome Indicator Set	<ul style="list-style-type: none"> • C 2.7- Unplanned hospitalisation for asthma, diabetes and epilepsy (under 19s).
Public Health Outcomes Framework	<ul style="list-style-type: none"> • Domain 1: Improving The Wider Determinants Of Health
NHS England Business Areas	<ul style="list-style-type: none"> • Prevention and early diagnosis (1) • Patient experience (4) • Equality and health inequalities (8) • Citizen participation and empowerment (19) • A modern model of integrated care (21)
Better outcomes for children and young people: our pledge (2013)	<ul style="list-style-type: none"> • The need for integrated care with a positive experience of transition to adult services. (Pledge 4)
NHS England 0 Five Year Forward View	<ul style="list-style-type: none"> • Empowering Patients • Engaging Communities • Integrated Care

5. National Work

CYP Transition – National Working Group

CYP Transition to Adult Services is one of the six priority work streams of Dr Jacqueline Cornish, National Clinical Director (NCD) Children Young People & Transition to Adult Services.

The CYP Transition National Working Group, chaired by the National Clinical Director for CYP/Transition, comprises of representatives from SCNs, CCG Leads (clinical and commissioning working on Transition for LTC, CAMHS or LD & SEND) and Local Authorities and is the national vehicle for refining the adaptation of the specialist transition service specification for non-specialist services.

As part of the commitment to lead improvement in transition planning for Children and Young People, an NHS England Clinical Commissioning Group [CCG's] engagement event was held on 2 April 2014 bringing together CCG leads with responsibilities for children and young people services, maternity services and children and adolescent mental health services [CAMHS]. A key outcome from this first event was an agreement to establish three themed working groups who would meet collectively for the first time in October 2014.⁸

The three newly formed working groups were brought together at a meeting that took place on Tuesday 7th October 2014. A total of 70 attendees from 11 Strategic Clinical Networks and CCG's across NHS England were represented along with additional representation from local authorities, social care and voluntary sector.⁹

A Summary Report of Outputs has been produced from this event and includes:

1. The overwhelming messages from all three groups were to recognise the need to :-
 - Enhance and improve engagement with adult receiving services
 - The importance of engaging commissioners, specialist commissioners, clinical commissioning groups, primary care, education leads and local authorities
 - Active engagement of parents, carers, families and young people in decisions about their care
2. Summary of agreed actions National and Local:

National Action

- Consider creating a central repository for all relevant resources including evidence based practice, policies, guidance, improvement models and tools so that commissioners and providers can be signposted to them quickly and with easy access
- Give consideration to the development of a CQUIN for transition for children and young people across NHS England for 2015/2016
- Explore what action can be taken nationally to actively promote the pooling of budgets where this is in the best interests of service users and their families
- Develop a set of clear quality indicators for all three areas linked to improving transition
- Set up three virtual working groups and provide support at a national level
- Set up some sessions on webinars / teleconference and provide training in these tools for the three working groups
- Consider how personal budgets can be used as a lever for change across all three specialities
- Identify knowledge and leadership skills gaps across commissioners and providers and seek to build additional capability in the system in collaboration with the three working groups, Health Education England and other partners including NHS Leadership Academy

⁸ Summary Report of Outputs November 2014, CYP Transition for Commissioners, Providers and SCNs Event held on 7th October 2014

⁹ Summary Report of Outputs November 2014, CYP Transition for Commissioners, Providers and SCNs Event held on 7th October 2014

National Action continued...

- Develop and implement an improvement capability plan in collaboration with Health Education England and the Leadership Academy which can meet the needs of staff within a realistic timescale
- All workshop participants to forward any good examples / documents / specifications etc to the NHS Improving Quality team for circulation more widely to further promote learning and sharing
- Raise awareness of the three working groups and their remit across the health and social care system to encourage further collaboration and joined up approaches in the interests of service users
- Work with Monitor and NHS England to address financial constraints and pricing issues
- Explore how at a national level we can further influence the importance of GPs to play a co-ordinating or shared care role in transition for children and young people
- Share the current iteration of the proposed NHS England Joint Commissioning Guidance widely including signposting CCG's to the guidance and their responsibilities with regard to transition across services for Children and Young People. Working with all partners including social care, charities and education to achieve a common aim and shared purpose of improving services at the point of care for the child or young person.
- Continue to develop the commissioning guidance and the strategic direction at a national level with a focus on improved outcomes for children, young people and their families.
- Collectively identify the national system levers for change and raise awareness of these so that everyone across NHS England can explore how they can support local plans to improve/change services in the interests of patients and service users. Identify collectively the opportunities for change using CQUINS, QOF for example.
- Consider nationally how the three groups can influence the Integrated Inspection and Regulation process as a lever to improve transition from Children and Young people Services to Adult Services. Build relationships with the Care Quality Commission to achieve increased influence and integration.
- At the national level explore how improved data quality and use of technology can be utilised to support an improved transition process for all children and young people across NHS England.

Local Action

- The three working groups to raise awareness of the national actions at the local level including sharing outputs from the day
- Provide feedback on any documents or good practice shared at the workshops to the three working group leads
- Actively support and participate in the three virtual working groups going forward
- Explore whether pooling of budgets can be agreed or tested out at the local level
- Develop an action plan at the local level that builds will and a commitment to increased collaboration with key partners such as education, GPs, charities, local authorities and Health and Wellbeing Boards
- Identify local training needs and work nationally and locally to address these needs
- Explore locally whether the South West dashboard which uses generic principles to measure services would be a helpful tool. These principles could form components of a transition checklist and applied to local services to define "what makes a good transition?"
- Explore whether the 'Southampton Ready Steady Go' and Islington good practice for transition example can be adapted at the local level
- Develop relationships at the local level with Public Health England

4. Details from individual Workshop discussions:

CAMHs- Summary answers from the session	
<ul style="list-style-type: none"> Using personalisation is key as a lever for change Reduce the funding blocks/disaggregating blocks Use system modelling tools to support service commissioning and change Co-commissioning pathways Identify key indicators for quality Share information on a 'boot camp' for commissioners to give appropriate training eg 'CAMHS commissioning for commissioners' Needs to be training on transition specifications Elicit feedback on specifications shared central CSU have been commissioned to develop a visual system dynamic model that will be created using information from a range of care pathways – anyone interested in getting involved at a local level for CAMHS please contact 	
SEND and LDs - Summary answers from the session	SEND and LDs - Actions Next Steps
<ul style="list-style-type: none"> Good care planning is needed Paediatrics are not preparing children and then blame adult services We commission adults and children's services separately so there is no money to shift Care Act and Children and Families Act – no interface We need to commission children's services to promote empowerment and independence Involving GPs 	<ul style="list-style-type: none"> Form a virtual group Implement a Transition Plan with a named professional Influence GPs to help get them involved There are 200 pieces of guidance around the Children and Families Act – provide one central repository Meet together twice per year
Long Term Conditions - Summary answers from the session	
<ul style="list-style-type: none"> The group recognised that currently services were more often designed for the organisation or service and perhaps were not as fit for purpose for the young person or patient Important to have a young person's values approach and identify the levers that increase the opportunities for a joined up approach rather than fragmentation. Need a joined up approach across agencies and work with parents to give them the confidence for supporting their child as they transition to adult services in a very empowering way. It is important that all services focus on goals and outcomes that are important to the young person and their family. Important we promote independence of the young person and that we have adult services involved earlier in the transition process 	

Long Term Conditions - Summary answers from the session

- Existing culture of staff along the care pathway including over professionalization needed to be addressed at every level of the services so that the needs of the young person or patient can be enhanced.
- What can we do collectively to address 'professional protectionism' so that we can smooth the transition process? Need to work together to identify and address the 'wicked issues' and resolve these for the benefit of the patient/young person.
- Working collectively at a national level to achieve a shared vision across the whole care system involving all stakeholders would be an important area to make progress in.
- One of the challenges was to encourage professionals to look at the needs of the child or young person rather than just through a 'disease specific lens'.
- Professionals needed to utilise available data and technology available to ensure the young person or their family had a clear and complete record of their treatment and understanding of what has happened to them. Can this be easily accessed by children and adult services
- Work collectively to capture good practice and share these examples widely with the three groups such as:-
- Examples of good co-ordination at the service level that prevents a young person or their family falling through the gaps?
- Share widely work at 'Southampton on Ready Steady Go' approach with the three groups
- The good practice that exists in primary care Islington
- Give consideration to joint secondary/primary care as way forward perhaps

SCN Transition Forum transition

The SCN Transition from Children and Young People to Adult Services Forum (SCN TF) is a national platform for SCNs to share knowledge and promote learning. The SCN TF will focus on opportunities to improve health services – mental health and physical - which have an impact on children and young people, young adults and their families/carers.

The SCN TF will bring together expert knowledge to share learning on what good services look like to improve health care for the local population now and for future generations. The forum will aim to promote best practice and share experience and coordinate programs where applicable.

The SCN Transition Forum was established to work as a cohesive group to share approaches in relation to Transition Services and to support the delivery of the national CYP agenda and when appropriate will support the work and provide evidence for the CYP Transition – National Working Group.

National Diabetes Working Group - Update

The National Working Group for Diabetes is chaired by Jonathan Valabhji National Clinical Director for Diabetes. The current work of the group includes:

- Models of Innovative Practice - Examine models of innovative practice and link with best practice tariff.
- User Engagement – both young people engaged with clinics and those that are disengaged.
- Literature Search - to identify what work has already been done around young people and diabetes and specifically work around the 16-25 age group
- Look at what is happening locally around the Region.
- Specification – using the Specialist Specification for a generic specification re: Diabetes.

6. Local Work

Leeds Teaching Hospital Trust

The Y&H SCN are supporting Leeds Teaching Hospital Trust to develop their transition programme, providing knowledge and insight to guide and inform service development across the Trust.

This includes:

1. Attendance at the Transition Strategy Board to establish a work programme
2. Attendance at the Transition Forum
3. Attendance at appropriate transition task and finish group process
4. Developing a stocktake of transition for CSU's in the Trust
5. Provide evidence to support the work programme
6. Support the development of standard documentation to be used Trust wide

Learning and good practice from the LTHT programme will be presented at the Y&H SCN Transition Task & Finish Group.

Sheffield Children's Hospital

Will get a summary from Rachel Tattersall

7. Stocktake

The Y&H SCN have undertaken a stocktake of Transition Services across the region for Clinical Commissioning Groups and Provider Trusts.

CCGs

I will Insert a brief narrative of findings here and include results in appendices

Provider Trusts

I will Insert a brief narrative of findings here and include results in appendices

8. Recommendations & Next Steps

This section will need expanding after further discussion with Emma, Emm, Fiona and Rachel

- **Transition Event**
 - For all providers and commissioners across the health and social care system.
 - Introduction and context: What happens if we do nothing? Drivers, National/Local context...
 - What are the priorities?
 - What are the Challenges?
 - What does good look like?
 - Outcomes and Benefits?
 - What would we want from a task and finish group?

- Transition Task & Finish Group
- Develop a vision for transition

Emmerline Irving
Quality Improvement Lead (Children)
Y&H SCN
November 2014

Amendment History

Version	Date	Amendment History	Initials
0.1	17/11/14	First draft for comment	EI
0.2	04/12/14	Emm Irving – Added Appendices 1: Lucy’s Story	E1

Appendices 1: Lucy's Story - SEND, Transition and Outcomes for Young People

Source: <http://www.lucy-watts.co.uk/2014/09/send-transition-and-outcomes-for-young.html?m=1t> Tuesday, 30 September 2014

The transition period is a difficult time. Young people have enough going on in their lives, so to be poorly and/or disabled just adds another dimension. Then when you factor in the change from children's to adult's services, it's a huge ordeal for them. Whether they've been disabled/poorly from birth, or conditions have presented themselves later on in childhood or into the teenage years, a good transition and all agencies (and different departments within these agencies) working together are vital. The individual needs to be at the centre of this, their views, needs, goals and dreams forming the basis of their care. The Special Educational Needs and Disabilities (SEND) reforms and the introduction of (Educational Health and Care) EHC plans aim to improve multi-agency communication and improve the experience for young people - including during the transition period.

I became unwell in January 2008 aged fourteen. I had been receiving physiotherapy at my local hospital for over a year and had been cared for by a range of different services including gastroenterology, orthopaedics, burns and plastic surgery. However all my problems deteriorated rapidly (after a slow decline from the age of ten) and suddenly we were thrown into the world of hospital admissions, scans, tests, wheelchairs, disabilities and social services. I started using a wheelchair but couldn't cope with going anywhere due to the pain of bumps and uneven ground. So leaving the house became so difficult and problematic I was virtually housebound. My education was non-existent as my school neglected to send work home or me or fill out the paperwork necessary for me to receive home tuition through the Children's Support Services despite my desperation to continue my education. I loved my schoolwork and couldn't understand why barriers were being used to stop me learning. If I had been expelled I would have received tutoring, but because I was sick it took three months of fighting to get any home tuition. When the Children's Support Services took over, I thrived on working towards my future.

After going from person to person and having test after test we were given the name of a specialist who would go on to diagnose me with Ehlers-Danlos Syndrome in October 2008, just days after my fifteenth birthday. I'd had months of people telling me I was fat and lazy, that I had a school phobia and was attention seeking, so to have a name for my condition and an understanding Professor who listened to me was a breath of fresh air. Unfortunately a consultant from the team led by this Professor called a meeting of the agencies supporting me and suggested that I shouldn't do my GCSE's, I should just focus on my rehabilitation as all I had was chronic pain and mum was allowing my illness behaviour. Despite working together with the Professor, he claimed Ehlers-Danlos didn't exist. He suggested forcing me to sit up saying I was lazy when actually I had Postural Orthostatic Tachycardia Syndrome, which was subsequently diagnosed in 2010. He also claimed my gut problems were in my head and I didn't need a feeding tube; fortunately I was later referred to the world expert on gut problems caused by EDS who diagnosed me with severe gut dysmotility/Chronic Intestinal Pseudo Obstruction. However I fought hard and completed my GCSEs in 2010 achieving an A* in Sociology, A's in English, Biology and Physics, B's in Maths and Chemistry, a C in French and two distinctions in IT.

I was deteriorating rapidly over the course of 2009, I now couldn't eat and was bed bound. In September 2010 I started going to college for an hour per day - sitting me up for as long as I could cope, and I proved all the doubters wrong. Unfortunately I only managed a term and a half in college before I became too poorly. I was very ill, the hospice were involved and my doctors were running out of options - we had tried almost everything. I had previously been started on enteral feeds via an NG tube in August 2009, having my PEG fitted in October 2009. My gut was failing miserably and I was not absorbing these feeds. As a last

resort I was started on TPN - intravenous nutrition - in May 2011, and had an Ileostomy formed in February 2012.

All along the way we faced problems and barriers, and fell into many loopholes. We had to fight for everything. My grandparents stepped in and paid for a stairlift in our old house because the waiting list was 18 months and I had no choice but to sleep in our open plan living space when I could no longer walk. We borrowed funds to purchase a rise and recline chair. We were provided with a grab rail through the Occupational Therapy Department in our toilet, but were only entitled to one. I couldn't pull myself up with one, so had to have the other one fitted privately. We had to fundraise for an electric wheelchair that reclined in 2011 because an assessment couldn't be made for an electric wheelchair until we had ramps in the property. However, the funding through Social Services had all been allocated for that year and we would need to wait until the following year (another 12+ months) to see if a grant would be made to provide ramp access to our bungalow. We regularly paid for private care at times to get what I needed. We had to fight for my education, fight for my treatment, fight for a pressure mattress and profiling bed, fight for my Social Services budget; a fight for so many things when the struggle to cope with me being ill was difficult for us as a family.

So much of our problems would have been avoided if agencies communicated and worked together. Part of my educational problem was that the school didn't see the point in statementing me. Had I been given an EHC plan, things would have been so much easier and drawing together all of my care would have stopped us having to play piggy in the middle. If only people had communicated, worked together and kept my wants and needs at the centre of my care, things would have been so much easier.

When I reached 19 my treatment from the consultant who inferred that "EDS doesn't exist" came to an end as he worked in the adolescent unit. By this stage my health had deteriorated so much I almost had an apology from him - he said he felt the medical profession had failed me! Under the medical team I now had around me, my care rapidly improved. My transition was not the best. It was hard and frightening going from being on a children's ward with my mum there all the time making decisions for me (and a paediatrician who would not talk to me or take into account what I had to say) to being on an adult ward with five dementia patients, mum only allowed in for visiting time and suddenly I was having to make my decisions by myself for the first time in my life, and life-changing decisions at that; it could have been better. I went through a host of big changes around that time (between the ages of sixteen and eighteen), getting a whole new team of doctors - adult doctors, transitioning over to adults services, starting college, fundraising for the electric wheelchair, my health deteriorating rapidly, multiple hospital stays, my weight dropping to under seven stones and being started on TPN, being forced to give up college due to my health and then having my Ileostomy formed....it was a hectic time.

Suddenly my care came together, education, the NHS and Social Services all working together to achieve the lifestyle that I wanted and aiming for the goals I had set myself. Yes I was still bed bound for the majority of the time, yes I was still deteriorating - and quite rapidly at that - and yes I had to give up college but life was on the up. This is the aim of the SEND reforms and EHC plans - bringing all the services together to work as part of a team and having the needs, goals and wishes of the children and young people at the centre of their care.

Look at my life now: it's not perfect, I'm very poorly and deteriorating and not in education at all but I am making a difference by writing and speaking and giving back to the services that have supported me. Things I have said and done are making an impact on the world (well, the UK). My doctors of various specialities, hospice nurses and carers, district nurses, continuing health professionals, personal health budget, wheelchair services, the voluntary/charitable sector and all others involved in my life are working together,

all with my quality of life, goals and wishes as their focus. It's taken seven long years of being poorly to reach this point, and my aim is to make it right for everyone, but I am achieving the things I want to and am supported well in doing this. My experience over the last two years is how everyone's care should be. Working together and having the individual's needs, wants and desires at the centre is how the best outcomes will be achieved. It's not just about education, health and care, it's about quality of life, achieving your goals and being supported to live the life you want to live.

Before I was Ill



To
watch
video
the
Council

Disabled Children
on the SEND reforms [click here](#)

Now



my
for
for