

Inclusion Ireland comment on regional and local consultative structures within the HSE

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Introduction

Inclusion Ireland is the national organisation advocating for the rights of people with intellectual disabilities in Ireland. Established in 1961, our vision is of a society where people with intellectual disabilities live and participate in the community with equal rights as citizens. Our focus is on the realisation of the core principles and values expressed in the United Nation's Convention on the Rights of Persons with Disabilities (CRPD).

One way in which Inclusion Ireland carries out its work is through its involvement with the various Health Service Executive consultative fora. Inclusion Ireland sits on the National Consultative Forum and also on a number of the regional fora to represent the interests of people with intellectual disabilities and their families. Representation at a local level is patchy - some areas of the country have family representatives on local fora, while other areas are not that well developed in terms of participation.

As the primary organisation supporting people with intellectual disabilities and their parents/families, Inclusion Ireland views these two groups as central to an efficient, relevant and cost-effective delivery of disability supports and services to those who need them. The participation, as partners, of these stakeholders is critical to a successful change process. Parents/families and their local parent groups will be the critical support base for people with disabilities living independently in the community. In addition to being the natural support provided by family and friends they are also the networks through which local community based supports and services will be demanded, and on occasion, organised. They can also be a key support in incubating the emergence of self-advocacy groups

Parents, and parent groups, are frequently described as blocking or being barriers to change. Inclusion Ireland believe that parents and their support networks are key agents of change and key enablers of achieving community connectedness for people with disabilities. Inclusion Ireland has over 46 parent and friends groups who are affiliated members of the organisation, and over 300 individual parent members. Inclusion Ireland aims over the coming years to build a partnership between these groups, self-advocacy groups and various HSE structures.

The role of advocacy

As an advocacy organisation, Inclusion Ireland supports people with an intellectual disability and their families to exercise and secure their rights. This goal is achieved through public policy advocacy, facilitating self advocacy and family empowerment and advocacy. This enables people affected by disability to have their voice heard in the decision making process.

One of the guiding principles of the Commission on the Status of People with Disabilities (1996) was to maximise the participation of people in the decision making process, especially in relation to decisions that affect their lives. This includes participation in the development and application of government policy. The concept of involving people with a disability as partners in the decision making process through active consultation is further emphasised in the United Nations Convention on the Rights of People with a Disability - people should be involved through their representative organisations in relation to legislation and policy that directly affects them.

The *Your Service, Your Say* strategy for service user involvement notes some of the many benefits of service user participation. Partnership processes lead to empowerment of people who access services, resulting in better health outcomes, increased satisfaction with services, increased feelings of self worth and improved relations with service providers. At a national level, policies are more accurately informed and can be better targeted to the needs of people. This, in turn results in cost effective services that have the confidence of people who use them. Informed policies will also serve to address social exclusion and health inequality issues, while delivering a service that suits the needs of the community (HSE, 2008). In addition, the *HSE Proposals on Disability Consultative Fora* emphasises the importance of partnership between service providers and people who use the service, and that all parties must be afforded an equal status. This helps to ensure that the needs of people with a disability are identified, prioritised and addressed.

Structures for consultative fora

At present, Ireland is in an era rich in disability related policy and the challenge is now to implement these policies at a local, regional and national level. People with disabilities and their families have broadly welcomed the recommendations of the reports on Congregated Settings, New Directions, Multidisciplinary services for children and the VFM and policy review. The narrative of these current policy reports is for community based, inclusive, individualised disability services for people. People with a disability need to be consulted, especially about decisions that directly affect their lives and the implementation of current HSE policy will see unprecedented change in how services are delivered to people. The people that this change will affect must be at the heart of the process.

At a local level a committee should meet to ensure services are best utilised to meet the needs of the local population and that the various policy reports are being implemented locally. In addition to service providers and HSE professionals, people with a disability and/or their family should be represented on the local committee. This will allow for people to inform those who are providing services of any of the issues that are affecting people locally and service provision can be targeted accordingly. At a local level there is scope for working groups on each of the particular policy areas to feed back into the local fora on policy implementation. This will allow the representatives of people with a disability to feed back developments in services locally to their local groups and also to representatives at a regional and national level.

A regional forum is essential to ensure there is coordination of disability services across the region and to ensure equitable access to a service for all people regardless of their particular disability. The regional group should prepare plans for the implementation of progressing disability services for children, new directions, congregated settings and VFM. Local groups that report success in the change process can share this information at the regional level to others facilitating evidence based practice. In addition, the representatives of people who use the services can feed back what is working, what is not working, what services need more attention, and what local areas are performing best/worst from their view point.

A forum at national level is essential in coordinating the change that is underway in how disability services are delivered. A national committee should be charged with implementing policy in the area of inclusion and full participation of people with a disability. To this end, it is essential that there is a close working relationship between the national forum and the regional fora. There needs to be formal reporting of what is happening regionally and locally in all policy areas and how resources are being best utilised to better the lives of people with a disability. Communication must flow in both directions; the national forum must be informed of good practice models on the ground and also issues that require closer attention. Information should come to the national consultative forum via HSE regional leads, service providers and people who use the services or their representative organisations in a spirit of true partnership.

Structures for participation

Inclusion Ireland recognises that families and people with a disability need to be involved in the consultative process. As stated, Inclusion Ireland has representatives on national, regional and some local fora. In addition, Inclusion Ireland has actively engaged in the processes of developing current policy. To further develop the involvement of families in the consultative process, it is the aim of Inclusion Ireland to build capacity in people through a training program, to enable them to partake in the existing fora in an informed manner. The more that people are involved at a grass roots level will lead to a better informed structure

at local, regional and national level. People with a disability and their family should be actively involved in the consultative process and not just there as token representatives.

The involvement of people with a disability and their families should be seen as a positive to the process and their participation through partnership valued. The consultative and change structure must be about people and not about the structure itself. The involvement of people should be at the heart of the process itself and at every level of the structures established to implement policy; this is effective partnership.

The communication pathway is crucial between the various levels of the structure. The regional level is key, as this is where local leads can feed into how the change process envisaged in VFM, congregated settings, progressing disability services and new directions is progressing in the local health areas. This in turn can be fed back to the national forum by the regional lead. Simultaneously, national policy targets and priorities can be fed down to the local areas through the regional structure. The lead of the regional forum is an important role as they should be the main conduit of information in both directions, between the national committee and the local fora. They should produce a regular progress report to the national consultative forum. This will provide clear feedback to the national committee, while ensuring priority goals to be fulfilled at a local level are clear and understood.

All of the change processes and policy implementations must be conducted through the local regional and national fora. Working groups may be required to implement the various current policies but each working group should report back to their local group. The local group lead person can in turn report back to the relevant regional forum. This would eliminate the possibility of any parallel processes and ensure that all structures fall under the national consultative forum. At present there seems to be a separate structure for Progressing Disability Services for Children and Young People, which has its own local, regional and national structure - this should feed into the national, regional and local fora that exist.

It is essential that the local implementation groups inform people and local support groups of the change that is occurring in disability services. Through its advocacy work Inclusion Ireland is aware that many people are not aware of the change that is taking place. It is incumbent upon the HSE, service providers and groups like Inclusion Ireland to inform people that services are currently undergoing great change on a number of fronts.

It was mentioned that the amount of meetings was an issue for some people, especially those who have to travel. Due consideration should be given to having a proportion of meetings via teleconference. Reports and agendas can be circulated in advance through email.

Consideration should be given to an expanded version of *Your Voice, Your Choice* to better involve Self-Advocates. The United Kingdom has a national forum for people with a disability. Membership of the national forum is drawn from a number of regional fora who in turn gain their membership from local advocacy groups. The national forum has access to government at the highest level. Issues that require attention can be brought to government, while at the same time policy makers involve people through the national forum.

Concluding recommendations

At present, parental and family involvement is being sought for a number of structures locally, regionally and nationally (Progressing Children's Disability Services; New Directions; Congregated Settings; NCF), whilst there is little investment in building the capacity of family members and their representative groups to participate. There is a culture within the intellectual disability service providers of not engaging with parents as partners. This is increasingly being acknowledged by service provider representatives, CEOs etc. There is a real opportunity for Inclusion Ireland and service providing organisations to work collaboratively to build family involvement. This will take some time and investment.

Ireland has been slow to support the emergence of independent self-advocacy groups for people with intellectual disabilities. The findings in relation to advocacy of Wave 1: Intellectual Disability Supplement to the Irish Longitudinal Study on Aging 2011 (IDS-TILDA) show that:

- Only 12.2% (n=92) of circa 740 people captured by the study stated they were members of a self-advocacy group;
- Of these, almost 70% (69.6) were members of groups inside an Intellectual Disability service with a further 14% involved within a community setting;
- Only 33.7% of those living in institutional care were involved in an advocacy group;
- 74.2% did not have an independent advocate;

The National Disability Authority stated at their annual conference in October 2012 that three quarters of the national disability spend of €1.4billion was expended on services that are now considered out of date and which are not delivering on the vision of national disability policy. The bulk of this expenditure goes to large institutional providers delivering services to people with intellectual disabilities. Much of the activity in Ireland described as self-advocacy takes place inside these institutions. While these may be important initiatives aimed at giving people who access services some involvement or 'voice' in the design and delivery of services they do not, in Inclusion Ireland's view, constitute independent self-advocacy. In some areas service-provider based groups may be the only available advocacy activity and may offer resources or a local base through which independent self-advocacy can be developed.

A priority for Inclusion Ireland in the short to medium term is to support and build the emergence of independent self-advocacy. This too will require time and investment.

It would seem overly ambitious to achieve genuine participation of people with disabilities and their family members on all the current structures.

Greater coherency and more formal communication is required between national and regional NCF structures. The national/regional nexus needs to be coherent if the local is to work.

There may be an argument for taking the time to build a clear understanding and compliance with participation and reporting requirements between regional structures and the NCF.

A formal review of the NCF has been muted; this should proceed as a matter of urgency and should be conducted by an independent body or individual.

The reporting relationship between Progressing Children's Disability Services and the RCF and on to the NCF should be clarified and adhered to.

Consideration might be given to a 'themed' approach to participation and consultation. Rather than having a number of local structures for New Directions, Progressing Children's Disability Services, Congregated Settings etc, Regional Forums could convene a number of themed 'workshops' as a way of enabling participation and consultation. This might result in more Regional level meetings, but fewer committees to be sustained.

Sources

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