

Deinstitutionalisation – time to move on to legislation?

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The HSE Working Group on Congregated Settings for people with disabilities, set up in 2007, published its report entitled *Time to Move on from Congregated Settings – A Strategy for Community Inclusion* in June of this year.¹ The report represents a significant step forward in promoting the deinstitutionalisation agenda in Ireland, with its core recommendations being that all individuals with a disability living in 'congregated settings' (a residential setting where the person lives with 10 or more people) should be moved into the community and that the institutional settings in which they live should be closed.

The report applies to 72 locations in Ireland where 4,000 people with disabilities are living in congregated settings. However, it doesn't include people with disabilities who live in community housing already, in nursing homes, in HSE run units for physical and neurological disabilities, mental health facilities or so called 'intentional communities',² such as the L'Arche and Camphill Communities. Figures from the Health Research Board and the Department of Health and Children indicate that there are over 300 people with a diagnosis of intellectual disability still resident in psychiatric hospitals³ and over 750 in former psychiatric hospitals or HSE run institutions.⁴

General summary of the report

The report has 31 recommendations. These describe a new model of support for people with disabilities in the community. The plan is to move individuals from institutional care to dispersed forms of housing in ordinary communities. The housing would be provided by local authorities and the individuals would access mainstream health and social services such as GP, home help and public health nursing. Other specialised services and hospital services would be provided based on individualised assessments.

Ten of the recommendations directly refer to the financial resources required for the successful implementation of the report through funding support structures, purchasing and building accommodation and the provision of extra social welfare benefits for the group. It also notes that the disability budgets have been "reduced by a minimum of 5% in the period 2008-2010 and there is now less flexibility within budgets to fund further movement into the community within existing resources".⁵

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Deinstitutionalisation is generally a good thing

Certainly the evidence internationally is that, in general, individuals with disabilities do better outside the institutional setting. One study by Young in 2006 of people with moderate to severe intellectual disability showed increased adaptive behaviour, choice-making and life quality in a group followed up after discharge from institutional living into a community setting.⁶ The corollary has also been studied and Rutter has written extensively on the detrimental effects of institutionalisation.^{7,8}

The report itself cites a number of studies to support the case for community living both from a quality of life and cost-effectiveness point of view.⁹⁻¹² However a study by Kozma, Mansell and Beadle-Brown is also mentioned in the report. In it 67 papers published between 1997 and 2007 were reviewed. In seven out of 10 areas (community presence and participation, social networks and friendships, family contact, self-determination and choice, quality of life, adaptive behaviour, user and family views and satisfaction) the majority of studies showed that community living was superior to institutional care.

In three areas (challenging behaviour, psychotropic medication and health, risks and mortality) research reported mixed or worse results.¹³

People with higher support needs – whether because of the nature of their intellectual and physical disabilities, their challenging behaviour or social impairment, often experience less good outcomes in the community than people who are more independent.¹⁴ In the general context of deinstitutionalisation, they are also typically the last to get out of institutions¹⁵ and, if they experience difficulties in living in the community, most at risk of being returned.¹⁶

The results with regard to challenging behaviour mentioned in the Kozma and other studies prompted Felce et al¹⁷ and Young and Ashman¹⁸ to argue that, on the whole, the staff employed in community services may not have the training required for dealing with challenging and self-injurious behaviour. Nord, Wieseler, and Hanson¹⁹ emphasised the need to set up intensive training programs as well as specialised services to deal with challenging behaviours in the community.

Given that 50% of those with severe and profound learning disabilities will suffer from a mental health problem at some point in their lives²⁰ and the association of mental health problems with challenging behaviours in this population,²¹ it is clear that those specialised services will require extensive input from mental health professionals.

These issues are not addressed in the report, which simply notes that the "general finding is that community-based service models achieve better results for the people they serve than institutions".²²

A more structured environment required

People with severe physical difficulties such as those requiring PEG feeding or catheterisation will require a high level of supervision and training for carers. For instance the National Institute of Clinical Excellence (NICE) in the UK have published a 48 page document detailing the appropriate infection control measures to be employed when maintaining PEG feeds, catheters and other parenteral devices.²³ Also individuals with mobility problems need to be monitored closely for the development of pressure sores or other sequelae of their physical problems.

The high level of training required to care for these individuals and the necessarily frequent medical reviews suggests that specialised accommodation will be required and dispersed housing in the community may not be suitable from a quality of care or cost effectiveness perspective.

An Irish study involving 285 subjects with Down syndrome reported an age-specific prevalence of dementia at 5.7% in people aged 40-50 years, 30.4% in people aged 50-60 years, 41.7% in people aged 60-70 years, and 50% in people over the age of 70 years.²⁴ The prevalence of dementia in the non-Downs intellectually disabled population has been debated in the literature. Zigman et al²⁵ in a cross-sequential study of 126 adults with intellectual disability over the age of 65, performed a neuropsychological battery on participants screening positive for dementia using the DMR. These participants were retested 18 months later. The cumulative incidence of dementia was found to be not significantly different to that of Alzheimer's disease in the general population. This contrasts with the findings of both Cooper²⁶ and Strydom et al²⁷ who reported prevalence rates of dementia in elderly people with intellectual disability that were higher than the general population.

Irrespective of their findings, these studies demonstrate how the management of dementia in the intellectual disability population represents a significant challenge. People with a diagnosis of dementia have more acute care needs and require more supervision and medical/psychiatric input due to wandering behaviour and behavioural and psychological symptoms of dementia (BPSD), which can include self-harming and assaultive behaviours. Again dispersed community housing is unlikely to meet their needs, especially as the illness progresses

Also individuals with autism may do poorly in a community setting. The variety and novelty of the community experience, which can enrich the lives of other individuals with intellectual disability, can be very challenging for those with autism. For instance any change in routine, which can be stimulating for non-autism sufferers, such as the changing of a planned activity or encountering different care or education staff, can increase anxiety and stress levels for a person with autism.²⁸ Sustained unpredictability may become unbearable and lead to deterioration in overall functioning.

Inspections

Currently there is no independent inspection process in place for community homes for people with intellectual disability (unlike for those individuals still resident in psychiatric hospitals). This has prompted the service in which I work, The Brothers of Charity Services (South East), to engage with the US body The Council for Quality and Leadership (CQL)

in order that an independent standards assessment mechanism be put in place for the organisation.²⁹ Anecdotally I have heard of other Irish intellectual disability services adopting a similar strategy in the absence of a statutory inspection mechanism.

The Health Information and Quality Authority did publish 'National Quality Standards: Residential Services for People with Disabilities in 2009'.³⁰ These set out quality and safety standards for people with disabilities in a residential setting. However the relevant part of the Health Act 2007 has yet to be passed in to law in order that inspections commence. Also to this day no such inspection mechanism has been set up for the monitoring of such quality and safety standards. The lack of safeguards for people with intellectual disability in a residential setting would be a major concern if and when the transfer to that setting takes place. Also the lack of capacity legislation reinforces that concern.

The *Panorama* programme aired on BBC on May 30 last, reporting service users at the Winterbourne Intellectual Disability Unit near Bristol in the UK being kicked, violently restrained and drenched with water, is a stark example of how things can go badly wrong in care settings. Of course RTE's *Prime Time* has recently raised concerns about standards in Irish intellectual disability institutional and community settings.³¹

Excluded, expelled and exported

A report published by the College of Psychiatry of Ireland this year entitled *Excluded, Expelled and Exported*³² identifies 55 adults with intellectual disability, mental illness and challenging behaviour who are currently in facilities abroad. These individuals live away from their families, friends and communities due to the lack of suitable facilities for them in this country. We mustn't forget while speaking about the transfer of people with disability to the community that there is a group of people with disabilities whose accommodation issues are even more acute.

Sick transit gobbles money

People working in the mental health area are well used to grand reports recommending worthy changes to established custom and practice and there has been plenty of comment on this topic by mental health campaigners.³³⁻³⁵ Most recently *A Vision for Change* was published in 2006 and this also promoted the establishment of a community based Mental Health Service and a move away from a service based on large institutions.

The previous report *The Psychiatric Services – Planning for the future* published in 1984 had a similar agenda and large tracts remain to be implemented.

Similarly I have been impressed by the number of reports published over the years by disability services stakeholders but implementation remains an issue.³⁶⁻³⁸

A striking example is The Department of Health and Children report *Quality and Fairness – A health system for you* from 2001³⁹ which describes the government's plan for "a complete programme to transfer people with intellectual disability currently resident in psychiatric hospitals to appropriate accommodation as soon as possible and not later than 2006". As mentioned already over 300 such individuals remain in psychiatric care a decade later.

Legislation

It could be argued that the biggest promoter of change and progress in the Mental Health Service, outside of the intellectual disability context, in recent times was the publication of the Mental Health Act (2001) and its subsequent implementation in November 2006. The establishment of the Mental Health Commission, with its statutory powers, as a result of that Act has been a significant driving force in the modernisation of Irish mental health practice.

Perhaps the Swedish approach should be adopted. The Swedes enacted legislation in October 1997 that gave December 31, 1999 as the final date for residential institutions to be recognised as a service. As of January 2000 all forms of support to persons with an intellectual disability were to be channelled through community based services.⁴⁰ *Time to Move on from Congregated Settings* suggests a seven year time frame for the implementation of its recommendations. The Swedes did it in two.

Declaration of Interest: None.

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