
What Now ... Where Next?

Introduction

These days there's great talk of change. A lot has happened in the disability area, although some might say that it's a case of "much done but an awful lot more to do".

The "much done" includes the Disability Act 2005, the EPSEN Act 2004, the development of the HIQA Standards for residential services and the UN Convention on the Rights of Persons with Disabilities. There has also been much talk about alternative ways to support our sons and daughters with an intellectual disability and/or autism.

The "awful lot more do" includes the fact that much of the legislation, the Convention and the Standards have not been implemented. While some service providers are seriously trying to support service users in a different way, most of our sons, daughters and siblings are experiencing the same traditional care models.

Nevertheless, there's change in the air. These changes have raised parents' expectations and ambitions. They have also raised their fears and hopes.

Change is definitely in the air. But there's a great lack of detail concerning what will await parents and family members when the changes have been made, if they are made. Will things

be better after the dust of change has settled?

While there's much talk, there's precious little detail. Lack of detail leads to many problems for parents. First, there's fear! Many parents have good reasons for fearing change – previous experience would warn them that change often means even further reductions in supports. There's also hope for some parents – in some cases it's the hope of desperation. Those among us, watching our family members with a disability going through bad times, may be forgiven if they feel change couldn't produce any worse results than the current situation. Therefore, they embrace it unquestioningly. There are also the many families, travelling through the world of disability, hearing good and bad reports and just wondering what all the talk is about.

This information pack attempts the huge task of looking with a balanced eye at the supports given to our sons and daughters with intellectual disabilities and/or autism. However, we are very much aware that one person's balance is another person's bias. Yet we'll try to get that balance. We will be looking at the quality of our sons' and daughters' lives today and how their lives might be improved. We intend to paint a picture of hope. However, this picture of hope will not be simplistic and unquestioning.

If we are to improve our sons' and daughters'

lives we are very clear about one thing. There is no formula for giving non-disabled people a good life. Likewise, there is no formula for giving their disabled fellow citizens a life which is happy and fulfilling. Therefore, we will not be giving a single solution or formula for improving their lives. Our sons and daughters are individuals with their own personalities, wishes and needs.

We hope the message from this information pack will be that people should be supported in making a life for themselves *in a way which suits them*.

In it we hope to give information to parents and family members about how their sons' and daughters' lives might be improved. We are very conscious of the huge commitment that most families give to caring for their family member with a disability. This commitment is gladly given but involves much time and effort. Therefore, we are not advocating that the time and effort given by families should be further increased. Instead we point out the ways our family members' lives may be improved without disimproving the lives of those close to them.

This resource pack is primarily for parents, family members and carers of people with intellectual disability and/or autism. However, others involved in the disability community may also find it interesting.

In summary, what do we ultimately hope that you will get from this resource pack?

- We hope you will get some information about the changes “in the air”.

- We hope also that parents and family members will be able to look at the new ideas with less fear.
- We hope that it will begin a conversation regarding its contents. We are aware that this pack doesn't have all the answers, but we hope that it will encourage further discussion and debate.

Finally, we hope that it will be one step in the process of improving our sons' and daughters' quality of life.

Thanks

The NPSA would like to thank the many people who assisted with the production of this information pack. People edited the material, gave opinions regarding content, assisted with the layout, assisted with the printing and supplied the funding to make it happen. Without all the help this resource pack couldn't have happened.

They are:

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