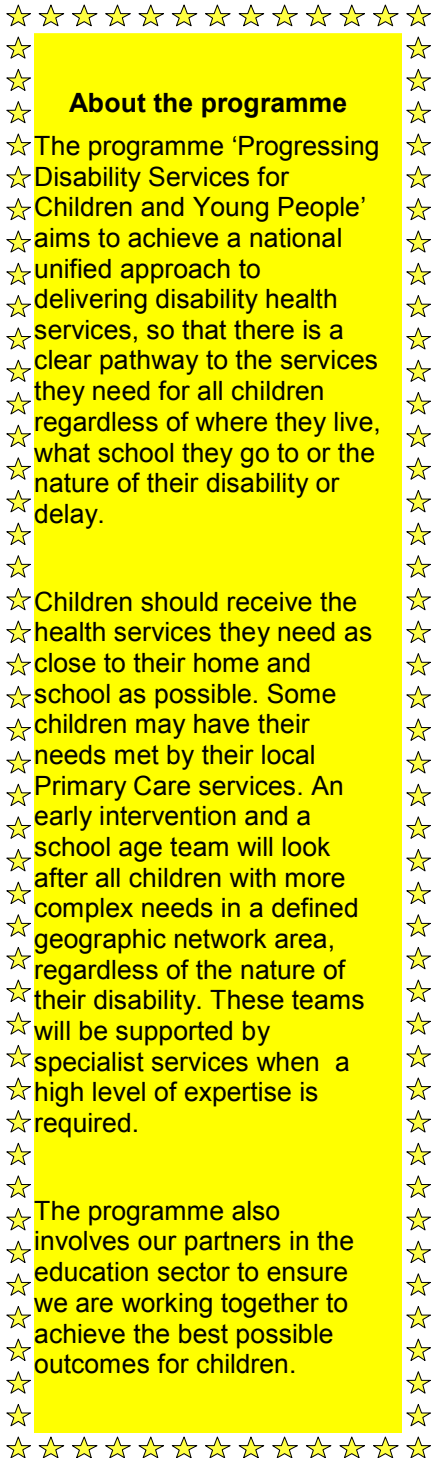




# Keeping you informed about this national programme for the restructuring of children's disability services



## 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.

## Framework for Collaborative Working between Education and Health Professionals

The Education and Health Working Group was established by the National Co-ordinating Group following the recommendations of the Reference Group Report 2009 and the Terms of Reference of the NCG, to look at issues at the interface between the health and education systems. The members of the group include a parent and representatives of the Department of Health, the Department of Education and Skills, the HSE, the National Federation of Voluntary Bodies, the National Council for Special Education and the National Educational Psychological Service. It is chaired by the Chair of the NCG, Breda Crehan Roche, CEO, Ability West.

The working group gathered information from existing services and consulted with parents and staff working in both sectors. Their report will be made available shortly and here are some of the key points.

### Recommendations

1. The formation of a permanent National Education and Health Steering Group to provide guidance to stakeholders in local areas in developing joint working, to monitor their progress and evaluate outcomes.
2. A national online directory of resources is established to include information and links on disabilities, health services, education, community supports and subsections for regional/local specific supports and services.
3. Education and Health Forums are established at local level under the direction of the National Education and Health Steering Group.
4. The Guidelines on the co-ordination of key transitions for children and young people with complex disabilities are used as a template for local education and health forums to develop their own pathways for key stages of transition.

### Education and Health Forums at local level

The local forum will bring people from the health services, schools and parents together on a regular basis to explore issues of common concern and find out how they can improve outcomes for children with disabilities. It will provide an opportunity to share information, work out ways they can smooth the path for children and their families and identify future needs in the area.

### Training

One particular area identified during the consultation was the need for the co-ordination of training for professionals and for parents in order to understand roles and share information and skills. The National Education and Health Steering Group will provide guidance with regard to the content of relevant training

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programmes in both sectors and aim to ensure consistency and eliminate duplication. Local education and health forums will identify the needs in the area, work to streamline existing programmes and develop others to address training gaps. They will also organise the production and dissemination of standardised information packages for teachers, early years staff, students and parents.

### **Guidelines for the child's pathway through key stages of transition in education**

The importance of the stages when children start school and move between schools was brought up frequently during consultation as a key area where co-operation between health and education services can impact positively on outcomes for children and young people with special educational needs.

The Education and Health group has put together templates for planning the transition stages for each child

- Into pre-school
- From pre-school to primary school
- From primary school to secondary school
- Leaving school

In each area schools and education services, the health disability services and parents should work out a timetable of what needs to be done, separately and together, to achieve smooth transitions and the best possible experience for each child. The templates have already been sent out to Local Implementation Groups to assist them in starting this piece of work. The guidelines are set out in flow-chart format to show what needs to be done and when. They should be adapted to suit local conditions. Health and education professionals and parents should analyse the events and actions with a view to identifying exactly who should be involved at each stage and with whom they should be working in partnership.

The Framework for Collaborative Working between Education and Health Professionals will be available shortly.

## **National Workshop for Local Leads—30th May 2013**

31 Regional and local leads from across the country attended a workshop held in Dublin on 30th May. The workshop was opened by Dr Cate Hartigan, Assistant National Director Disability services. She gave a brief background to the programme which started in 2010, based on outcomes from the Reference Group Report, and which when completed will give equity of access to disability services for children and families across the country. She acknowledged the huge amount of commitment and energy among the current leads and stressed that this programme has the full support of Minister Kathleen Lynch. There are currently 25 local implementation groups across the country and 55 Network teams already established.



Caroline Cantan, National Programme Co-ordinator gave an overview of the programme and the steps towards implementation. This was followed by a presentation on parent engagement and representation by Lorraine Dempsey, Special Needs Parents Association which showed the importance of parent involvement in planning for and implementing the change programme. This was followed by discussions in small groups on experiences of the implementation in local areas which allowed the local leads to share their achievements and challenges with each other. Other topics during the day included forming interagency agreements, the identification of required specialist services and the individualised family centred plan.

Feedback from the day has been very positive and the leads found it very helpful. It was an excellent opportunity for them to meet each other and build a support network.

## REGIONAL LEADS

**South**(Kerry, Cork, Waterford Wexford  
Carlow, Kilkenny, South Tipperary)

**Aisling Lenihan**

Aisling.lenihan@hse.ie

**West** (Donegal, Sligo, Leitrim, West Cavan,  
Roscommon, Mayo, Galway, Clare, Limerick  
North Tipperary)

**Gerard Tully**

Gerard.tully@hse.ie

**Dublin Mid Leinster** (Dublin South of the  
Liffey, Wicklow, Kildare, Laois, Offaly,  
Longford, Westmeath)

**Bernie Nyhan**

Bernie.nyhan@hse.ie

**Dublin North East** ( Dublin north of the Liffey  
Meath, Louth, Cavan, Monaghan)

**Anne Melly**

anne.melly@hse.ie

*Everyone who will be  
affected by these changes  
should make sure they are in  
touch with what is  
happening locally.*

*Contact your Regional Lead  
to find out about how you  
can get involved.*

## News from around the country

### Carlow/Kilkenny

Parent evenings took place during April & May. Any parents interested in joining a parent committee in either county should contact Jennie McAleese, local lead for this area. Jennie can be contacted by email on [jennie.mcaleese@hse.ie](mailto:jennie.mcaleese@hse.ie) or by mobile on 087 9979535

Jennie McAleese

### Midwest

#### Gaining from the experience of services who have already reconfigured into Network teams

Mid west—Limerick . Anne Long, Children's Service Manager in Limerick has offered to talk to teams who are about to reconfigure to share her experience with them. She has also offered that staff can visit their service and speak with her staff in Blackberry Park in Limerick. Anne can be contacted on 061 498733 or by email on [anne.long1@hse.ie](mailto:anne.long1@hse.ie)

### HSE change hub

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. When you have enrolled go to **Practice and Development Hubs**, then click on the **Change Hub**. On the top line you will see **Reconfiguration Resources**, click on that and open **Progressing Children's Disability Services**. You will find the key documents such as the Report of the Reference Group on Multidisciplinary Services for Children 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.



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## Consultation on outcomes for children and families

The Standards and Performance Reporting Working Group consulted on a draft outcomes-based performance reporting framework for children's disability teams last November through an online survey with service users, parents and staff. The large number who responded and the strong approval rating of the outcomes we had derived from international research, was very encouraging. The comments were all carefully considered and the framework revised where appropriate. We are very grateful to the researchers with Disability Federation of Ireland and the National Disability Authority who analyzed the data and produced a report which will be made available shortly.

We want everyone who took part to know that their contributions are very welcome and are heard. The survey was also an opportunity for people to voice their opinions and observations about children's disability services in general. The Group themed those comments as follows and forwarded them to relevant sub groups and organizations for their consideration:

- Health and Education working together
- Participation in community life
- Governance of services and information needs

The Standards and Performance Reporting Working Group is currently engaged in conducting focus groups with staff around the implementation of this performance monitoring system, and also completing work on a final draft of the Framework document which will be presented at the meeting of the National Co-ordinating Group in July.



## Autism Spectrum Disorders: From Research to Practice

The Irish Centre for Autism and Neurodevelopmental Research at NUI Galway in collaboration with Autism Speaks will host their 2nd International autism conference entitled "Autism Spectrum Disorders: From Research to Practice on the **11th and 12th of June**.

Over two days there will be key-note addresses as well as workshops aimed at providing practitioners, parents and researchers with the latest evidence based approaches to diagnosis, clinical management and adult service provision. Workshops are aimed to provide practical solutions for parents in the home as well as the latest health and educational approaches for health and educational practitioners.

On day two of the conference an Irish autism database and repository initiative, currently under development by NUI Galway, TCD and Autism Speaks, will be presented. The goal of this initiative is to inform the development of clinical practice, service delivery and autism research in Ireland and we invite all attendees to participate in a consultation session on day two to help shape this important development.

To register or for further information please see [www.conference.ie](http://www.conference.ie). Registration is €120 for professionals and €60 for parents and students. Spaces are limited so please register early.

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