





Keeping you informed about this national programme for the restructuring of children's disability services

About the programme

The programme 'Progressing Disability Services for Children and Young People' aims to achieve a national unified approach to delivering disability health services, so that there is a clear pathway to the services they need for all children regardless of where they live, what school they go to or the nature of their disability or delay.

Children should receive the health services they need as close to their home and school as possible. Some children may have their needs met by their local Primary Care services. An early intervention and a school age team will look after all children with more complex needs in a defined geographic network area, regardless of the nature of their disability. These teams will be supported by specialist services when a high level of expertise is required.

The programme also involves our partners in the education sector to ensure we are working together to achieve the best possible outcomes for children.

The Health Service as a whole has to operate within the funding available to it and this is a major challenge for all stakeholders, including the HSE, voluntary service providers, services users and their families. We need to make the best possible use of the resources we have, and if we work to get the structure right we will have strong foundations to build on.

What is a Children's Disability Network Team?

The aim of this programme is to have Children's Disability Network Teams throughout the country so that all children and young people with complex needs will have access to the services of their local team as needed.

A Children's Disability Network Team (Early Intervention and School Age Teams or one team for children from birth to 18 years) provides services for all children with complex needs and their families in a given geographic area, regardless of the child's diagnosis, the category of their disability (physical, intellectual, autism etc) or where they go to school.

But this programme is not just about access to services, we have other important aims regarding how a team works together and with the child and family.

Team working

There has been plenty of research into what makes a team work well. An effective team should have:

- A shared clear vision with common objectives
- Well-documented clearly defined structure
- Clear roles and responsibilities
- Effective team leadership
- Ongoing opportunities for skills development and supervision
- Agreed arrangements for management and accountability
- Good communication
- Regular monitoring and evaluation
- Shared premises with appropriate infrastructure
- Opportunities for formal and informal communication

Family Centred Practice

The other key objective is for teams to operate a family centred model with the family seen as members of the team.

Family centred practice recognises that the wellbeing and development of the child is dependent on the wellbeing of each of the family members and the family as a whole. This involves recognising that the family is the primary and most essential resource for the child with disability (contdp2) (contd from p1) and developmental delay and that the service role is complementary and secondary to that of the family. The primary aim of the service is to support the family in nurturing their child's development and this is documented in an Individual Family Service Plan.

Individual Family Service Plan

An Individual Family Service Plan (IFSP) is a written plan agreed by the child/young person as appropriate to their age and understanding, their family and the team, with priorities and desired outcomes and the identified services which are needed to support the achievement of goals.

Reasons for having IFSPs

- The process of developing an IFSP is a cornerstone of family centred practice
- It ensures the family are partners in the process
- It is a guide for interdisciplinary team working
- It shows the parents' and the child's priorities
- It focuses on the child's and the family's strengths
- It specifies outcomes and functional goals for the child and for the family
- It specifies how the team and other supports in the family and in the community are going to help to achieve the goals
- It reviews the previous year's progress and measures the achievement of goals

The IFSP may be agreed at a meeting of the team members and family but it does not have to be, as long as the parents, the child/young person, (as appropriate to their age and understanding) and the team members all take part. Time and resources can make organising individual meetings for every family every year very difficult and families do not always want to take part in a meeting. So the process could for example be combined with a therapy appointment or a home visit or a phone conversation with the key worker.

The Development of Children's Disability Network Teams

Current resources are limited and not all teams are in a position to fully achieve the objective of an IFSP for every child in the short term, but we are working towards this goal. The additional 80 posts in 2014 and the further 120 posts for 2015 to be allocated to Children's Disability Network Teams are most welcome and they will be a significant help in supporting the ongoing development of teams and implementation of this programme

Booklet launched on Post-School Education and Training

The NCSE & the NDA have launched a booklet with information on options for adults and school leavers with disabilities. This booklet provides general information about post-school education and training options and supports for people with disabilities.

A wide range of programmes and supports in post-school education and training is available for people with disabilities. These generally aim to assist people with disabilities;-

- in accessing education and training appropriate to their needs,
- in making the transition from schools and in progressing successfully through the various post-school pathways in further and higher education and training.

Various pathways are available. The individual's choice needs to be accurately informed about the availability and suitability of the various options and supports.

The booklet is available on the NCSE(<u>www.ncse.ie</u>) or NDA(<u>www.nda.ie</u>) websites. A hardcopy is also available from your local SENO.

AT and Me by Keith Hayes

I am a 38 year old man who was born with Cerebral Palsy. Assistive technology was part of my life before I even knew what AT was about.

Cerebral palsy affects me physically by a speech impediment and I have restricted movement in my hands (fine motor skills) and legs due to muscle spasms. Believe me, this has not stopped me from achieving and AT has been a big support in my life.

Assistive technology covers a range of areas in my life from every day home/Social life to daily work.

From an early age I have had a speech impediment and I did not want to rely on communication aids. So I refused to use them and I have to say for me I made a good choice. That did not mean it was a good choice for everyone else. I did have to work hard with a speech therapist and now I can speak much clearer where people can mostly understand me.

From the time I was a toddler till I was 24, I could walk with the support of a Rollater or the back of a wheelchair at home. Sometimes we forget the Rollater is a crucial piece of AT equipment. As a teenager I wanted to wear jeans like everyone else but I didn't want to have to rely on friends and family to close the buttons on my trousers so I was given a buttonhook. This simple piece of equipment has given me independence and privacy to be able to close my trousers/ jeans and in my eyes the buttonhook is like gold dust to me.

IT came into my life at the age of 18 and a few years after, AT really opened my eyes to a whole new world Unfortunately when I left school I was still unable to read due to the school curriculum. I was determined to achieve in life and I knew I had to be able to read. I was introduced to a programme called Kurzweil 3000, which allowed you to upload text and the computer would read it out to you. The important thing here is that when it's reading it highlights the word so I could begin recognizing words. This shows the programme can be used in a variety of ways.

At the age of 25 I had to start using a power Wheelchair as I kept falling. Without this technology I would not be able to get around or live independently. This has given me freedom in my work, home and social life. The most important thing that I would see around assistive technology is that it evolves and improves which enriches people's lives. People should embrace new ideas to enhance the ones they already have.

'Kindly reprinted with permission from Keith Hayes. Originally published in Enable Ireland's National Assistive Technology Training Service's e-zine, October 2014'.

Look - no stabilisers!

Feedback from one of our readers Christy Keely on the article we published in October's bulletin

"As an adult with a moderate form of Cerebral Palsy it was exciting to read about the success of the bike project. As a child I discovered the hard way (crashes, falls, A + E visits etc) how a regular bicycle could transform ones life and since then the bike has become one of the most important things in my life. In fact now that I am getting older and experiencing lots of problems walking, cycling is the activity that continues to keep me physically active and mentally well. So important is the bicycle to me that when I die I have arranged with my local undertaker to design a coffin that will accommodate myself and the bicycle. After all one never knows what lies beyond the grave"

Seasons Greeting

We would like to wish all our readers a very happy & peaceful Christmas.





HSE change hub has been upgraded!

This is the HSE's Learning and Development website which is open for all to enrol, not just HSE staff. There is a wealth of information and written material of interest on this site, including the Progressing Disability Services for Children & Young People programme. **How to visit & view our page**

Step 1: Register



Step 3: Click on the Change Hub



Step 5: Click on view under Progressing Children's Disability Services



Step 2: Click on Practice Development Hubs



Step 4: Click on Projects & Initiatives



Step 6: You are now on our page!



You will find the key documents and guidelines as they are issued, plus an extensive library of existing service documents and relevant articles.

Don't forget to visit the site for updated documentation.