REACH Journal of Special Needs Education in Ireland, Vol. 19.1 (2005), 16-22

Disability Act 2005: A Response

This article is based on the written submission of the National Parents' and Siblings' Alliance on the Disability Bill 2004 but is updated to reflect the changes to the Bill which occurred during the various stages of its passage through the Oireachtas. It deals only with Parts 1 and 2, services to people with disabilities, of what is now the Act.

SEAMUS GREENE is Director of the National Parents' and Siblings' Alliance and the parent of a daughter with an intellectual disability.

BACKGROUND

In the Autumn of 2004 the Oireachtas Justice Committee invited interested groups and persons to make submissions on the Disability Bill 2004 which was published in late September, 2004. The National Parents' and Siblings' Alliance (NPSA) made a written submission and were invited to give a verbal presentation on November 16th.

Following considerable lobbying, the Bill was passed by the Oireachtas in June 2005 with relatively few changes and was signed by the President on July 8th, 2005. Although the Act is now passed, this does not mean that it will come into operation immediately. Each part must wait for a ministerial order before it is implemented. This is different to the Education for Persons with Special Educational Needs (EPSEN) Act which had to come into operation no later than twelve months after the President signed it. So, the EPSEN Act came into operation on July 19th, 2005, by default. On the other hand, if the Minister were to choose, the Disability Act 2005 could be left on hold indefinitely.

INTRODUCTION

Our Constitution states that all people should be treated equally. In recognition of this the Education for Persons with Disabilities Bill had its name changed to the Education for Persons with Special Educational Needs Bill. The reason was to emphasise that the purpose of such legislation is to create structures which will satisfy the *needs* of people with disabilities in order to allow them to live in this country as equal citizens. It is logical for any society to develop systems which satisfy the essential needs of its citizens. However, in Ireland, it has not been part of the culture of our lawmakers to address the essential needs of people with disabilities and so, the disability community continues to call for legislation to remove this inequality. Such legislation must begin with the assumption that people with disabilities are equal in society and therefore, rather than being dependent on charity, have the right to be treated in the same way as their non-disabled peers.

The Disability Act 2005 fails to do this. Its effect is, in fact, to give legislative support to the inequities that currently exist. For this reason we say that it must be drastically re-drawn and that without this being done we could not take it seriously in any way.

It is the belief of the NPSA that the Government does not understand or does not wish to understand the difference between assigning resources to cater for the *needs* of people with disabilities and finding a formula that makes the allocation of funds an administratively simple process. This can be seen in the education area in relation to the custom of allocating resources to mainstream schools on the basis of a pupil's diagnosis rather than on the pupil's need.

In our submission we concentrated on the major issues in the Act. There are many others which could only be addressed when essential changes have been made.

DEFINITION OF DISABILITY

The definition of disability in the Act is an example of failing to address the needs of people with disabilities. It is very narrow and aimed at excluding a large number of people from receiving an assessment and resulting services. We cannot accept the argument that the definition is narrow to ensure that limited resources are aimed at those in most need. Essentially, in using this definition, it means that the Government still has no intention of providing the services that people with disabilities need to live as equal citizens. Surely, the most important point is that the definition should ensure that *all* people receive the services they *require*.

We believe that the fears of those who espouse a narrow definition are misplaced. If the assessment process is properly organised and carried out by appropriately qualified people, then the Assessment Report will contain a statement of each person's real needs and will, by definition, not contain what they do not need. Thus resources will be channelled towards the resolution of such needs.

During its passage through the Oireachtas the definition was changed slightly. However, the definition in the Act is still some distance from taking account of the points made above.

RIGHT TO AN ASSESSMENT

Despite the fanfare at its launch and, in particular, the claims that people would be given an unconditional right to an assessment, in reality the Act contains no such right. The original Section 5, after it had been carefully translated from the language of obscure legal wording in which it was written, actually put an onus on the relevant minister to sort out all other issues before considering the needs of those with a disability. Therefore, in a bad year financially, it would have been quite conceivable that there would not be enough money left to allow for assessments.

When the NPSA made its presentation to the Joint Oireachtas Committee on Justice, Equality and Law Reform, the Government TDs present were quite scathing about this point. Deputy Peter Power (Fianna Fáil) stated, "Section 5 is clear-cut in its statement that 'an assessment under this section shall be carried out without regard to cost or the capacity to provide any service identified in the statement as being appropriate to meet the needs of the applicant concerned'". Section 5 was later re-written and this time the wording was very clear. It stated unambiguously that assessment would be resource-based. It must be said that Minister Frank Fahey, speaking for the Government, has stated that he finds it impossible to imagine that money would *not* be available for assessment.

ASSESSMENT REPORT AND SERVICE STATEMENT

The process in the Bill of separating the Assessment Report and the Service Statement means that people might never receive certain services stated in their Assessment Report. There is nothing in the Bill that compels any decision makers to refer back to the Assessment Report and eventually ensure that everyone fully receives what they require. The NPSA believes that the Assessment Report should constitute the active document on the provision of a person's needs. The aim should be for the document to remain open until such time as the needs of the person are satisfied.

A second difficulty which arose during the later stages of the Oireachtas debate was aired by Minister Fahey in the Seanad. This occurred when discussing the duties of the Assessment Officer and the Liaison Officer. The job of the Assessment Officer is to carry out assessments. The Act states that "an assessment under this section shall be carried out without regard to the cost of, or the capacity to provide, any service identified in the assessment as being appropriate to meet the needs of the applicant concerned" (Disability Act 2005, Part 2, Section 8.5).

On the other hand, the Liaison Officer must take into account

> *(d) the practicability of providing the services identified in the assessment report,*
> *(e) in the case of a service to be provided by or on behalf of the Executive, the need to ensure that the provision of the service would not result in any expenditure in excess of the amount allocated to implement the approved service plan of the Executive for the relevant financial year* (Disability Act 2005, Part 2, Section 11.7)

During the Seanad Debate on the Bill (July 14, 2005), Senator Tony Kett stated "the assessment officer is the person one looks to to give one's assessment without any consideration of how much it might cost whereas the liaison officer is quite the opposite, being the person who is cost-conscious when he or she is setting out one's service statement. …. For this reason, these two positions could not be intertwined".

Minister Fahey replied by saying, "The two roles are fundamentally different and it is in the best interests of people with disabilities that they remain separate. This is not to say that the same person could not fulfill both roles at the same time, that of the assessment officer as a statutorily independent officer and that of the liaison officer".

In the opinion of the NPSA this is a matter of major concern. It is impossible to imagine a person, as assessment officer stating the needs of the disabled person regardless of cost and, having become the liaison officer, to suddenly change mode and list the services the person will actually be given having taken into account the resources available.

“WHERE RESOURCES ALLOW” AND “WHERE PRACTICABLE”

The combination of these phrases in the Bill constitutes huge barriers to people ever achieving what they require.

One of the important aspects of rights-based legislation is the pressure it puts on Government to ensure that the people needed to provide necessary services are available and in place. So, for example, if many people need speech therapy and there are no trained people available then the fear of court action will encourage the decision makers to train sufficient people to satisfy the expected need. In this Bill not only have people no right to take court action other than on a point of law but neither is there any other form of onus put on Government to actually ensure that the necessary people are in place to provide services. The phrase “where practicable” ensures that the opt-out clause will be constantly used, that is, “Sorry there’s no one on the ground to provide the service and therefore it’s not practicable to provide it”.

Also, history has shown that, where there is no pressure on government to provide services for people with disabilities then they will be left at the bottom of the heap. Ironically, this can often mean that when they reach adulthood not only have people with disabilities been damaged by State neglect but also the intervention then required is even more costly. Therefore, it goes without saying that it is the belief of the NPSA that the only really effective way to force Government to treat people with disabilities in an appropriate fashion is through proper rights-based legislation.

MULTI-ANNUAL FUNDING

It has become a common cry of the Government that they are providing multi-annual funding and that this will resolve all the issues. The NPSA welcomes the promise of a funding package. Obviously, if regular funding had been provided in the past we would have confidence in governments’ willingness to treat people with disabilities like all other citizens. However, this is not the case and, in five years time, the multi-annual funding will stop but babies with disabilities will continue to be born. All they will have to protect them is legislation, and this particular bill will do little in that regard.

The above point, made before Budget Day, was illustrated when the Budget was announced. Despite the fact that the figures sounded very impressive the actual allocation was far from satisfactory. The figure quoted was €890 million. However, this was an accumulated figure measured over four years. The actual sum given in 2005 for improved intellectual disability and autism services came to €40 million of which €24 million was taken back on what the Government called “value for money” cuts.

The NPSA has calculated that, if the sum involved in the multi-annual funding package was extended until the present waiting lists were eliminated, in 2020 there would still be a small number from today’s waiting list without a service. Obviously, in the meantime, many others would have joined the waiting lists. The Government has said that they will increase the promised sums each year as need dictates. The next budget will show how serious they are regarding that promise.

SERVICE PROVISION AND COMPLAINTS PROCEDURES

The system of service provision and complaints is expensive and cumbersome. Having received an assessment, a person might go through four different stages of the next process:

- First the Liaison Officer decides which of the person's needs are not going to be satisfied and which will be satisfied. This is stated in the service statement.
- Then the Complaints Officer will try to resolve any contentious issues informally.
- Then the Complaints Officer will try to resolve the issues formally.
- Finally, the Appeals Officer will go over the same ground again.

In all cases the officers are bound by the "resources" and "practicability" restrictions. It is difficult to see many situations where there would be other reasons for not giving services. Therefore, the system is merely a very expensive means of saying "no" in four different ways. Clearly, the end result is that much of the funding for disability will be consumed by a huge bureaucracy rather than on much needed services.

It seems that the drafters of this bill believed that the appearance of taking the needs of people seriously was more important than actually doing so. In the process they are using huge sums of money to do it - money that could be better employed providing services.

The complaints superstructure is not independent. In Part 2, of the four deciding officers (including the Assessment Officer), three work for the health board and one works for the minister. It is difficult to see how these people, in making their decisions, will not come under pressures and influences such as the culture of the health board, the knowledge of what staff etc. are available, the fact that they will be making findings against their own colleagues or, in the case of the Appeals Officer, the attitudes of the minister.

SECTION 20

It is the belief of the NPSA that Section 20 is this Act's version of Section 47 from the Disability Bill 2001. Essentially, its effect is to ensure that people cannot take any court action except on a point of law, which of course is constitutionally available to all of us. We believe it should be removed.

OTHER ISSUES

As has been stated above, the main difficulty with the Disability Act 2005 is that, in the words of the Disability Legislation Consultation Group (DLCG), it is "fundamentally flawed". For as long as this is the case it is very difficult to take the details seriously. In short, we believe that this Act needs major amendments. However, if the Government manage to resolve these issues to any satisfactory extent then other issues would need to be addressed. We will not discuss these in detail at this stage as we feel there is no point until the substantive issues are corrected. However, we would simply state that unlike the

Education for Persons with Special Educational Needs Act 2004 there is a remarkable lack of detail in this Act.

For example, there is no indication as to the composition of the assessment team. Equally, there is no indication as to what qualifications the Liaison Officers and the various Complaints Officers will have. Also, there are few time-frames given within which the various procedures must be carried out. There is some doubt if the Assessment Report could include reference to residential and respite places. However, as stated already, these and other issues are merely academic at this point.

IN CONCLUSION

The Disability Act 2005, is a fundamentally flawed document. We believe that it should never have been passed and that it will only be satisfactory when a large amount of amending legislation is introduced which addresses these flaws.

The text of the Disabilities Act 2005 may be had by accessing www.irlgov.ie; under “Other Links” click on “Houses of the Oireachtas”; under “Legislative Information” click on “1997 – 2005 Acts of the Oireachtas in PDF format”. The Act is dated July 8th 2005.