

“Draft” Position Paper on People with Mild Intellectual Disability (MID)

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Psychologists working with people with intellectual disability are concerned that the needs of adults with mild intellectual disability are not being met adequately either by generic, mainstream services or by specialist services for people with intellectual disability.

The PSI Learning Disability special interest group are proposing:

1. A position paper on the needs for adults with a Mild Intellectual Disability (MID), and
2. That PSI facilitate a policy making initiative inviting representatives of the intellectual disability sector, relevant mainstream services and service users to critically review concerns and current service provision for this population.

Introduction

Policy framework on learning disabilities since the late 1960's in the U.S. and since 1980's in Ireland has been to:

- Provide services for people with mild intellectual disability through non-segregated, generic or mainstream health, education, income maintenance, housing and social services i.e. mainstreaming; and
- Target specialised longterm supports from the Intellectual Disability sector to people with with moderate to profound intellectual disability.

The social policy of “mainstreaming” children and adults with mild intellectual disability has some roots in the 1960s approach of the (U.S.) President’s Committee on Mental Retardation, which identified the concept of the “Six Hour Retarded Child” in its 1969 report. This reflected an understanding of *that* time, that these children only needed special supports in school but that out of school and post school, they became adults who adopted typical social roles without any great difficulties, without needing help. Irish social policy reflected in the “Needs and Abilities” policy on mild intellectual disability probably fits within this American approach or context. Since the 1960s, society has changed radically in terms of technological advances. A greater degree of sophistication and material wealth is now required to adapt to modern life. Research since the 1969 report has now shown that people with mild

intellectual disability have been at greater risk than the “normal” population and have not been able to avail adequately of mainstream services. These risks include:

- Poverty & Homelessness
- Physical ill health
- Injury & Violence
- Psychological Disorders
- Victimisation & Maltreatment
- Lowered Life Satisfaction
- Child removal, foster care
- Judicial System failures
- Women are at even greater physical and mental health risk, and
- Women have lowered life satisfaction.

Persisting with exclusively mainstream services, without adaptation for people with mild intellectual disability perpetuates the risks that such people face in life.

Prevalence of Mild Intellectual Disability

The National Intellectual Disability Database (NIDD) is the statutory mechanism for reviewing and planning services for people with intellectual disability in Ireland. There were 24,917 people registered on the National Intellectual Disability Database (NIDD) in 2005. The administrative prevalence rate for mild intellectual disability is 2.16 per 1,000. There is therefore a considerable underestimation of the prevalence of adults with MID. “This figure is not a true reflection of the prevalence of mild intellectual disability as *only those with mild intellectual disability accessing or requiring intellectual disability services are included in the database*” (NIDD 2005, italics added). Conservative estimates would suggest that the true prevalence of MID is likely to be 8.0 per 1,000. In one recent study in Cork City, it is estimated that less than 10% of adults with MID are known to the intellectual disability services (Feehan & Daly, unpublished paper).

Less than one in four (23.4%) of the population with moderate, severe, or profound intellectual disability who are availing of day services is aged 18 years or under, whereas one in two (40.7%) of the population with mild intellectual disability who are availing of day services is aged 18 years or under. The higher number of children with mild intellectual disability in receipt of services reflects the number of children in

special education, a proportion of whom do not transfer to the adult intellectual disability services upon leaving school. At least two factors are at work here. Many adults with MID do not want to be associated with the intellectual disability sector and as adults will avoid contact with this sector. Secondly, the intellectual disability sector are increasingly not providing relevant services to this population so such adults will not want/need to access the traditional services of this sector.

The numbers registered on the NIDD have decreased by 499 people (2.0%) since 2004. This reduction in NIDD follows a similar pattern over recent years. These reductions are largely accounted for by the removal from the NIDD of those adults with MID “who no longer required intellectual disability services”. There is an explicit policy of including and retaining on the NIDD “only those people with mild intellectual disability who are in receipt of, or in need of, intellectual disability services.” However, the evolving practice in intellectual disability agencies is **not** to create new services for adults with MID and conversely to focus their resources on individuals with moderate, severe or profound intellectual disability. Therefore adults with MID in the main will not therefore need the services of the intellectual disability sector because such agencies are/will not be catering for their needs.

Pervasiveness of MID

There are two identifiable “groupings” of people with mild intellectual disability. One group is comprised of individuals who have been formally diagnosed as having a learning disability, perhaps having come from a special school background or having received special support in a mainstream school and/or receiving services from a learning disability service. There is another, much broader group of people who have not been formally diagnosed but who nonetheless have high levels of impairment and who present with various personal and social problems.

The difficulties experienced by both groups include at least some of the following:

- Use of “cover-up” techniques;
- Erratic appointment keeping;
- Vagueness about basic facts;
- Travel problems;
- Illiteracy;

- Problems managing money;
- Overwhelmed by routine demands;
- Difficulty in new situations;
- Poor independent living skills;
- Low motivation;
- Difficulty understanding consequences of actions;
- Likely to be overtaken by events;
- Communication difficulties;
- Difficulty sustaining relationships;
- Difficulty recognising own needs;
- Being influenced or led in an exploitative way; and
- Acting out in response to frustration.

These difficulties are long-term and lifelong. The demands of ordinary life (i.e. social, educational, domestic, safety, communication) create ongoing threats to people with mild intellectual disability.

The needs and issues of adults with MID affect a range of agencies and services including the Gardai, the judicial system, Adults Mental Health Services, child protection services, vocational training and social welfare. Anecdotal clinical evidence suggests that professionals in mainstream agencies with responsibility for providing services to this population do not have sufficient experience or understanding of the issues and have difficulties and challenges with people with MID. In relation to children with mild intellectual disability who are in statutory care, there are additional implications for when they leave care i.e. post 18. The usual “after care” is a transition phase between 18 and 21 years and this is insufficient and inadequate to assist young people with mild intellectual disability to move toward independent adulthood. Specialised, ongoing, adult support services need to be made available to these young people when they leave care. Child protection and welfare issues are also further complicated when children have parents who have intellectual disability and this is not an uncommon event.

For a variety of reasons, adults with MID are relatively invisible in terms of social policy in Ireland and in terms of service delivery by the intellectual disability sector.

This heterogeneous group of people with many un-met needs. One reason for this lack of attention to the general needs of adults with MID is the relative ‘invisibility’ of this population. Many people with MID desire to be as self-sufficient as possible, do not want to be seen as different and therefore do not seek out services (Tymchuk et al 2001). There is frequently a stigma attached to receiving services from the learning disability services. For example, O’Callaghan (1997, p.23) found that more than a third of former students from a special school in Cork did not want to tell people where they were educated because “*people might think they are stupid*”.

Another reason for the lack of attention given to this population is that there is no single agency or office with the responsibility for meeting the needs of this group. De facto social policy in Ireland is that adults with MID who are not currently receiving intellectual disability services or who have no plans to receive these services are best serviced within generic, mainstream services. The “Six Hour Retarded Child” paradigm of 1960s America is pervasive to 21st century social policy in Ireland.

Deficit in Social Policy for MID

The NIDD is an ineffective mechanism for examining the needs of adults with MID and there is no other planning mechanism available. There is no coherent or adequate policy to address the very real needs of such adults in Ireland. People with mild intellectual disability in the main would prefer not to be associated with the intellectual disability services because of stigma. This preference needs to be respected. However, the intellectual disability services have some expertise with this population and this could be made available on a multidisciplinary consultancy basis to the mainstream services that are now providing care and other services. Ongoing and active networking between the relevant agencies is necessary. This could be a role that the intellectual disability services could adopt on behalf of this client group.

People with mild intellectual disability are different to people who do not have an intellectual disability. In mainstream education, this difference *is* recognised and additional resources in the form of resource teaching and (occasionally) special needs assistants are provided to enable these children to more successfully benefit from mainstream education. Mild intellectual disability is a life long disability and will not be ameliorated by (time-limited) additional tuition, training or education.

Increasingly, children with MID are receiving appropriate education within mainstream settings and therefore will not come to the attention of the intellectual disability sector. While many adults with MID will not need the traditional services of the intellectual disability sector, it is a fallacy to persist with the view that such adults will be appropriately serviced within mainstream society without the need for adaptation by such mainstream services. If children with MID require specialised, additional supports to avail adequately of mainstream education, then it is highly likely that adults with MID require specialised supports to adequately avail of mainstream services.