

WHAT NOW ... WHERE NEXT?

PART A

HOW THINGS ARE NOW

– for people with intellectual disability and/or autism.

What is it like to be a person with an intellectual disability and/or autism or a family member in contemporary Ireland? This section takes a quick look at how it is for many people.

OVERALL LOOK AT THE SITUATION:

According to the National Intellectual Disability Database (NIDD) Report 2009 there are 26,066 people with intellectual disability or autism in the country. Many would dispute this figure (see section on NIDD, page 8). However, for the moment, let's take this as a correct figure.

Of those registered on the database 17,284 people are attending day services. The bulk of these people are living at home, mainly with family members. 7,974 people are receiving residential services. 992 are living independently or semi-independently. Respite services were used by 5,336 people.

The figures quoted above refer to day services, residential services and respite services provided directly by the HSE or service providers funded by the HSE. Some of these providers are looking at innovative ways to provide supports for people with intellectual disability and/or autism. However, in general, the concept of "services" equates with the trio of residential, day and respite services.

Here are some questions that are asked about people with disabilities and their lives:

DO PEOPLE WITH DISABILITIES HAVE A GOOD QUALITY OF LIFE?

It is often assumed that our family members are happy and haven't a care in the world. Yet if we asked ourselves would we swap places with them, few would jump at the option. If our sons or daughters are so happy, why shouldn't we want some of their happiness?

The answer to that question is that, in general, they don't have a great quality of life. Our family members with disability have relatively little control over their lives. They are often continuously supervised and they are often isolated from their non-disabled peers. In short, for many, they are not accorded the same status in society as the rest of us.

This poor quality of life has been identified by research which was conducted in Ireland in 2007. It was entitled "The quality of life of people with disabilities in Ireland in 2007" and was undertaken by Bob McCormack and Margaret Farrell, then working with St. Michael's House in Dublin. They found that the quality of life of people with disabilities was considerably worse than that of their non-disabled fellow citizens. While the average quality of life of people with disabilities was bad, for those with a severe or profound intellectual disability, it was much worse. Those living in institutions also fared very badly, while people living independently or at home, tended to fare better. A short summary of the findings can be seen in Appendix 1 at the back of this information pack.

HOW DO PEOPLE WITH INTELLECTUAL DISABILITY AND/OR AUTISM SPEND THEIR LIVES?

Many people with intellectual disability and/or autism access service providers. Most of these agencies would claim that they provide a wide variety of activities for their service users.

However, there is a general pattern about many of them. For example, day services often involve groups of people doing the same thing at the same time. Residential services involve a number of people living in the same accommodation. Respite services very often involve a number of people going to the one respite house.

These models have developed because it was considered to be more cost effective for people to be grouped. In this way it was believed that each group could be under the care of a relatively small number of people.

This would be a satisfactory arrangement for the individuals concerned if every person within the group in a day service wanted to do what the agency provided for them and if every person within the group wanted to do that activity with the other people in the group.

It would work in a residential house (or other form of residence) if every person in the house was prepared to share their home with a number of other people and was prepared to share with the particular people in that house.

It would work in a respite house if every person in the house wanted to spend a holiday in the

company of those others who have been selected by the service provider to share his or her holiday.



So, what happens if a person with a disability doesn't want to be told how to spend their day or doesn't like the people they're expected to spend their day with or to live with? This often depends on how the disabled person expresses their discontent. If he/she is a quiet individual and not given to complaint then they might never complain and may appear to be enjoying the process.

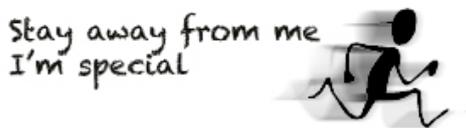
If they voice their complaints in a calm fashion, the service provider might either try to persuade them to continue with the group or might attempt to make some modifications to the activity or the group. If they are consistently vociferous or more physical in their complaints they might be labelled as being "challenging".



WHERE DO PEOPLE WITH INTELLECTUAL DISABILITY AND/OR AUTISM SPEND THEIR DAY?

Most services are run exclusively for people with intellectual disability and/or autism. That

is, there are no service users who don't have a disability. Most activities are "special" activities. That is, they are run specifically for people with disabilities and don't involve non-disabled people except for the staff of the service provider. Therefore, the day is spent within a particular "special" campus. Even if they leave the campus they accompany each other and do things together. The result is that they are virtually surrounded by an invisible barrier which essentially keeps people away from them.



IS IT POSSIBLE THAT A SERVICE USER COULD HAVE AN INDIVIDUAL PLAN FOR THEIR LIFE?

By and large, people have very little choice as to what they do. The degree of choice varies from provider to provider but, in general, it is far from satisfactory.

In terms of planning a person's life, many providers use Personal Outcomes Measures. This is controlled by the Council on Quality and Leadership (CQL) which is a US organisation that works with service providers. Their vision is "community inclusion, dignity and quality of life for people with intellectual and developmental disabilities".

The providers use Personal Outcomes Measures for their person centred planning process. There are twenty three measures in all and they are aimed at judging a person's quality

of life (the full list of these outcomes is listed in the Appendix 1). CQL advocate a gradual improvement in a person's quality of life. The plan is called an Individual Plan or IP.

The first year the IP will address three areas of the person's life and will aim for particular outcomes in these areas. So, they might say that the person will have the following improvements in their life: "Improve my social life", "Improve my independence" and "Increase my participation in the community".

The next part is to decide what particular goals will be achieved within these categories.

Under "Improve my social life", it might be agreed that the person's friends will be invited to visit every month.

Under "Improve my independence", it might be decided that the person will be taught how to get the public bus to his/her day centre.

Under "Increase my participation in the community", it might be agreed that the person will join a walking club and will go out for walks with the club once a month.

Each year the IP will introduce three new areas to the plan but will also continue with the previous years' goals.

This is a laudable attempt to improve a person's life. However, it does not appear to produce radical change. Because of the nature of the process, any improvements to the person's life are likely to be within the current

system. What this means is that little or insufficient emphasis is given to developing services or supports outside of that which can currently be provided or are usually available. Further, parents indicate that in many cases they are not consulted, so the improvements are very often influenced by service provider staff. Also, the earlier improvements are often forgotten by staff and “fall by the wayside”.



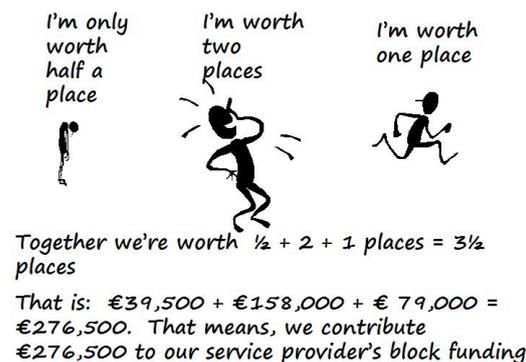
HOW ARE SERVICE PROVIDERS FUNDED?

At present, most of the supports for our sons and daughters are provided through service providers. The service provider initially applies for money to provide a service for the person. When applying, there is a great deal of information given about the person. Nevertheless, there is little connection between the way funding is given and the real needs of the person.

The Health Service Executive (HSE) tends to give bundles of money called “places”. Each “place” is worth a certain amount. For example, a residential “place” before the recession was worth €79,000. A person with high needs might be given two “places” (€79,000 multiplied by 2 = €158,000). Another person might be funded for half a “place” (€39,500). Most people would get one “place” (€79,000). Obviously, using this method, there is quite a

crude relationship between the money and the person’s needs.

Over the years as a person’s needs change, the connection between the funding allotted to an individual and his/her needs becomes ever more blurred. Eventually, for most service providers, the funding just becomes mixed into one pot of money. Periodically, the “pot” is increased by an agreed percentage to keep up with the cost of living (in bad times it might be reduced). The “pot” might also be added to by the HSE giving the service provider extra “places”. The funding for the extra places quickly becomes part of the “pot”. This whole system is often called block funding.



In recent years, some service providers have tried to calculate the actual cost for each person within a service. In this way they would have a list of all their service users and a particular cost attached to each person. Obviously, if they added up all the costs the total should equal the service provider’s total income. This process is called unbundling.

Unfortunately, although the idea of unbundling sounds like a good idea, the funding process has not been consistent between service providers or within different areas of the country. For

example, after the unbundling exercise it is quite possible that two people with similar needs with two different service providers could have quite different bundles assigned to them.

Therefore, there are major difficulties in the present system. For example, if the Government announced that people with disabilities could take their "pot" of money from their service provider and use it to satisfy their real needs, some, with different service providers or in different parts of the country, would get a lot more or a lot less than others.

HOW DO PEOPLE WITH INTELLECTUAL DISABILITY AND/OR AUTISM GET A SERVICE?

In the case of a child or a person who has not had any service, generally, parents approach a service provider for a place with that agency. That provider, if they have an available funded place might accept the person (child or adult) into their service.

If they don't have a place free the service provider might offer to negotiate with the HSE for the funding for a place.

Sometimes the parents approach the HSE themselves. This is not a regular occurrence.

Once the person is with the service, most, if not all, negotiations occur between the service provider and the HSE. For example, consider a person who is with a service and his/her parents felt it was time to ask the service provider for a

residential place. The provider would decide how urgent the case was. If it was an emergency case, at the next opportunity they would put a case for funding to the HSE. In the meantime, they might make temporary arrangements for the person by, for example, giving him/her a place in a respite house.

On the other hand, if, in the opinion of the service provider, the case was not urgent then the person would be put on a waiting list. Generally, families are not made aware where their family member is on the waiting list or when they might hope to get a place.

Most years, a sum of money is assigned to funding extra day, residential and respite places. In lean times this might only cover emergency places. In better times more money will be assigned to allow people to be taken off the waiting lists.

WHAT ARE RESIDENTIAL SERVICES LIKE?

A small number of residential services are in institutional settings, that is, people live in large buildings. In some cases these institutions only provide dormitory accommodation. Several television programmes have highlighted the huge problems with some of these institutions.

Many people are living "in the community" in houses that are situated in housing estates. These, very often, provide accommodation for between four and seven people and are usually called Community Houses. Most people in these residential settings are cared for by staff

employed by whichever service provider is providing the accommodation.

A very small number of people with intellectual disability and/or autism are living independent lives, some supported and some totally on their own.

At present, there are no inspections of these residential settings, although standards have been prepared by HIQA (see Appendix 3). Residents have no right to such basics as being informed in writing what to expect from the service.

WHAT POWER HAVE PARENTS IN THE SYSTEM?

Parents and other family members have very little power in the whole process of providing supports for their children. If they are looking for a service from the HSE and if they are strong people and are prepared to badger all authorities or are even prepared to take their cause to public representatives, the media or even the courts, they might improve the position for their son or daughter. However, there is no guarantee of success even if they have a just cause and are very vocal.

Sometimes legislation contains appeals systems where parents have a right to complain. However, all of these systems are resource-based. That is, if the Government has not allocated enough funding then there is no point in appealing because the appeal systems cannot insist that money be made available.

Different service providers have developed different ways of empowering parents. However, most of these systems give the service provider the final say. There is no independent appeals person within the service structure who could look at a person's case and find against the service provider.

Sometimes, service providers set up Parents' Councils to give parents a voice. However, they are often tightly controlled.

In some cases, service providers allow parents to sit on the Board of Management. Again, it is often a tightly controlled process. It has even happened that systems are developed to ensure that parents who might be inclined to ask awkward questions are excluded from boards.



HOW DOES THE STATE PLAN SERVICES FOR PEOPLE WITH INTELLECTUAL DISABILITY AND/OR AUTISM?

(i) The National Intellectual Disability Database

The Health Research Board (HRB), see Appendix 4, is charged with maintaining a database called the National Intellectual Disability Database (NIDD). According to its website "The National Intellectual Disability Database (NIDD) is a set of information that outlines the specialised health services currently used or needed by people with intellectual disability." It also goes on to say that the database informs government and those who plan on a regional level with regard to:

- Details of people with "intellectual disability". "What are their ages, gender and level of intellectual disability, and how have these changed over time?"
- "How many people with intellectual disability are receiving specialised health services and what services do they receive?"
- "How many people with intellectual disability are waiting for specialised health services, what service are they waiting for and when, in the next five years, do they need these services?"

The NIDD was established in 1995 and has more than 25,000 registered on the database. It is managed by the HRB on behalf of the Department of Health and Children.

Points about the NIDD.

- a. People on the NIDD are described as having "intellectual disability". The Database actually caters for people with intellectual disability and people with autism. At the same time, it never mentions autism.

- b. People cannot be compelled to have their name on the database. Basically, it is a voluntary process. Thus some people are not registered on the database.
- c. Because of the fact that it equates intellectual disability with autism and never differentiates between the two, parents of people with autism are sometimes reluctant to have their sons' or daughters' names on the database.
- d. In 2007, an audit of NIDD was undertaken. It found that there were great inaccuracies in the database:
 - Overall data on NIDD was 72.2% accurate (19.3% inaccurate, 8.5% missing). This means that more than a quarter of the overall information about our sons' and daughters' needs which was sent to the HRB was either incorrect or was missing.
 - Current day services was 76.8% accurate.
 - Future residential services was 49.6% accurate. This means that when it came to stating the number of people who needed a service, more than half the information wasn't accurate. We don't know in what way it was inaccurate, but would guess that the need for residential places was exaggerated.
 - The audit highlighted a significant gap in relation to the involvement of families in the return of data to the NIDD: those who carried out the audit

recommend that this be addressed by developing mechanisms for the inclusion and involvement of family members in the care of their loved ones.

- e. It's interesting to compare the NIDD figures with a survey done by the Central Statistics Office of Ireland. In 2006 they conducted a National Disability Survey (NDS) that indicated that there were 50,400 people in Ireland with an intellectual disability. The reason for the discrepancy has been attributed by the HRB to a difference in the way each group defined a person with an intellectual disability. The NDS includes all intellectual disability from mild to profound, whereas the NIDD in general only includes those deemed to be in need of a specialised health service. Considering the above points this is hardly a complete explanation.

(ii) The NCSE Database

The National Council for Special Education (NCSE) is charged with overseeing and improving the process of education to children with special needs. Part of their remit is to keep a database of the children that receive assistance from the NCSE.

According to the NCSE the "Special Educational Administrative System (SEAS) is a purpose designed and built computer system to provide an efficient and effective special education administration system for use by the NCSE staff and management. It enables SENOs (see Part E, section on Education) and other NCSE staff to efficiently manage and

maintain school, pupil, and SENO information, maintain applications for teaching hours, SNA (see Part E, section on Education) posts, assistive technology and transport. Statistics are produced from the System which assist the research function of the Council."

SEAS is purely for internal use and it is not published. Obviously, this database will only ever contain information on children up to age eighteen.

(iii) HSE Reports of the Assessment Process Under the Disability Act 2005

Under the Disability Act 2005 each person with a disability is entitled to an assessment of needs. At the time of writing, the Act has only been implemented for people who were under the age of 5 in June 2007.

Under the Act, the HSE is obliged to produce an annual report in relation to the overall needs identified, including an indication of the periods of time ideally required for the provision of the services, the sequence of such provision and an estimate of the cost of such provision.

In agreement with the Department of Health, the HSE's stated aim is to produce a report which identifies the shortfall in service provision as defined by the assessment of need process under the Act. That is, the gap, if any, between the needs identified and the actual services provided.

So far, such data has not been assembled. The main reason is that, so far, the software is not

available to do so. There are other issues including difficulties in reporting people's needs. There is also the fact that the assessment currently only covers children. The HSE claims that it is difficult to predict how young children will respond to particular interventions. Sometimes, they "outgrow" their need for an intervention or may need considerably more than was originally predicted.

One worrying thing about the assessment process is that it takes an average of twenty-six hours to conduct a first assessment. This might be spread out over several days and performed by several assessors. This time is considered by the authorities to be too high, considering that each person assessed might be expected to also have an annual review. There are very real fears that if the assessments continue at this level the system will not be able to cope.

FINAL COMMENT

The NPSA is very keen that the above should be seen as a comment on a system rather than a comment on particular service providers or individuals employed by service providers. We are very much aware that staff at all levels work in this area because they want to help and support people with disabilities. We have no doubt that there are many good people working in services and there are many good services.

What we describe above is a situation where shortage of cash and the culture within services make it difficult for the majority to provide the perfect service.