



Guidelines on parent and service user representation on local implementation groups 24.6.13

It is essential that there should be at least two parent/service user representatives on each local implementation group for this programme from the earliest stage, so that parents/service users are at the table when key principles for services are discussed and agreed. Where possible, parent representatives should have a nominated substitute in the event of their being unable to attend a meeting.

In areas where sub groups are established under the local implementation group, it is preferable to have other parent representatives nominated on to the sub groups to avoid over burdening the LIG parent representatives.

It needs to be very clear what we are asking of parent representatives, their role in the process, time frame for the work, expectation of their availability to attend meetings and boundaries to their responsibilities. Representatives need to be selected by parents themselves through a transparent process. They need to communicate with other parents on an ongoing two-way basis.

Information for parents on the programme

The national bulletin on the programme is issued through many channels regularly. Service providers, schools etc are asked to distribute widely to staff and parents through email and printed copies. Local Implementation Groups could add local news into the bulletin.

Areas should organise information meetings aimed specifically at parents. When organising local parent information meetings, details of the meetings should be disseminated to every parent possible via local service providers & HSE teams (including those on waiting lists), Health Centres, special schools, County Childcare Committees, School Principal Networks or individual schools and national organisations with access to existing parent networks. Local radio & print media is also an option to consider.

The following list of national organisations to contact is a guide only and is not exhaustive:

- ❖ Inclusion Ireland
- ❖ Disability Federation of Ireland
- ❖ Not For Profit Business Association
- ❖ National Federation of Voluntary Bodies
- ❖ National Parents Council

- ❖ Special Needs Parents Association
- ❖ National Parents and Siblings alliance
- ❖ Autism Ireland/ Irish Autism Action
- ❖ Down Syndrome Ireland
- ❖ Dyspraxia Ireland
- ❖ Dyslexia Ireland
- ❖ HADD

There may also be parents' groups in the area or local branches of national organisations that should be contacted directly. Some smaller groups have a very narrow or specific purpose so they need to be aware of the broader brief required.

Follow up parent information sessions should be arranged at a local level within twelve months of the initial parent information meetings in order to update parents familiar with the programme and to also engage with parents who have not been informed of the programme.

Finding parent representatives

Selection of representatives and substitutes should be through a democratic process with a mechanism to give representation of the broad range of families and differing circumstances, based on clear criteria such as age of child, category of disability, whether they are in receipt of services or not, geographic area etc.

Providing parents with the supports they will need

Parent representatives and substitutes must be given a full briefing on the project with all appropriate documentation and an opportunity to meet at least once with the local lead for one-to-one discussion in advance of their first meeting of the local implementation group.

The parent representatives and substitutes on local implementation groups should have access to a body of other parents to ensure a broad representation of issues involved are available. Also it will ensure that as many parents as possible can feed into the process and there should be an onus on representatives of reporting back to the wider parent group. One suggested model is that a parents' reference group is formed in the area with all interested in the project, and this group could send representatives to the local implementation group on a rotating basis as well as nominate other parents to sit on sub groups as necessary. The parent representatives on the LIG and sub groups should be in a position to liaise with each other separately to ensure continuity and also feed back to the wider parent reference group.

Meetings of the reference group could include social networking, Skype, teleconferencing, email thread, online forum (eg boards.ie) as well as face-to-face, so that parents who cannot attend actual meetings can get

involved. Opportunities for all these forms of meeting should be supported by service providers wherever possible using available facilities. The HSE Organisation Development and Design Unit / Performance and Development Department may be in a position to facilitate parent meetings, including helping to form clear terms of reference and lines of communication.

In order to give meaning to the goal of including parents in this programme in a voluntary capacity, expenses for parents in attending meetings, accessing training etc must be recognised. This should be identified as a necessity for this programme at regional level with a budget made available. (See National Guidelines for Service User Expenses 2011)

Service user voice

It needs to be clarified exactly what the role of service user representatives would be. Young people of 18 years and younger may not want to be or feel comfortable with being on a committee planning the detail of service structures, but their views on how services are and should be delivered and how the services have impacted on them are invaluable.

It may be more appropriate therefore for the local implementation group to consult with service users (as a guide children aged over 12 years) on a once-off forum basis rather than as long term members of a group, but not totally precluding the option of follow up consultation at periodic stages throughout the programme. A workshop or focus group with skilled facilitation could cover a wide range of issues including consultation on how young people would like their health services delivered in general and on how they would like to be informed and included in decision-making concerning their individual services and supports.

Adult service users could also give very valuable feedback and views on the services and supports they experienced as children. So opportunities for them to hear about the programme and to get involved should be considered an essential part of the process. Users of adult disability services via service providers and adult self-advocacy groups should be approached to enable this consultation.

Some resources on involving service users

Disabled Children and Young Persons Participation Project Northern Ireland

<http://www.engage.hscni.net/bestpractice/projects/childrensproject.html>

Consulting with children with disabilities as service users: Practical and Methodological Considerations (Trinity College Dublin 2007)

http://www.tcd.ie/childrensresearchcentre/assets/pdf/Publications/consulting_full_review.pdf

- Engaging young people with disabilities (Case Study)

<http://www.myplacesupport.co.uk/The-Buzz/haltons-the-buzz-project-engaging-young-people-with-disabilities.html>

- Ask Me: Consultation with people with disabilities (National Disability Federation 2002)

<http://www.nda.ie/resourceNew.nsf/askme.pdf>

- Involving Young People in Conference Planning: A model for Action (HSE 2006)

<http://www.hse.ie/eng/services/ysys/SUI/Library/Guides/ConferencePlanning.pdf>

- Disability Service user Involvement Resource Kit (Australia)

<http://www.communities.qld.gov.au/resources/disability/publication/quality-resourcekit-2.pdf>

- Engaging Persons with Disabilities in Services

http://www.vaservice.org/uploads/public/Resource_Library/Disability_Inclusion/Engaging_Persons_with_Disabilities_in_Service.pdf