

*Disability, Difference
and Democracy.
Some Rights and Wrongs.*

by Dr Pauline Conroy

TASC is happy to host a space for alternative viewpoints.
The views expressed in TASC *Thinkpieces* are those of the authors.

**Disability, Difference and Democracy.
Some Rights and Wrongs.**

Pauline Conroy B. Soc. Sc, M.Sc. PhD.

The historical treatment of disability in Ireland

There are 326,000 people in Ireland who have declared that they have a disability – about eight per cent of the population. Depending on how the statistical data is gathered, the proportion of people with disabilities could rise to 15 or 20 per cent. The majority of us will become older and frailer eventually, with increasing propensity to develop enduring health conditions which will interrupt the course of our lives. Many people with disabilities still live in a disabling environment with restricted opportunity to live a self-determined life. This think piece critically analyses some of the major changes in services, laws and ideas in relation to disability which have come into being in the last 15 years.

Social, cultural and economic forces have functioned to block the achievement of a full citizenship status for people with disabilities. Among the obstacles are the scattered privatisation of service provision, a related lack of transparency in how public expenditure is actually incurred and a reluctance to cede the autonomy and independent living arrangements which people with disabilities want and expect as equal citizens. To understand where we stand today, we need to look back a bit to the heritage of exclusion, segregation and discrimination.

End of the Heroic-Tragic Era

The heroic-tragic era of policy in relation to disability has almost come to an end. This was the era when people with disabilities were regarded as without equal humanity or ability, save for a few exceptions. The exceptional persons were and still are held up as heroic, remarkable, extraordinary and unusual. They were not even regarded as a reserve army of labour, since their work was not considered to have any human capital value. In their time, there were champions: Lady Valerie Goulding in starting a rehabilitation movement or Christy Brown inspirationally touching a public nerve. The emergence of organisations such as the National Association for Cerebral Palsy in 1948, the Polio Fellowship and Rehab in 1949, the Irish Wheelchair Association in 1960 and the National Association for Mentally Handicapped of Ireland in 1961 – now Inclusion Ireland - these were radical departures but did not subscribe to an individual or collective rights based approach to disability, or if they did, were not perceived to do so. Some of the negative attitudes towards disability in the 1950s are illustrated by the survivors of Ireland's polio epidemic,¹ and by survivors of special residential institutions for children.²

¹ Nuala Harnett (ed) (2007) *Polio and Us – Personal Stories of Polio Survivors in Ireland*, Post Polio Support Group,

² Paddy Doyle (1989) *The God Squad*, Transworld Publishers, see also Commission of Inquiry into Child Abuse, (2009) *Commission to Inquire into Child Abuse Report, 2009, Confidential Committee, Volume III.*, Stationary Office, Dublin, pp. 235-261.

People with disabilities were regarded as tragically deficient or inherently without great capacity or ability. In the case of the Catholic schools for the Deaf, concerns about the wholesale proselytism of the souls of Catholic children by Protestant clergy had been one the main motivation in the establishment of religiously separate education for Deaf children.

*'...even though famine was sweeping the country and millions of Irish were dying or leaving the country on emigrant ships, the Catholic Committee in Dublin made a nation-wide appeal to raise funds for establishing ...St. Mary's School for Deaf Girls and St. Joseph's School for Deaf Boys in Cabra, Dublin.'*³

Following a nineteenth century tradition of segregating people who were different, dissenting or threatening into large private closed institutions: prisons, hospitals, and asylums, people with disabilities were often separated from their parents at an early age and sent to residential schools where they were prepared for manual and menial occupations or reserved jobs. Hence given their 'difference,' combined with a perceived lack of productive capacity, a view formed that people with disabilities had little to offer. Thus, they were effectively interned in institutions. 'Personal tragedy' resulted in institutional confinement. People with disabilities were to experience and suffer a particular form of social control.⁴ The era of segregation commenced and disabled people were displaced from the workplace,⁵ and from public life.

The Medical Model of disability

While nowadays much is made of the humanitarian and charitable claims of the segregated system, this is an attribute that remains to be demonstrated in evidence. With the 20th century, the medicalisation of disability advanced with ever greater emphasis placed on diagnostic, treatment and curative approaches to efface, erase or make people with disabilities and health conditions disappear, including miraculously at Lourdes. Instead of being locked away, children and adults with disabilities were to be normalised out of their difference.

Their conditions are attributed to a traumatic physical and psychological effect, which create impairments. This assumes that persons with a disability are unable to ensure a reasonable quality of life for themselves. This view is the basis for the medical model of disability. Pat McDonnell in his 2007 sharp critique of the medical model describes it as portraying a '*personal problem of and for the individual concerned, and solutions are offered primarily in terms of individual (re) adjustment*'. A view

³ Patrick A. Mathews (1996) *The Irish Deaf Community, Volume 1*. The Linguistics Institute of Ireland, Dublin, p.61

⁴ Mike Oliver, (1990) *The Politics of Disablement*, Macmillan, Basingstoke.

⁵ C. Barnes and G. Mercer, (2003) *Disability*, Polity Press, UK.

among many professionals who accept the medical view of disability is that persons with a disability are incapable of managing their own lives.⁶

In contrast, a second explanation is based on the social model of disability, developed by sociologist Mike Oliver. This proposes that economic, cultural and social barriers faced by persons with a disability are the main barriers to the attainments of their citizenship rights.

A legislative flurry in the nineties

The new era of change combined the emergence of organisations of people with disabilities, rather than for people with disabilities and the challenging of segregated institutions. By the late eighties and the early nineties, thinking internationally was shifting with the United Nations adoption of the *Standard Rules for the Equalization of Opportunity for People with Disabilities* in 1993. The rules had a significant effect in many countries including Ireland and on Ireland's establishment of a *Commission on the Status of People with Disabilities*. The *Standard Rules* articulated the influence of many organisations of people with disabilities in developing a new concept of disability, which established a relationship between the limitations experienced by people with disabilities and the design and structure of the environment, as well as the attitudes of the general population. This was the social model of disability, a critique of the medical model and the eventual opening out of civil rights perspectives.

The Commission on the Status of People with Disabilities was a landmark event in both process and outcome. The Report of the Commission – *A Strategy for Equality* - marked the arrival of a disability social movement and the modernisation of concepts and practice. By 1995, there had been a distinct turnaround in thinking about disability on the part of people with disabilities and their families and on the part of many academics, intellectuals and public servants including inside major international organisations. Outside of this narrow radius, thinking about disability remained locked in helpless stereotypes and charitable collection boxes at supermarkets.

The five-year period from 1995 to 2000 was a fast growth period for Ireland in terms of employment, population, direct foreign investment, inward migration, the growth of purchasing power and a Peace Process in Northern Ireland. An atmosphere of high optimism prevailed which dared to hope that improvements in the status of people with disabilities would finally take place, untrammelled by budgetary constraints, cultural backwardness and charitable concepts.

There was a flurry of innovative legislative drafting:

- Education Act, 1998 which appeared to guarantee equal access to education for all – but did not,
- Employment Equality Act in 1998 including nine grounds for discrimination, of which one was the disability ground and establishing the Equality Authority. The Act made statutory provision for unequal pay between people with disabilities and people without disabilities in Section 35

⁶ M. Oliver as note 4.

(1) where their productivity is lower than a person without a disability. This laid a basis for wage subsidy schemes and for the institutionalising of unequal pay,

- National Disability Authority Act in 1999,
- In the field of public and private services an Equal Status Bill was published in 1999, which failed to be enacted due to disability considerations on the first time round. The Bill was later amended and enacted in 2000,
- The National Social Service Board was converted into Comhairle and conferred with new responsibilities for disability related information provision,
- A Disability Bill was published in 2003 and was later withdrawn,
- The Mental Health Act, 2001 was enacted but much of it was not commenced.

Establishing a new legislative framework was an essential prerequisite to turning ability/disability issues and discourse away from the sacrificial frugality of the past towards a more promising and statutory future. The Good Friday Agreement in the mid nineties guaranteed the establishment of equivalent Human Rights Commissions North and South of the island and which saw the publication of a Human Rights Commission Bill in 1999. The 1994 social partnership agreement *Programme for Competitiveness and Work* departed from practice and devoted an entire section to reform of measures to remove policies, which were barriers to people with disabilities.

The outcome of the five years produced several new state institutions and new legislation to provide for equal treatment in a wide range of fields. Huge effort in consulting, drafting, reflecting and considering the legislation and the institutions was provided by organisations of people with disabilities, their families and by staff in the public and not-for-profit sector. However there was considerable resistance to change. Some not-for-profit services, some public representatives among those with a charity-oriented perspective and among housing and transport providers still saw disability rights as a financial burden to accommodate a minority. Despite their exhaustion from lobbying, organisations and groups of people with disabilities, their families, and supporters insisted on highlighting the flaws in the new battery of legislation.

The Main Policy Landmarks of 2000+ and their Directions

Many of the 1990s laws had to be amended or new laws drafted to take account of disability rights more specifically. It was a period of impatience that despite the initiatives of the 1990s, change was occurring at such a slow pace and some disabled people were not apparently benefiting at all from new services or approaches.

- The Equal Status Act of 2000 had to be amended in 2004 to comply with new anti discrimination Directives emanating from the European Union, related to disability specifically,⁷

⁷ Council Directive 2000/43/EC, Council Directive 2000/78/EC Directive 2002/73/EC. See Preamble to Employment Equality Act, 2004.

- The same occurred for the Employment Equality Act in 2004. Section 35 of the Act was retained without any significant public commentary on unequal pay,
- *The Health Strategy Quality and Fairness: a Health System for You 2001* was a policy document, which caused an amount of excitement in its day. It was an opportunity lost in terms of providing immediate ease of access to services for people with disabilities and equitable distribution of services and entitlements,
- The Disability Act, 2005 was an achievement relative to conditions of the 1990s and a disappointment in that it contained reform but was not especially radical. Some view it as overly restrictive in relation to definitions of disability, limited in scope, and regard the assessment of need system to be convoluted and complex. The absence of clear remedies, legal redress, complaints and appeals was a serious concern and a deficit noted by the Irish Human Rights Commission. Many key provisions have never been commenced five years later. The Bill obliged half of Government Departments to produce Disability Plans,
- A new Education Act had to be introduced The Education for Persons with Special Education Needs Act, 2004 as the Education Act, 1998 was just not working for children with disabilities,
- The Comhairle Act had to be amended in 2004 to provide for an Advocacy Service, since rights and information were not flowing to people with disabilities,
- The establishment of a Mental Health Commission by statute and a Mental Health Act 2001 broke the policy connections to a nineteenth century approach to mental health difficulties. The Act allowed for several new civil liberty checks and balances for persons in Centres offering treatment for mental illness. The report of the *Vision for Change: Report of the Expert Group on Mental Health Policy, 2006* succeeded in synthesising the many demands for forward looking strategies for those at the margins of the edge of society,
- The adoption of the Human Rights Commission Act in 2000 led, eventually, and not without controversy, to the establishment of a Human Rights Commission under the Chairmanship of Mr Justice Donal Barrington (now retired) and the appointment of Commissioners.

For many the early years of 2000 will be remembered for the intensity of discussion over the need and content of a new Disability Act. This was the site of many rallies, assemblies and meetings organised by people with disabilities, their families, supporters and friends. A collaboration (Disability Legislation Consultation Group) between large organisations, federations, service providers, and lobby groups of people with disabilities agreed on the core elements of a new Bill in 2003 Independent Needs Assessment and Advocacy figured high on their Agenda. This progressive movement was sustained by the fact that 2003 was the European Year of Disability that the Programme for Government committed to publishing a Disability Bill in 2002. *The Programme for Prosperity and Fairness, 2000 – 2002*, and the *Sustaining Progress: Social Partnership Agreement, 2003 – 2005* clauses on disability issues added strong legitimacy to a radical legislative reform as well as reform of sheltered services and sheltered employment.

Disability Services – a private affair on the quasi-market

Private bodies supply the majority of residential, day service, training and sheltered work-oriented services for people with disabilities. This is especially the case for people with intellectual disabilities where 90% of services emanate from private providers. In the market of day services in Ireland, the Department of Health and Children and the Health Service Executive are purchasers of services from a vast array of private suppliers (service providers). The fact that there may be no profit in the transaction between purchaser and supplier is of no relevance to the marketised relationship. Some of the suppliers are 'preferred' and obtain funding (using different statutes) on a more advantageous basis than others.

The user's relationship is such that they cannot purchase services directly and this is a characteristic of 'quasi' markets. The user is essentially secondary to the market, the terms of which are fixed by purchasers and suppliers. In contrast to, for example financial services, this is an as yet relatively unregulated market and with few fixed statutory standards to ensure equality of product or service between various suppliers for the same amount of money.

As in any market arrangement, niche markets and sub sectors in markets appear over time, specialising in workshops, vocational training and supported employment. As this occurs, so do monopolies manifest themselves in sub-sectors or niches. This can be accompanied by mergers and acquisitions, whereby one service entity in say Limerick, takes over the work of another in the same sector but in a different region of Munster or region adjacent to their own. The appearance of monopolies is not a moral issue; rather it is an inevitable consequence of market operations over time. It is of concern when there is an abuse of market position with implications for other suppliers, users regulation or standards or an actual distortion of the functioning of the market. There is evidence of some underlying resentment, that some private not-for-profit providers reduce choice for adults, parents and children with disabilities.⁸

A study of the Comptroller and Auditor General⁹(2005) suggests that Ireland had reached quite an advanced level in the relationship between purchasers and suppliers. In Ireland, within a market of competing bodies, 69% of all funding to not-for-profit bodies in the field of disability went to just 25 organisations in 2005.

Across the market, 'battles' are fought out sometimes with some suppliers, sometimes with purchasers, sometimes with groups of users and in combinations of all or none. Important among these issues has been that of the recognition and identity of people with disabilities. As with sexual orientation or gender, the drive to assert difference and to develop claims on the basis of affirming, legitimising and articulating difference has been vocal in the last twelve years. Claims have been based on the disability rights attached to (often medicalised) categories of difference and degrees of difference.

Some of this institutional movement has prompted new respectful interaction; some has encouraged separatism, intolerance and even chauvinism. The identity model, according to US theorist Nancy Fraser,

⁸ Author's observations.

⁹ Comptroller and Auditor General, 2006, Value for Money Report No. 52, *Provision of Disability Services by Nonprofit Organisations*.

suggests that failure to recognise difference is a misrecognition or harm. Battles over identity recognition and recognition of difference displace battles over redistribution. This problem can be codified in law or in a multitude of institutional sites. What the battle over recognition, in relation to disability in particular, does not address, is the issue of redistribution of resources, such as day services, training resources, work and income generating opportunities, supports to independent living, rights and entitlements. Indeed going a step further, an over amplification of identity – as persons with a disability – could reduce surveillance on maladministration of resources.

Recognition of difference involves giving recognition to the specificity of some groups (Autism Spectrum Disorder or wheelchair users) and their difference. Redistribution, which is contradictory to recognition of difference, emphasises sameness, and the right of individuals and groups to be treated equally to others. The tension between the two principles can be frequently pitched to the point of hostility or blaming. This can take the form of ‘blaming’ policies of the Health Service Executive as being overly oriented to difference and recognition of identities while blaming the policies of FÁS to be overly oriented to sameness by offering entitlements to and opportunities for training and work.

At the end of the first decade of the 21st century, individuals and families with disabilities, who had only just started getting their say in policy development found themselves bearing harsh cuts in paltry services and paying for their own services. Between 2008 and 2010, the basic payment: Disability Allowance has been cut along with other social welfare payments. This affected 95,000 claimants. An estimated 10% of Special Needs Assistant posts for children with disabilities in mainstream classrooms and in Special Schools have been cut. Adults living in residential centres full-time or part-time have to hand over up to 80% of their social welfare payments to service providers to pay for their own keep. The hours of Personal Assistants to support independent living have been reduced.

Conclusion

The historical barriers to full citizenship have yet to be lifted for and by people with disabilities. Despite extensive discourse and narrative concerning equal rights and equal status, some basic provision still lack, some of which have been enacted in legislation which has never been put into operation. Going to the theatre, enrolling your child in secondary school, entering the polling station – such are major battlegrounds of rights and resources. The right to live independently with people of your own choosing or none, in a place of your choosing with the essential adjustments for everyday living- these are modest enough proposals in a modern democracy.

Service provision is wrapped up in a quasi- market of funders and suppliers of services to the detrimental exclusion of individual service users, their advocates or families. This quasi market forbids mobility between providers depriving the service user of the most basic element of the capitalist market – the freedom to purchase.