

ACCESS TO SERVICES FOR PEOPLE WITH DISABILITIES

The Potential for Improved Enforcement of Legal Rights through a Personal Advocacy Service

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A INTRODUCTION

According to the 2002 census, there are 323,707 people with intellectual or physical disabilities in Ireland, a significant proportion of whom are resident in institutions. Many of these people have no information about their legal rights, are denied access to essential services and on a more pragmatic level, have no control over the minor details in their lives which most people take for granted, such as what to eat or wear or who will help them when they need assistance. Until now, the law which attempted to protect these marginalized groups was based on traditional notions of welfare and charity, or formal protection from discrimination.

However, as Banks states, the time has now come to enact more interventionist resource-based measures, “to break down the barriers which make the law inaccessible for people with disabilities.”¹ A step forward in this direction has been the Government’s Disability Strategy, which includes the Education for Persons with Special Educational Needs Act 2004, the Disability Act 2005, and the Citizens Information Act 2007. These legislative instruments contain provisions to ensure that people with disabilities can have their needs assessed and associated services provided, thus enabling them to participate more fully in our society.

B WHAT IS ADVOCACY?

This is where the relatively new concept of “advocacy” for people for disabilities becomes important. Due to the nature of disability, it is difficult for many people to negotiate the formal legal process required to obtain these rights. At a very basic level, advocacy has been described in the Goodbody report² as “a means of supporting or speaking up for someone, their needs and rights”. This is echoed in the definition of the functions of a personal advocate in the Citizens Information Act 2007, in which advocates should aim to ‘assist, support and represent the person [and] promote the best interest of his or her health, welfare and well being.’³

At present, advocacy for people with disabilities in Ireland is provided solely by community and voluntary organisations. In the past, this advocacy tended to be informal, but with the establishment of the Citizens Information

¹ Banks, R. “More than Law ‐ Advocacy for Disability Rights” in Jones, M. & Bassar Marks, L.A., *Disability, Diversability and Legal Change* (The Hague; Boston: M. Nijhoff Publishers, 1999) at p. 343.

² Goodbody Economic Consultants *Developing an Advocacy Service for People with Disabilities* (Commissioned by Comhairle: Dublin, 2004).

³ Section 7D, Citizens Information Bill 2006.

Board,⁴ the advocacy of non-governmental organisations is being recognised in an increasingly formal structure. However, according to the legislative provisions of the Disability Strategy, the State must take more responsibility for providing effective advocacy services to people with disabilities. In the Goodbody report, it was envisaged that this responsibility would include establishing a Personal Advocacy Service (PAS), supplemented by a Programme of Support for Advocacy Services in the Community and Voluntary Sector, as well as providing a Community Visitors Programme⁵ to deal with the treatment of people with disabilities who are long term residents in institutions. The Citizens Information Act sets out the legal framework for an independent State-operated PAS, under the guidance of the Citizens Information Board, to assist people with disabilities in accessing their legal entitlements.

C COMMUNITY AND VOLUNTARY ADVOCACY IN IRELAND

Of the three strands to developing advocacy services in Ireland recommended by the Goodbody report, only one has formally commenced. This is the Programme of Support for Community and Voluntary Advocacy Organisations. The Citizens Information Board has allocated specific funding to distribute to the organisations which adhere to its Advocacy Guidelines, and the Budget for 2007 provided an extra €16 million in measures to assist people with disabilities, including allocating funding to the Citizens Information Board for developing a PAS and implementing the Disability Sectoral Plan.⁶

The Goodbody Report expected that this programme would be implemented 2 years prior to the establishment of a PAS. The aim of this strategic approach is that the voluntary advocacy organisations will have some time to identify the most vulnerable groups and areas in which advocacy is particularly urgent, so that the State-operated PAS can focus on the most urgent advocacy cases when its work commences.

The primary justification for the establishment of an independent State body to provide advocacy services for people with disabilities is that it is difficult to ensure coherency, transparency and equal distribution of resources to all people with disabilities simply by providing funding to local community and voluntary advocacy groups. Therefore, there is a clear need for a State service to step in to meet the advocacy needs of people with disabilities, rather than delegating responsibility to voluntary organisations, even those which operate under the Citizens Information Board's Advocacy Guidelines.

D WHAT IS A PERSONAL ADVOCACY SERVICE?

⁴ The Citizens Information Board (formerly Comhairle) is the Irish national agency responsible for supporting the provision of information, advice and advocacy on social services to ensure access to services.

⁵ The Citizens Information Board has stated in its strategic plan 2006-2009 that it will also take responsibility for establishing a Community Visitors Program in Ireland, similar to the program provided by the Office of the Public Advocate in Victoria, Australia.

⁶ Summary of 2007 Budget Measures – Policy Changes, Department of Finance.

A PAS is to be an independent state body whose function is to assist people with disabilities in accessing essential social services. This will be done through assisting people in making applications for services and submitting formal complaints if services which the person is entitled to are not provided. Advocates should also provide support and training to the person and their family while the applications or complaints are being made. Qualification for this advocacy service will be based on need, so if a person with a disability needs a service which he or she is unable to obtain without the assistance of an advocate and there is a substantial risk of harm to the person if they do not receive the service, they are entitled to a personal advocate.⁷ Both adults and children with disabilities are eligible to apply, but in the case of children, it must be proved that their parent is not capable of assisting the child in obtaining their entitlements.⁸ Applications must be made in writing and should state the services which the person is seeking, but the Minister can specify another acceptable form of application.⁹ In acknowledging the issue of potential lack of resources, the legislation has also specified grounds on which the PAS should prioritise their services, namely, urgency of needs and risk of harm, degree of benefit of having an advocate appointed and availability of alternative advocacy services to the person.¹⁰

The Comhairle (Amendment) Bill was the first legislative instrument to contain provisions for the establishment of the PAS. This Bill was presented to the Dáil on 17th September 2004, by the then Minister for Family and Social Affairs, Mary Coughlan. According to Oireachtas records it was never debated and never passed beyond the first stage in the Dáil. The Bill was originally intended to form part of the National Disability Strategy along with the Disability Act and Education for Persons with Special Educational Needs Act, but seems to have been overlooked in the legislative process. It was replaced by the Citizens Information Act, which was introduced as the Citizens Information Bill by the current Minister for Family and Social Affairs, Seamus Brennan, on 13th October 2006. This Bill became law on the 21st of February 2007. The new Act mostly echoes the provisions of the 2004 Bill as discussed above, but it also alters the overall structure of the Citizens Information Board and grants an expansion of powers in its provision of information services and funding opportunities. However, some important amendments to the original provisions have been added, and these are discussed below.

Firstly, in Section 1, the Act sets out the regulations and responsibilities of the Citizens Information Board in terms of its relationship with voluntary advocacy organisations. This section recognises that the Board needs to co-operate with both statutory and voluntary bodies in promoting advocacy for people with disabilities. In addition, it provides that the Board can set out

⁷ Section 7A (2), Citizens Information Act, 2007.

⁸ Ibid . This seems to be a provision to protect the Constitutional rights of the family, but could also be considered a cost-saving mechanism, since the PAS plans to deal only with the most serious cases of denial of rights. The Bill takes the view that if parents are capable of advocating for their children they should do so, rather than applying for an advocate on the basis that a personal advocate may be perceived as being more effective.

⁹ Section 7B (1), Citizens Information Act, 2007.

¹⁰ Section 7A (4), Citizens Information Act, 2007.

terms and conditions for giving support and funding to voluntary organisations which provide advocacy services, having regard to its aim of creating an integrated, reliable and comprehensive information service.

An important adjustment to the original wording of the 2004 Bill is Section 7A.3 which states that a person will not cease to be a qualifying person solely because he or she is in receipt of a social service. While any advocacy service is required to prioritise cases according to urgency of the client's needs, it is encouraging that the legislation has recognised that a person will not be excluded simply because some form of service provision has been given to them. Perhaps the most innovative feature of the new Act is that it establishes a streamlined appeals process for decisions to refuse applications to the PAS.¹¹ This provides opportunities for appeals of decisions at every stage of the advocacy process. The applicant now has the right to appeal if the Director of the PAS refuses their application for a personal advocate. This refusal can also be reversed if new evidence comes to light. In addition, Section 9.3.6 provides that the appointments and decisions of the Citizens Information Board must be reviewed every 3 years, not every 5 years as suggested by the 2004 Bill. Personal advocates have substantial powers under the new legislative framework. For example it is an offence to obstruct the advocate when he or she is carrying out their functions, and advocates have the right to enter at any reasonable time any place where care or training is provided to their client and make inquiries.¹²

Unfortunately, the legislation has not provided a legal framework for the Citizens Information Centres and Services, or other voluntary organisations to refer cases to the PAS, although it remains to be seen whether this will occur in practice. However, the Act has retained the requirement in prioritising cases that the Director of the PAS has regard to the availability of other advocacy services, presumably those available in the community and voluntary sectors. This is one aspect of the Act which proved controversial during the parliamentary debates on the legislation. If this model is adopted in the future, it could be a means for the State to deny responsibility for service provision to people with disabilities, contrary to the aims of their National Disability Strategy. The Disability Federation of Ireland has criticised this provision along with the requirement that to qualify for a personal advocate, the person with a disability must apply in writing, or such other form as the Minister may specify, stating what services he or she is seeking to obtain.¹³ These provisions require the qualifying persons to already understand their rights and express them adequately. It is argued that the aim of an advocacy service is to enable a person to express their needs and access appropriate services, so that these requirements may be obsolete.

Fortunately, during the Committee stage debates on the Citizens Information Bill, an amendment was introduced to specify that application in

¹¹ In line with the appeals process contained in the Social Welfare Consolidation Act 2005, Chapters 2 and 4 of Part 10.

¹² Section 7D (2) and (3), Citizens Information Act, 2007.

¹³ Disability Federation of Ireland, Submission on the Comhairle (Amendment) Bill, April 2006.

writing would mean filling out an application form and that this could be done by any person on behalf of an applicant.¹⁴ Another amendment has also set out the responsibility of the Director of the PAS to inform specified persons about how a potential qualifying person can make an application to for a personal advocate.¹⁵ The definition of specified persons includes carers, relatives or organisations involved in the promotion of the health and welfare of the potential applicant.

The Citizens Information Act has not specified who will qualify as advocates. If the PAS advocates are to be professionals, an issue arises as to whether they should be trained as social workers or whether a network of professionals from various backgrounds will be called upon, depending on the type of advocacy required in a particular case. However, in the parliamentary debates on the Act, the Minister for Family and Social Affairs introduced an amendment to require that all personal advocates should have such qualifications, expertise and experience relevant to personal advocacy as the Citizens Information Board considers appropriate.¹⁶ As an example he stated that “third level education, experience of dealing with clients in relevant areas and good judgment” would be some of the essential attributes of personal advocates.

Training of advocates, both for the PAS and for community and voluntary advocacy organisations is vital to ensure the independence of advocates from other service providers and promote the effectiveness of advocacy services. In its strategic plan 2006-2009, the Citizens Information Board has recognised the importance of training advocates with regional seminars for volunteers and formal accreditations e.g. FETAC’s “Information, Advice and Advocacy Practice” module. It is envisaged that the new legislative structure provided by the Citizens Information Act will facilitate the creation of further formal training programs for personal advocates in the future.

E THE AUSTRALIAN APPROACH

The Goodbody report undertook a study of the various advocacy systems in operation in twelve different jurisdictions and highlighted the Australian advocacy service, in particular the Office of the Public Advocate in the State of Victoria, as a potential model for advocacy services which could be followed in Ireland. In Australia, most States provide funding for voluntary advocacy organisations but in Victoria, there is direct State provision of advocacy services by the Office of the Public Advocate (OPA), a statutory office, accountable to the State parliament.

The Public Advocate in Victoria is appointed by the Governor in Council pursuant to the Guardianship and Administration Act¹⁷ and is responsible to the Victorian Parliament. His or her role is to represent the interests of people with a disability, “aiming to promote their rights and

¹⁴ Amendment 39, Committee Stage Amendments to the Citizens Information Bill 2006.

¹⁵ Amendment 33, Committee Stage Amendments to the Citizens Information Bill 2006.

¹⁶ Amendment 13, Committee Stage Amendments to the Citizens Information Bill 2006.

¹⁷ Section 14, Guardianship and Administration Act 1986 (Vic).

dignity and to strengthen their position in society.”¹⁸ In Australia, advocacy is regarded as being closely linked with Guardianship and other decision-making mechanisms for people with disabilities. Responsibility for appointing Guardians to protect vulnerable people with disabilities who are deemed not to have decision-making capacity is vested in the Victorian Civil and Administrative Tribunal (VCAT),¹⁹ and VCAT often appoints the OPA as Public Guardian, to protect the rights of people with disabilities.

Through co-operation with VCAT, the OPA has been instrumental in conducting investigations in situations where people with disabilities are at risk of abuse, neglect or exploitation. The OPA also advises the Minister and other interest groups on issues of legislative reform. For example, the OPA dealt with concerns regarding the Disability Act 2006 by meeting with the Minister for Community Services to discuss the implications of compulsory treatment for persons with an intellectual disability. Having expressed concerns about the application of the Act to people with cognitive disabilities, the Minister in her second reading speech gave an undertaking to the Public Advocate that a possible extension of this part of the Act will be investigated.²⁰

The individual advocacy service provided by the OPA is based on Section 22.2 of the Guardianship and Administration Act, which sets down the principles that the wishes of the person must be considered, decisions made must be in the best interests of the person and the least restrictive solution must be sought. This differs somewhat from the principles of advocacy used by many community and voluntary groups both in this jurisdiction and in Australia, as it does not act solely according to the wishes of the person, with the primary aim of empowerment. As mentioned above, the PAS as established in the Citizens Information Act will require advocates to apply a principle of best interests in advocating for the rights of those they represent. The Australian concept of best interests as formulated by the OPA could therefore be of use in the Irish context.

The OPA approaches the ‘best interests test’ in a novel manner by incorporating both subjective and objective perspectives. It attempts to discern how the person’s interests and values are affected by their present situation and weigh the relative importance of their different interests in the decisions to be made. This test distinguishes between two different types of interest, critical and experiential. Experiential interests are things liked due to the experience of the activity, for example, music, or art. If we cease to get pleasure from these experiences we will lose interest in them. However, critical interests are values of the overall direction we want our lives to take and represent what we believe to be a meaningful and good life. The OPA is carrying out research in this area which demonstrates that critical interests usually outweigh experiential interests.²¹ In the case of guardianship and

¹⁸ OPA Mission Statement, Annual Report, 2006.

¹⁹ Section 3 and 19, Guardianship and Administration Act 1986 (Vic).

²⁰ Scrutiny of Acts and Regulations Committee, Alert Digest 3 of 2006, “Disability Bill 2006, Second Reading Speech, 1st March, 2006.”

²¹ Annual Report 2006, Office of the Public Advocate, Victoria.

decision-making, the aim is to balance both critical and experiential best interests of the person.

Having taken into account the person's subjective interests, a guardian or advocate may still have to make a substituted judgement. The test here is if the represented person had decision-making capacity, what decision would they come to? This part of the test involves an objective element of analysis. It is a difficult balance which the OPA is trying to achieve by using this test. Perhaps the most difficult challenge for the Public Advocate in this respect is to understand why the represented person may be making choices which appear to conflict with his or her best interests or well being. This may be simply because the person gives different weight to competing values at stake or it might be due to serious defects in decision-making capacity.

Since Guardianship deprives the person of the autonomy to make decisions, it is viewed as a last resort by VCAT and if the OPA is to exercise decision making power on behalf of the individual it must adhere to the principle of the least restrictive option in order to protect individual autonomy. However, the potential conflict between the best interests of the person and their expressed wishes is also a concern for advocates in determining how best to represent a client, which will have to be dealt with in the new legislative provisions in this jurisdiction.

The main difference between the PAS and the OPA is that the OPA has substantial responsibilities in the area of guardianship, an issue which has not been addressed in the Citizens Information Act 2007, but which is in need of reform according to the Law Reform Commission.²² In Ireland, there is no system of guardianship for persons with a cognitive disability, short of the cumbersome Ward of Court procedure, which is increasingly viewed as outmoded and unsuitable to the needs of many people with disabilities.²³ The guardianship responsibilities of the OPA are in accordance with their aim of protecting people with disabilities from abuse, neglect and exploitation, aims of the PAS which are echoed in the new legislation. If the PAS were to form part of a broader State support which included an updated guardianship system, this would involve major reform in the area of determining a person's capacity to make decisions and provision of mechanisms for substitute decision-making.

F CONCLUSION

The establishment of a PAS in the provisions of the Citizens Information Act is a positive step in the promotion of legal rights for people with disabilities. However, the PAS will be unable to operate effectively in a vacuum, and to this extent it will require full co-operation from all bodies involved in the provision of social and healthcare services. PAS can be used as an enforcement mechanism to strengthen the positive rights set down in Part

²² Consultation Paper on Law and the Elderly, 2003 and Consultation Paper on Vulnerable Adults and the Law: Capacity, 2005.

²³ Ní Chulacháin, Siobhan "Wardship: Time for Reform", 2000 (5) Bar Review 239.

II of the Disability Act 2005.²⁴ However, this part of the Disability Act has not yet commenced. In the Sectoral Plan prepared by the Department for Health and Children, the Minister announced that this part of the Act should be commenced for children under 5 from June 1 st, 2007, in line with the provisions of the Education for Persons for Special Educational Needs Act 2004. The Minister envisaged that Part II would be commenced for all other people with disabilities by 2011. This statement has raised concerns about the potential for PAS, since it is designed primarily to assist adults with disabilities.

The involvement of community and voluntary advocacy organisations in this jurisdiction has led to an improvement in enforcement of rights for people with disabilities. It is also encouraging that these bodies are now eligible for funding once they have complied with the Citizens Information Board's Advocacy Guidelines.

However, the interaction between these bodies and the PAS has not been specified in the legislation. In Australia, the OPA uses grassroots activity to operate community-based programs, through which various groups of volunteers are accountable to the Victorian Parliament. This could be a potential model for addressing the extent of community and voluntary involvement in advocacy in the new Irish legislation.

Further legislative expansion on the principles which will guide the operation of the PAS and its role in protecting the rights of people with disabilities is needed for the system to realise its full potential. It is hoped that this article, along with the commentary of disability support organisations on the new legislation, will raise the profile of advocacy and give rise to legislative reform in this area, as well as highlighting the potential for reform of guardianship services for people with disabilities. It is important these steps are taken so that the PAS is not merely seen as a token gesture for people with disabilities. Otherwise "the advocacy service in years to come [may] be the subject of ministerial excuses, as at present, with regard to systems failure."²⁵

²⁴ This Part sets out legislative rights for people with disabilities to have their needs assessed and associated services provided to them.

²⁵ Seymour Crawford, T.D. Second stage debate on the Citizens Information Bill 2006.

BIBLIOGRAPHY

Albrecht, G. L., Seelman, K. D. and Bury, M., *Handbook of Disability Studies* (USA: Sage Publications, 2001)

Armstrong, F. & Barton, L. (Editors) *Disability, human rights and education: cross cultural perspectives* (Philadelphia: Open University Press 1999)

Barnes, C., Barton, L., & Oliver, M. (Editors) *Disability Studies Today* (Cambridge: Polity Press, 2002)

Blanck, P. (Editor) *Disability Rights* (London: Routledge, 2005)

Campbell, J. & Oliver, M. *Disability politics: understanding our past, changing our future* (London; New York: Routledge 1996)

Corker, M. & French, S. *Disability Discourse* (Buckingham; Philadelphia: Open University Press, 1999)

Doyle, B. *Disability Discrimination: Law and Practice* (Bristol: Jordans, 2005, 5th edition)

Doyle, O. *Constitutional Equality Law* (Dublin: Thompson Round Hall, 2004)

Ginsburg, N. *Divisions of welfare: a critical introduction to comparative social policy* (Sheffield: Sheffield Region Centre for Science and Technology, 1992)

Goodley, D. *Self-advocacy in the lives of people with learning difficulties: the politics of resilience* (Buckingham: Open University Press, 2000)

Gray, B. & Jackson R. (Editors), *Advocacy and Learning Disability* (London: Jessica Kingsley, 2002)

Minnow, M. *Making All the Difference: Inclusion, Exclusion and American Law* (London: Cornell University Press, 1990)

Quin, S. & Redmond, B. *Disability and Social Policy in Ireland* (Dublin: University of Dublin Press, 2003)

Quinn, G., McDonagh, M. & Kimber, C. *Disability discrimination law in the United States, Australia and Canada* (Dublin: Oak Tree Press, 1993)

Thomas, C. *Female forms: experiencing and understanding disability* (Buckingham; Philadelphia: Open University Press, 1999)

Whyte, G. *Social Inclusion and the Legal System: Public Interest Law in Ireland* (Dublin: Institute of Public Administration, 2001)

Comhairle, *Entitlements for People with Disabilities* (Dublin: 2002)

Comhairle, Report of the CIC/Comhairle Working Group on Advocacy (Dublin, 2003)

Comhairle, The Jigsaw of Advocacy (Dublin: 2003)

Department of Health and Children, in association with the National Disability Authority, National Standards for Disability Service (Dublin, 2003)

Comhairle Guidelines for provision of Advocacy Services (Dublin, 2005)

Duane, E. "Children with Disabilities and the Law" [2004] 2 IJFL 8 Forum of People with Disabilities, Advocacy: A Rights Issue (Dublin, 2001)

Goodbody Economic Consultants, Developing an Advocacy Service for People with Disabilities (Commissioned by Comhairle: Dublin, 2004)

Irish Human Rights Commission, Observations on the Disability Bill 2004 (Dublin, 2004)

Kamba, W. "Comparative Law: A Theoretical Framework" [1974] 23 ICLQ 485

Kimber, C. "Equality and Disability" (2001) 6 Bar Review 494, (2001) 7 Bar Review 66

Office of the Public Advocate – Annual Report 2006 (Melbourne, 2006)

National Disability Advocacy Program, Enhancing the National Disability Advocacy Program, Consultation Paper, (Canberra, 2006)

National Disability Authority, Exploring Advocacy (Dublin, 2003)

National Disability Authority Submission to Joint Committee on Justice, Equality, Defence and Women's Rights regarding Disability Bill 2004 and Comhairle (Amendment) Bill 2004 (Dublin, 2004)

Nolan, B. On rights-based services for people with disabilities (Dublin: The Economic and Social Research Institute, 2003)

Quinn, G. "Intellectual Disability Cut-Backs: Politics without Principle" (Paper delivered at Menlo Park Hotel, Galway, 3 June, 2003)

Sykes, D. "Towards a model of disability advocacy practice" (Paper presented at ASSID National Conference Melbourne November 12-25th 2001)