



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 given the current economic environment, this has become a major challenge for all stakeholders, including the HSE, voluntary service providers, services users and their families. However 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.



Outcomes for Children

The Standards and Performance Reporting Group has nearly completed its work in developing a framework for children's disability teams to measure their performance according to outcomes for children and their families. This will mean a change from the way services are currently measured which doesn't tell us about the differences they have made to the lives of children and families.

What do we mean by 'outcomes'?

We define an outcome as a benefit experienced by a child, their family or the wider community as a result of the services and supports provided.

The outcome statements in the Framework are not 'special'. They are universal outcomes for all children, young people and families living in, participating in and contributing to the same real-world daily life.

Each outcome statement has a set of goals to define it clearly, and indicators which measure the contribution of services and supports and the degree of success in reaching the desired outcome for the child, young person and their family.

The Report of Findings from the Consultation on Outcomes

The group identified the draft set of desired outcomes based on international research and then consulted with service users, parents and staff through an online survey, and also with international researchers, on whether these are the right outcomes and if any were missing. A report, produced by researchers from the Disability Federation of Ireland and the National Disability Authority, gives the results of the survey along with comments made on each outcome and comments on services in general.

Participation

18 children and young people, 199 parents and 283 staff took part in the survey. Of the parents, two thirds had children in the 6-18 years age range and 5 had adult children aged between 18 and 24 years. Of the children and young people, 14 were aged between 6 and 18 years, 1 was under 6 and 3 were over 18.

Views on Outcome Statements

There was broad support for each of the draft outcome statements with high numbers (between 76.5% and 100%) ranking them as important or very important. Comments on each draft outcome statement have been grouped in the report by theme and by group (i.e. parents, children and young people or staff).

The report also includes many comments made in the survey which raised important issues relating to Progressing Disability Services for Children and Young People programme or children's disability services more generally:

contd on page 2

In the interest of the environment, please print this bulletin in black and white.

- ◇ Scarcity of resources in disability services
- ◇ Inadequacy of supports in mainstream education
- ◇ The need for a clear pathway to services with equal access and information
- ◇ Variable quality of services
- ◇ Public attitudes to disability
- ◇ The need for additional supports in order to participate in the community

These comments have been forwarded on to relevant groups, such as the National Co-ordinating Group for the programme, the National Education and Health group and national umbrella disability organisations– the Disability Federation of Ireland, Inclusion Ireland, National Federation of Voluntary Bodies and Not for Profit Business Association.

Review of the Framework following the survey

The Standards and Performance Reporting Group reviewed the outcomes statements, goals and indicators thoroughly in light of the comments received. Examples of changes made in response to comments are:

Draft outcome statement and goals

*Children and young people take part in home life, school life and community life in the same way as other children.
This means:*

- ◇ *Children and young people can use community services and facilities that other children are using*
- ◇ *Children and young people live, learn, play and socialise in places with their peers*
- ◇ *Children take part in the everyday life of their community*

Comments on this outcome from the survey

“ There are some children with social disabilities such as Aspergers that may not feel that they need to socialise in the same way or as much as other kids, I think it is important that teachers and healthcare professionals recognise this as a difference rather than an negative thing”

“ Not all children can do things the same way as other children. The emphasis on mainstreaming, while essential for some children with special needs can lead to a decrease in appropriate services for children who struggle with mainstream and require a more structured or calm environment. Opportunities to participate must be based on the individual needs of the child and not polarised by all mainstream or all segregated services”

“Not all children are the same and the extent that they wish to partake in social life needs to be respected and it should not be expected that they have to socialise to a standard but rather to the extent they are comfortable and happy”

In response to these comments the outcome statement and goals have been changed to:

Children and young people take part in home life, school life and community life

- ◇ *Children use community services and facilities as they wish*
- ◇ *Children and young people live, learn, play and socialise with their peers*
- ◇ *Children take part in the everyday life of their community*

Draft outcome statement and goals:

Families understand their child/young person’s needs, what they are able to do well, and what they find difficult as they are growing up.

This means:

- ◇ *Families have easy to understand information about their child’s needs as they are growing up*
- ◇ *Families work together with services so that they can understand what their child is able to do well and what they find difficult*
- ◇ *Families work together with their child or young person and services to set goals about what the child or young person is able to do, what they are good at, and what they find difficult*

Comments on this outcome from the survey:

“ The statements make it sound like external services are telling them what their child is good at and capable of. I don’t think I’ve ever been informed my child was good at something I didn’t already know they were good at”

“ Badly worded points as it is information gleaned from the family that will determine what works best for the child . Equally services work with families so that they understand the child and not the other way around” (contd on page 3)

This outcome statement and goals have been changed to:

Families understand their child or young person's needs, what they are able to do well and what they find difficult as they are growing up

- ◇ *Families have easy to understand information about their child or young person's needs as they are growing up*
- ◇ *Families and services work together so that they can understand what the child or young person is able to do well and what they find difficult*

What's Next?

The final report entitled *Outcomes for Children* will comprise the values and principles guiding the framework, the framework itself, key recommendations on how this new way of measuring our effectiveness can be implemented across Children's Disability Teams and guidance for services informed by focus groups with Children's Disability Teams.

Dublin South / Dublin South East Parent Information Meeting

There will be a public meeting for parents of children with disabilities (0-18) in St. John of Gods, Carmona Services, 111 Upper Glenageary Road, Dun Laoghaire, Co. Dublin from **7.30pm until 9.30pm on 24th September 2013.**

All parents from the Clonskeagh and Dunlaoghaire areas are invited to attend this meeting, and become involved in the Progressing Disability Services process throughout the area. This meeting is specifically focused on looking at the present services available to children with disabilities in this area, and how that service can be improved to ensure a more equitable, accessible and fairer system for all children with disabilities.

This process is already well underway throughout the country and this area is one of the last remaining to be commenced, so we would welcome as many people attending as is possible.

There will be a number of representatives from the service providers in the area attending on the night giving presentations, answering questions and linking with parents around their concerns regarding the delivery of services in the area.

This is an opportunity for parent involvement in the Local Implementation Group for the programme on how services are provided, the parent subgroup for the area, and other subgroups to the process, so there is an opportunity for parents to become involved in real change for disabilities services.

Directions to St John of Gods

<https://maps.google.co.uk/maps?f=d&saddr=R111/Upper%2BGlenageary%2BRd&daddr=&hl=en&geocode=&mra=ls&sl=53.279867,-6.134706&sspn=0.015857,0.035534&ie=UTF8&ll=53.279698,-6.134538&spn=0.015858,0.035534&z=15>

If you need any further information please contact Disability Manager - celine.judge@hse.ie or linda.friel@hse.ie (Performance and Development unit)

Look forward to seeing you all there on the night.

Wicklow Parent Information Meetings

Parent information meetings have been arranged to update parents in the Wicklow HSE area of Progressing Disability Services for children and young people and to invite parents to participate as parent reps on sub groups.

Wicklow Health Centre- Conference room – **10th September 10.30AM – 12**

Bray Health Centre – Board room – **11th September 10.30AM – 12**

The contact email for Wicklow parents is pds Wicklow parents group@gmail.com

In the interest of the environment, please print this bulletin in black and white.



MID-WEST DISABILITY SERVICES

Workshop for all staff working in Early Intervention and School Age Teams
to be held at venues across the country

Training in Family Centred Practice

An Evidence Based Approach to Intervention

- ◇ Learning in Context (Routine Based Interviews)
- ◇ Authentic Assessment
- ◇ Working with Families Using Coaching
- ◇ Inclusion and Inclusive Practice
- ◇ Collaborative Teamwork and Key Worker Models of Service Delivery

Speaker: Ms Denise Luscombe, Senior Physiotherapist and National President of Early Childhood Intervention, Australia

Limerick (Midwest)

16th September 9.30 - 4.30 and 17th September 9.30 - 1.00

South Court Hotel Raheen Limerick

For further info please e-mail: anne.long1@hse.ie

Cork (Enable Ireland)

Wednesday 18th September 9.15 – 4.30

Enable Ireland, Lavanagh Centre, Ballintemple, Cork

For further info please e-mail: dgeary@enableireland.ie

Bray (Enable Ireland)

Thursday 19th September 9.15 – 4.30

Wilton Hotel Bray, Co. Wicklow

For further info please e-mail: jtoher@enableireland.ie

Dublin (St John of God)

Friday 20th September 9.15 – 4.30

Green Isle Hotel, Newlands Cross, Dublin 22

Bookings taken only through survey monkey: <http://www.surveymonkey.com/s/3TM6NGV>