

Progressing
Disability
Services
for Children
& Young People

Working together to support children and families

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



West Cork go live!

West Cork Child development services went live in January 2013. This new service is a partnership between CoAction West Cork and HSE, working together to deliver team based services at local level for children with disability, complex developmental delay and Autism



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.

Testing national access to services

The Draft National Access to Services Policy has been completed and is available to read on the Change Hub www.hseland.ie. The policy outlines the different levels of service (Primary Care Team, Children's Network Disability Team and Children's Specialist Disability Services) and how the decisions will be made on where each child's needs will best be met. The criteria for making those decisions are being tested in four areas – Cavan/Monaghan, Midlands, Waterford and West Cork - from March to July. There will then be a detailed evaluation and review of the policy before it is submitted for national approval.

Survey on Outcomes for Children and Families

Thank you very much to everyone who took part in the online survey on desired outcomes for children and families. These outcome statements were based on national and international research, but the Outcomes Framework for Accountability Working Group wanted to ensure that they were the *right* outcomes from the young person's and family's perspective by asking you.

The high level of participation by parents, young people and staff was very helpful and encouraging. In addition to indicating their level of agreement with each of the given outcomes and to advising on any missing desired outcomes, participants gave a wealth of comments, including some relating to other aspects of the programme which will be taken on board and used to inform the wider programme.

The aim of the working group is to describe how to measure the quality and value of services by the outcomes achieved for individual children and families as a result of those services. The move to measuring outcomes, rather than just number of children in services and services delivered, involves a major change of approach and thinking for staff, service users and their families. But as well as making services accountable, it will clarify what our overall objective is – to support children to achieve their maximum potential and independence.

The Working Group will be reporting on the results as soon as possible and will inform parent groups and staff at that time.

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*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.*

West

Mayo Services—Services for School Age Children

In Mayo we have established a Local Implementation Group with key representatives including parents, to plan and move forward the school age disability services locally. We are initiating a pilot project with a sample of children and families trialling a cross-agency approach based on therapists and practitioners working with children with two or more complex needs. This is an opportunity to trial and review the strengths and challenges of a team approach around each child in response to their needs.

The cross-agency approach puts the child and family at the centre of a team based, needs led and responsive approach involving therapists, practitioners, health and education personnel and support staff. The principles and values agreed at the Local Implementation Group, will underpin the implementation of the project.

We hope the learning from this “pilot” will provide the foundation in progressing Disability Services for children into a fully cohesive and co-ordinated team-based, needs-led approach.



Ruth Kneafsey

Dublin North East

Meath services

In Meath we have had another really busy year in Children's Disability services.

The Meath children's disability service will see any child where there are concerns the child may have a disability. The teams carry out diagnostic assessments, interventions and provide information and support to families.

In 2012 approximately 200 children were referred to Early intervention services (0-6 years) and 225 to the School aged team (6-18 years). In the school aged service over 40% of children are referred for Autism diagnostic assessment or interventions around the issues that challenge these children and families. The next biggest cohort, 24%, of children referred have significant Speech and Language difficulties and often present with psychological and sensory/coordination issues.

The continuing pressure on services means that much of our work includes parent education which is delivered through a mixture of individual and practical educational group work for both parents and their children.

The Meath teams deliver a service based on the home address of the child. We believe that for the child to have a happy and successful childhood their family, local community and school may need information and support to achieve this outcome. We believe this can happen when parents /carers/teachers are educated and trained in ways to enhance the child's lived experience.

The Meath disability teams will continue to work with Meath Primary Care, Child Protection, Education and other local and community services to ensure that children and their families are best guided to the supports that meet their needs at any particular time.

Penny O'Connell

Dublin SW Parents Progressing Disability Services.

Parents of a child or children with a disability all have different stories to tell about their experiences with Health and Education service providers, both positive and negative. How can we as parents use these experiences to help shape the best possible service for all children with disabilities? How can parents and service users help assist with a limited budget to provide better services? How are health services linked to the education system? One possible way is to give the parents of children a say at regional and local level and hopefully this will percolate into a system that spends its money more wisely. "It's a forum for communicating where the services can be improved, and in some cases where the services may be operating ineffectively", suggests one parent. Local groups can discover creative ways of getting better value for everyone, a system that lives the phrase '*nobody gets left behind or forgotten*' which was made popular with kids who saw the 2002 *Lilo and Stitch* movie.

Idealistic stuff, yet, the backdrop to the formation of Parents' Progressing Disability groups throughout the country and more recently in the Dublin South West Area with parents from the D12 and D24 areas of Dublin. Our current group manifests itself on the community focused social media site BigTent under the name **Dublin SW Parents Progressing Disability Services.**

"We are about progressing services for all children, not just our own children, but for all disabilities, not just the ones we may be most familiar with" says one of the DSW parent group reps. The same initiative is happening in Dublin South City and Dublin West covering the areas of Dublin City Centre, Ballyfermot, Cherryorchard, Lucan and Clondalkin and 2 public meetings are being held across this large area to facilitate parents to get involved.



This initiative working in partnership with Parents is part of a system that the HSE is rolling out nationwide, forming regional clusters of parents and guardians, people collectively familiar with the services, problems and opportunities in their region, who interface with the 'system' in the hope of improving it.

Although not a support group for a particular disability (although our group site does list these groups), it is a group of people who have decided to work with the system, and to try to progress and improve it. The group has a code of conduct which stresses confidentiality of sensitive information and respect for diverging viewpoints, but we do need to identify where deficiencies are within the current system and suggest solutions to those issues. Two of our members attend the Dublin South West local implementation group (LIG) and this is one of our ways of potentially changing things. In summary the parents... 'hope we can make positive changes.'

To learn more about the Dublin 12 and 24 group ; They hold meetings usually on the first Wednesday of every month in the HSE office beside Captain America's in Tallaght (beside one of the entrances to the library on Chamber Square) between 7.30 PM- 9.30 PM. The group is looking for more members and will organise a larger venue when numbers increase. Currently we have over ten parents subscribed to the group and over forty parents have attended other meetings. To find us and join visit :

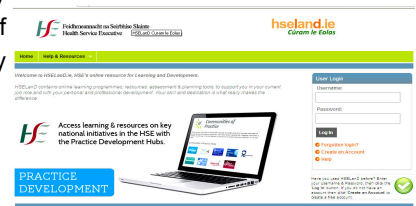
<https://www.bigtent.com/groups/dubswparpds>

Dublin South West Parents group

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. Progressing Children's Disability services had **1,567** visits during 2012 on www.hseland.ie.

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





The National Coordinating Group for Progressing Disability Services for Children and Young People and the National Federation of Voluntary Bodies will jointly host

One day workshop on family centred practice

on Tuesday 12th March 2013

in Portlaoise

Keynote Speaker - Prof Roy McConkey

Who should attend this event?

Parents/carers of children with disabilities and those working in children's disability services

ONLINE BOOKING is available at <http://form.fedvol.ie>

For more information please email Mary.Barrett@fedvol.ie

Family Leadership Adventure Break A Good Life for Everyone in the Family

The Cavan Centre, Ballyjamesduff, Co. Cavan

5th to 7th April 2013



Do you want to think about and experience a different way of supporting your family member with additional needs?

Do you want to make some time to think about you and your family's future?

Do you want to have a fun weekend with the whole family?

Leap are offering family leadership weekends for the whole family to come together in an inclusive, fun environment to begin to develop and share a vision of a good life for their son or daughter with a disability and for themselves. These weekends are about friendship, fun, finding support and family leadership.

The aim of the weekend is to have fun with all the members of the family and try out some new activities, ideas and experiences. The weekend will also be about finding inspiration in what families are doing together when living with disability and sharing practical insights in how to support family members live a fuller, better life.

Parents and adult siblings take part in workshops that invite them to think about the future and to think about what good support looks like for their family member while other children and teenagers are busy taking part in a range of accessible workshops with our dedicated team of leaders and volunteers.

For more information about Leap visit www.leapireland.com for more information about the Cavan Centre visit www.cavancentre.ie

The weekend costs €40 per person (all inclusive) so for a family of four the weekend costs €160. The weekend is suitable for families with children from 3 -18 years. For more information please contact **Claire at leapireland@gmail.com or 086 1931227** .

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