

Minister, Distinguished Delegates, Good morning

I would like to thank the organisers for giving me the opportunity to speak at this event which brings together so many key players in the field of social services for disabled people.

Today, I represent the European Disability Forum, the umbrella organisation for the disability movement in Europe. EDF represents over 50 million people with disability across Europe and its members include the National Councils for People with Disabilities from the 27 member states as well as over 100 disability specific European NGOS. EDF gives a common voice to disabled people in Europe, and we are particularly working to influence and be a partner to the European Union as well as to the Council of Europe. I am also deeply involved with organisations representing people with Down syndrome and their families, locally here in Ireland and on a European and International level. However first and foremost, I am the father of a 28 years old man with Down's syndrome, who lives an independent life although he still lives at home. This is what gives me the background to be speaking to you here today.

The theme for today is ENHANCING the quality in social care services for disabled people. What I will try to do is to tell you how the picture looks in the eyes of disabled persons and their families. My hope is that this perspective can inform our discussions today. At the end of the day, only disabled people and their families are the ones who are able to say whether a social service is of quality or not. All other evaluations of such services are instruments that should serve to enhance the user's quality of life and the experience of this quality.

I will take my starting point in the right for disabled people to live included in their community whether as Children or Adults. As children we should expect that people with disabilities can expect to be educated in their communities and that perhaps the primary responsibility for the education of people with disabilities should be with the Education ministries rather than social services or health. However today I wish to concentrate on the provision of social care services to our adults and the need for these to be community based – because, most importantly, this is the basis for the proper provision of services to disabled people.

Community based services will be built around but not central to the provision of housing to disabled people which can be a core service in itself. It is this kind of service that offers an enormous potential to improve the quality of life of disabled people, and it is a sector where we see many problems all over Europe, even in 2008.

My starting point is underpinned by Article 19 of the recently adopted United Nations Convention on the Rights of Persons with Disabilities states the following:

States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs

These points match very well with the parallel action line of the Council of Europe Disability Action Plan. So the international policy framework is in place. It is true to say that these two international human rights instruments enjoy strong support and backing from the disability movement. But what does this mean when we are talking quality of social services?

In a European context this means that the human rights violations taking place in residential institutions across Europe must come to an end. There are still, thousands and thousands of people with all kinds of disabilities still living in big institutions – without any kind of private space, without the possibility to go out of the institution, without proper contact to their family, without the possibility to get an education and receive training, and are deprived of any means to break out of this unacceptable situation.

I know that much work is being done to remedy this situation here in Ireland and we are hearing announcements of people with disabilities particularly people with Intellectual disabilities being moved to community settings from long stay residential centres into the community. This is to be welcomed but we must ensure that EU structural funds are not used to build further long stay institutions for people with disabilities any where in Europe.

We need to build up a community based system of care services with a range of custom made services for the person with a disability. One size does not fit all. Care services should cover the spectrum of total independent living. Tailor made supports should be put in place to cover the spectrum of outcomes whether it is living independently with your family, to smaller homes for groups of people who prefer to live together with others living totally independently in the community. This wide range of different settings is not only important in order to meet the individual person's needs, it is also the key to ensuring that there is a real choice for the disabled person and their family .

One thing which might seem obvious is that we will have to stop thinking in terms of physical structures or what has been termed as an edifice complex. In my opinion, this kind of mindset on physical structures still sometimes derails our efforts. We should instead try to think in terms of service delivery and logistics. By this I mean that it should be taken as a given that we have disabled people living in many different places in many different ways in our societies. What is needed for them is a service system that can support them in their daily tasks. This requires flexible planning and close consultation and cooperation with individuals and families. The independent living movement has demonstrated that it is manageable to put such a system in place. What we need to do now is to ensure that the supports in place matches the whole spectrum of disabilities, including persons in need of a high level of support.

The possibility for the disabled person and their family to be involved in the choice of residential setting creates a totally different framework for the provision of services. If you can say “I would prefer this or that”, or “I will definitely want to avoid this”, it empowers you to put pressure on the service provider. And this is the case regardless of how the services are financed. The possibility to vote with your feet so to speak is fundamentally what gives you the power to ask to have your requirements fulfilled.

In addition, the choice for disabled people and their families is a way of changing focus for service providers. Not only is intense dialogue needed in order to make the right choice for both users and providers, also, the expressed wishes and choices of disabled people and their families will be a constant and continuous evaluation for service providers. I am of the opinion that this kind of feedback is absolutely essential.

In order to put in place a system that allows for a real choice, advice and counselling is very important. As a basic prerequisite, advice should be given by independent persons, and not the service providers themselves. Now this is not to say that service providers should not be involved along the way. It is rather to say that disabled people should have persons with experience and knowledge to support them in the dialogue and their choice, and that such persons should not have vested interests. It is even more important to remember that some people will need so-called supported decision-making in order for them to be able to make the right choice. And this should be seen as an integral part of a system for advice and counselling.

The custom made service to be adopted for a person with a disability should not be restricted to what is already on offer from the service provider. Rather for a quality service to be delivered the provision should be adapted to suit the individuals need rather than the individual adapting his requirements to suit what is on offer by the social care provider. I have personal experience of this where the provision of a service to my son was being tailored to suit what the service provider had to offer. There did not appear to be a choice but eventually when my wife and I kept pushing them they became more creative and a reasonable result ensued. We are still in negotiation with them about other issues. DSI recently completed a survey of parents concerning the provision of service to their sons and daughters. The respondents were basically satisfied with the service they were receiving but felt that it fell very short of a complete and appropriate service. I am aware of three instances where families have had to relocate in order to get an appropriate service for their child with disability because the local service providers were not prepared to adapt to accommodate the family. The almost monopolistic provision of services in parts of the country leaves people with disability with little choice but to accept what is on offer.

It is probably clear from what I am saying that the quality which I am talking about is something that goes across traditional organisational, financial and psychological boundaries. Quality lies in the experience of the disabled person and their ability to make choices and influence daily life. This also means that quality can not be measured only as an aspect of the delivery of a particular service, say assistance with dressing, physical rehabilitation or supported decision-making. Quality can in its true sense only be measured by getting an impression of whether the full package of services available to a person, supports them in reaching their full potential, and even more fundamental, how the person themselves feel about the situation. This should be taken into account when formal

evaluations are carried out. Service providers should be obliged by their contracts with public authorities be obliged to contribute and take active part in such person-centred, cross-sector and interdisciplinary evaluations with the aim of providing a more holistic service.

There is not the time today to explore the resources need to accomplish the above or even the funding of same. Much can be achieved with existing resources with a little bit in imagination and thinking slightly outside the box. I know this from personal experience. However the provision of social care services to people with disabilities should not be seen to be an easy target in the present economic environment. Rather it has been proven that the proper delivery of an appropriate service can in the long run reduce costs and be more of benefit to society in general.

What in essence I have been leading up to is that a genuine partnership between disabled people and their families, the authorities, the service providers and importantly representative organisations of disabled people is a prerequisite if we want to achieve the holistic service I argued for above. It means that all the parties need to engage in this partnership and be prepared to take on board the experience of people with disabilities and their representative organisations. Organisations of disabled people should be willing to engage in such partnerships at international, national and local level assuming they are given adequate resources to be a reliable and legitimate partner that can contribute with expert knowledge in relation to their specificity.

I think I will stop here to allow for sufficient time for questions and discussions. In a nut shell my message is that the right to live included in your community is the basis, and that services should be tailored to allow for this, not the other way round.

Thank you very much for your attention.