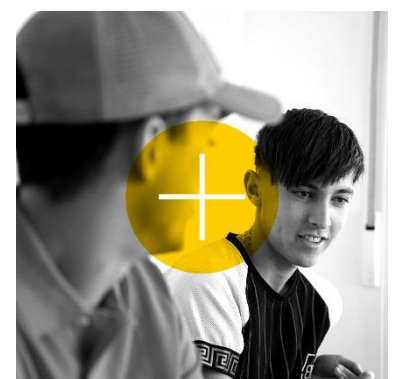
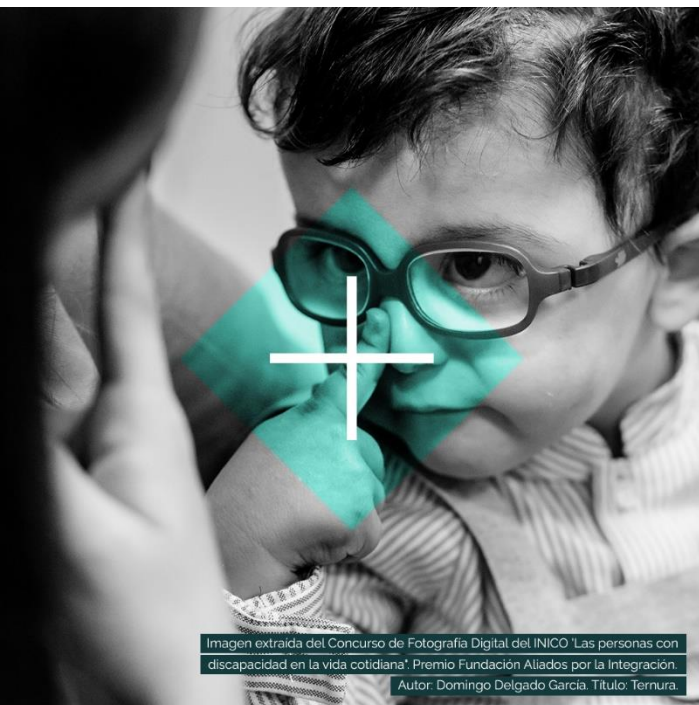


Case studies on international policy and implementation – Case 1

Ireland – Living in the community for persons with disability and mental health difficulties



Estrategia estatal
de desinstitucionalización
Para una buena vida en la comunidad

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NOTES

Scope: This paper focuses on the experience of deinstitutionalisation specifically in the mental health sector and intellectual disability sectors in Ireland and covers relevant policy in these areas. This is a brief, high-level summary of many years of work and effort and is by no means a definitive summary of the topic.

Language: The language referring to people with mental health difficulties or intellectual disabilities has changed significantly over the years. As far as possible the language which is preferred or recommended by the individuals themselves is used. However, titles and quoted content of older documents may contain language which is no longer in use.

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Key messages

Rooted in a charitable system of social control and shelter for the poor, Ireland, in the 19th century, developed a system of institutionalized care for people with disabilities and mentally ill. This resulted in a high rate of institutionalization compared to their neighbours. Since the 1960s, a slow process of reform demanded more humane and community-integrated care settings. Supported by a number of commissions and policy formulations, various attempts to phase out institutional care were undertaken. However, only from the beginning of this century, community-based support gained more traction, with a focus on self-directed living of persons with specific care needs.

- Historically, institutionalized care had been provided both by state actors and private charitable providers
- Economic crises hindered change. Two efforts for changing towards community-based models got stuck in economic crises (in the 80s and after 2008). No budget allocation for transition was available, and provider organizations were conservative towards maintaining existing services.
- Some of the deinstitutionalization processes led to ‘Transinstitutionalization’ in the sense that persons with disabilities were sometimes moved from institutions to nursing homes and persons with mental health issues ended up smaller institutional settings.
- Vision is important, but not enough. The landmark reports of 1984 and 2006 triggered important policy attention and public debate. However, they were not supported by actionable plans, budget allocation for change processes, and a clear assignment of political leadership or administrative responsibility.
- A specific financing tool – the Social Reform Fund – reinforced implementation, by demonstration programmes and training. Human resources reskilling training and organizational advice to implementing organizations was also provided. These efforts demonstrated new and effective person-centred ways of working.
- New skills profiles and staffing needs were defined during the process. Although there is an important role for clinical staff, non-clinical staff – called ‘community connectors’ – were more appropriate for the day-to-day support provision.
- Central to the success of the reform process was listening to service users and codesign of community-based alternatives. To be successful and adapted, the policy process need to build strong mechanisms for the capacities and voices of those using services to be at the heart of the service reform efforts.
- Integrated, cross sectorial coordination is key, specifically when moving from central level provision towards decentralized support services rooted in local areas. Coordination between social care, health care, housing departments and other actors was essential.
- It is necessary to focus on funding of new models of service provision, by identifying and modelling potential costs for deinstitutionalisation and future care based on current needs assessment profiles of residents. Community-based self-directed care needs to be tailor-made which can generate a significant difference between support packages for each of the users.



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1. Historical background

Ireland has a long history of institutional care. A programme of construction of mental asylums began in the early 19th century in Ireland, with Acts of Parliament providing for the setting up of asylums for the “lunatic poor”. This continued to the 1890s, ultimately providing the beds for one of the highest rates of psychiatric hospitalisation in the world.¹ The workhouses were constructed to provide shelter for the poor.² Overflowing in the Irish great famine (1845-1849), they were repurposed over the years into district hospitals and other health facilities and County Homes.³ Although the purpose of County Homes was to provide residential care for the ‘old and infirm’, many soon included unmarried mothers, children, and people with intellectual disability or mental illness.⁴ The state was the provider of care in much of this institutional infrastructure, although religious orders also had a significant role as care providers, particularly for people with disabilities.

1.1. Mental health

Initial moves towards deinstitutionalisation began with the *Commission of Inquiry on Mental Illness*, which was established in 1961 to examine services for the mentally ill and to make recommendations for their improvement.⁵ This Commission was prompted by concern at the high rate of people in mental hospitals in Ireland at that time; 7.3 per 1,000 population compared to 4.6 in England and Wales and 4.3 in the USA. Its report made recommendations for the development of community services for the mentally ill, such as outpatient clinics and day services. However, a commitment to the development of hospitals for long stay patients was also made. The deinstitutionalisation of the population in mental institutions did not begin in earnest until the 1980s, accelerated with the publication of *Planning for the Future*, which set out a clear policy vision for a comprehensive, community oriented mental health service and a commitment to eventually close large psychiatric hospitals.⁶

The number of patients in Irish psychiatric units and hospitals has been declining steadily over the last five decades or so, with numbers dropping from 19,801 in 1963⁷ to 2,308 in

¹ Commission of Inquiry on Mental Illness (1966)
<https://www.lenus.ie/bitstream/handle/10147/45690/8634.pdf?sequence=1&isAllowed=y>

² <https://irishworkhousecentre.ie/about/>

³ [https://en.wikipedia.org/wiki/County_Home_\(Ireland\)](https://en.wikipedia.org/wiki/County_Home_(Ireland))

⁴ https://www.nationalarchives.ie/wp-content/uploads/2019/03/PRF_106780_SURVEY_OF_HOSPITAL_BOOK_V7.pdf

⁵ Commission of Inquiry on Mental Illness (1966)
<https://www.lenus.ie/bitstream/handle/10147/45690/8634.pdf?sequence=1&isAllowed=y>

⁶ *Planning for the Future* (1984) <https://www.lenus.ie/handle/10147/45556>

⁷ Walsh, D (1971) *The 1963 Irish Psychiatric Hospital Census*. Dublin: Medico-Social Research Board.

2019. Particular declines were seen in the 1980s and 1990s when there was a strong focus on deinstitutionalisation. In 2019 almost one fifth of people in psychiatric hospitals had been resident for five years or more, and most of this cohort were older people (over 65 years of age).⁸ However, numbers reveal only part of the story on deinstitutionalisation in mental health services. Implementation was very slow, with insufficient development of community based mental health services. The experience is considered in more detail below. From the outset, most institutional care for the mentally ill was provided in state institutions, with a small number of private institutions. This mix of public and private care is still the case today.

1.2. Intellectual disabilities

Until the 1950s, the only public provision for adults with intellectual disability consisted of residential care in mental hospitals, and in County Homes.⁹ There were two institutions for children (founded in 1869 and 1925), both of which were run by religious or charitable organisations. By 1960 there 2,620 beds in residential institutions for people with intellectual disability. All but one of these institutions were run by religious orders. From the 1950s, the development of community-based services began to emerge, spearheaded by Parents and Friends Groups.¹⁰ These organisations began to develop residential services which were less institutional, often within domestic house settings.

The policy commitment to deinstitutionalisation of services for people with disabilities was not as clearly stated as that for people in mental hospitals. A Government White paper in 1960 affirmed a commitment to build more institutions. However, from as early as 1965, smaller scale accommodation was recommended, along with the discontinuation of the older institutions, such as mental hospitals and county homes.¹¹ While various reports and policies in the 1980s and '90s recognised the need for community care and special education, they also included a commitment to continuing residential care. Because of historical models of provision, this was often in large scale institutions. In general, independent living was not seen as a possible goal for many people with intellectual disabilities. Therefore, a policy of deinstitutionalisation was not emphasised, and these settings continued to be used for several decades thereafter. While a Department of Health document on *Policy and Services for Persons with Mental Handicap* stated that “people with mental handicap [should] enjoy a life that is as normal as possible within the community for as long as possible”, the need for institutional care was also a core principle of the policy. The aim of the *National Disability Strategy (2004)*

⁸ Daly A and Craig S (2019) Irish Psychiatric Units and Hospitals Census 2019. HRB Statistics Series 40. Dublin: Health Research Board.

⁹ For a more detailed overview of policy and service provision in this area see Chapter 2 of the *Value for Money and Policy Review of Disability Services in Ireland* <https://www.hse.ie/eng/services/list/4/disability/newdirections/value-for-money-policy-review-of-disability-services-in-ireland.pdf> and Chapter 2 of *Time to Move on from Congregated Settings (2012)*

¹⁰ Groups of parents and friends who came together to provide services for people with intellectual disabilities.

¹¹ Commission of Inquiry on Mental Handicap (1965) <https://www.lenus.ie/handle/10147/243761>



was the equal participation of people with disabilities in society through a mainstreaming policy, which included the mainstreaming of housing provision for people with disabilities.¹² However, none of these policies made a commitment to close existing large institutions and there was still considerable reliance on institutional care. In spite of the policy statements, and the development of smaller residential services based within communities, there were 693 admissions to congregated settings in the period 1999 to 2008, which exceeded the number moving out.¹³ It was not until 2011, with the publication of *Time to Move on from Congregated Settings*, that an unambiguous statement was made regarding the closure of congregated settings.¹⁴ This report acknowledged that over 4,000 people continued to live in congregated settings and that continuing to provide 'better institutions' was not enough: "...improvements in community housing relative to former institutional residences are not sufficient for good quality of life outcomes, and a lifestyle as close as possible to that experienced by other citizens should be the aspiration".¹⁵

A substantial number of people with intellectual disabilities had been resident in the larger mental institutions. As these facilities began to downsize and close, people with intellectual disabilities were often among the last remaining residents and many continued to reside in inappropriate psychiatric settings. Although a programme of moving the remaining residents from these settings began in the 1990s, 147 people remained to be transferred to more suitable residential accommodation at the end of 2010.¹⁶

The human rights of people with intellectual disabilities were not evident as a central concern in policy until the publication of the report of the *Commission on the Status of People with Disabilities*.¹⁷ This was titled a *Strategy for Equality* and placed a strong emphasis on human rights through the promotion of equality for people with disabilities and addressing discrimination. Crucially, this was the first policy in the area of disability which had a strong inclusion of people with disabilities, through extensive consultation and membership of the groups involved in formulating the report.

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) was signed by Ireland in 2007 but not fully ratified until 2018. However, the CRPD provided

¹² National disability Strategy (2004) <https://nda.ie/monitoring/national-disability-strategies/previous-disability-strategies#:~:text=The%20Government%20launched%20the%20National.services%20for%20people%20with%20disabilities>.

¹³ Congregated settings are defined as a residential setting of ten or more people.

¹⁴ *Time to Move on from Congregated Settings* (2012) <https://www.hse.ie/eng/services/list/4/disability/congregatedsettings/time-to-move-on-from-congregated-settings-%E2%80%93-a-strategy-for-community-inclusion.pdf>

¹⁵ *ibid*

¹⁶ Kelly, F. and Kelly, C. (2011) Annual Report of the National Intellectual Disability Database Committee 2010. Dublin: Health Research Board

¹⁷ Commission on the Status of People with Disabilities (1996) <https://www.lenus.ie/handle/10147/560531>



a strong focus for advancing the human rights of people with disabilities and mental health difficulties in Ireland. Centres such as the Centre for Disability Law and Policy in Galway University provided important support for this work.

2. Process of deinstitutionalisation

2.1. Mental health

In spite of the recommendations in the Commission report in 1966, by 1980, the numbers in mental hospitals had decreased by only 6,000 or so, and progress in developing mental health services in the community was very slow.¹⁸ A working group came together to develop a new mental health policy and the position at that time was summarised well in their report titled *Planning for the Future*.¹⁹

“At present, the psychiatric hospital is the focal point of the psychiatric service in most of the country. Large numbers of patients reside permanently in these hospitals. Many of them have lived there for years in conditions which in many cases are less than adequate because of overcrowding and capital underfunding. In addition, staff and public attitudes have tended to concentrate effort on hospital care as a result of which community facilities are relatively underdeveloped. The hospitals were designed to isolate the mentally ill from society and this isolation still persists.”²⁰

Progress was made in implementing some aspects of *Planning for the Future*. The development of new services and structures, and the movement of people from large institutions did take place. However, culture and practice did not change substantially, and although people were moved from an institution to a residence in the community, “...the treatment they received and their daily lives often did not change substantially. Many of these people, though now outside the institutions that might formerly have housed ... remained ‘institutionalised’ and isolated from the general community.”²¹ The management, organisation and funding arrangements of services did not change. As a result, the focus remained almost exclusively on the hospitals. In consequence, the development of the comprehensive services envisaged for the community took was very slow and patchy throughout the country – with some few examples of good practice.

Looking back at the implementation of *Planning for the Future* in the 1980s and 1990s with our current understanding of implementation science, crucial gaps can be identified.

¹⁸ Commission of Inquiry on Mental Illness (1966) <https://www.lenus.ie/bitstream/handle/10147/45690/8634.pdf?sequence=1&isAllowed=y>

¹⁹ Planning for the Future (1984) <https://www.lenus.ie/handle/10147/45556>

²⁰ibid p. xi

²¹ A Vision for Change: Report of the Expert Group on Mental Health Policy (2006) p. 56 <https://www.hse.ie/eng/services/publications/mentalhealth/mental-health---a-vision-for-change.pdf>



There was no systematic implementation plan. There was a poor understanding of the huge effort required in terms of human and financial resources, technical expertise, emotional commitment and time, to bring about the type of system change envisaged in *Planning for the Future*. Service managers, who were fully engaged in day-to-day management of mental health services, were expected to also develop a new community-based service model. The 1980s were a time of recession and poor economic development in Ireland, and while some extra financial resources were allocated, sufficient human and financial resources were not made available to fully implement this policy. There was active resistance to closure from staff who resisted changes in practice and potential changes to their working conditions; from families who were concerned about care for their family member; and from communities who did not necessarily want people with long-term mental health difficulties living among them. The voice of people using services was notably absent and there were few explicit concerns about the human rights of these individuals in the policy. There were other factors – large hospitals were big employers in rural areas of Ireland, and the potential loss of this economic activity was resisted.

The policy vision of what services might be developed in the community to replace the institutions and what ‘new care’ might look like, was not sufficiently or compellingly articulated by clinical or political leaders. What was implemented was selective. Day hospitals and psychiatric units in general hospitals were developed so that the larger institutions would no longer be used for acute treatment. While substantial numbers of long stay psychiatric beds in institutions closed, almost no institutions fully closed. Thus, potential cost savings were never realised as only portions of large institutions closed, leading to the need to maintain many aspects of the institution. This partial closure, it could be argued, served to maintain financial resources in the hospital/institutional model at the expense of community-based services.

Twenty years after *Planning for the Future*, an expert group was brought together to develop a new mental health policy. *A Vision for Change*²² set out a compelling, comprehensive, and detailed vision of what the future of mental health care in the community should look like and was broadly welcomed. People using services and families were involved in the policy making process which included extensive consultation. *A Vision for Change* recommended the creation of structures and processes to enable real participation in decision-making around mental health services for service users and families. In contrast to *Planning for the Future*, citizenship and human rights were underpinning principles of *A Vision for Change*. The policy made a strong commitment to complete closure of remaining institutions, with funds realised from the sale of lands to be used to develop community based mental health services. This was stymied with the great recession of 2008. The approach to implementation, while regularly monitored and more robust than that of previous mental health policy, did not have the systematic national approach necessary to achieve the scale of change

²² A Vision for Change: Report of the Expert Group on Mental Health Policy (2006) p. 56



required. Particular challenges were moving human and financial resources from institutional care and achieving the significant cultural shift away from an institutional mindset.²³ In addition, a significant burden of change was already impacting the mental health service system. The Mental Health Act 2001 began to be implemented in 2006, and a significant restructuring of the health services from eight separate health boards into one national health authority was also happening from 2006 to 2008.

While there was progress in the closure of institutions, people were often moved to community residences, which were, in effect, smaller institutions.²⁴ In 2011 approximately 2,790 people were still living in community residences – 1,177 of whom were in medium or low support residences and therefore did not need a high level of care. A renewed impetus to ‘complete’ the process of deinstitutionalisation in mental health was provided by the Service Reform Fund, described in more detail in Section 3 below.

2.2. Intellectual disabilities

As described above, the process of deinstitutionalisation for people with intellectual disabilities has had a different trajectory to that of mental health, with the first explicit policy commitment to deinstitutionalisation made relatively recently in 2011. Progress has been slow; 4,099 people lived in congregated settings in 2011 and approximately 1,953 individuals remained in those settings by the end of 2019.²⁵ The *Service Reform Fund* has had a significant role to play in the process of deinstitutionalisation for people with intellectual disabilities and is described in section 3.

It is clear from this high-level review of the policy and process of deinstitutionalisation for people with mental health difficulties and intellectual disabilities, that an ‘institutional mindset’ has underpinned the approach to care. It is well-intentioned and concerned with ensuring people are safe and cared for, but it leads to strong resistance to the belief that people with support needs can live their own lives through support that is not based in a residential care setting. An institutional setting is often the only option for people who need support with increasing numbers of people with disabilities under the age of 65 being placed in nursing homes for older people. This mindset still has a strong influence. Just this month (February 2023) a parliamentary committee was told: “Institutional thinking also allows us to shut one door and open another, repeating cycles of

²³ Keogh, F. (2009) From vision to action? An analysis of the implementation of A Vision for Change. <https://www.lenus.ie/handle/10147/112857> Johnstone, H. (2014) All vision and no change? Institute of Public Administration: Dublin

²⁴ <https://www.mentalhealthreform.ie/wp-content/uploads/2018/05/Briefing-note-on-24-hour-staffed-community-residences.pdf>

²⁵ <https://nda.ie/uploads/publications/main-report-moving-in-moving-on-pdf-version.pdf>



segregation. We closed some group homes [for people with disabilities], but 1,300 people under 65 are now living in nursing homes.”²⁶

3. The Service Reform Fund²⁷

The Service Reform Fund (SRF) was created in 2017 by the Department of Health, the Department of Housing, Local Government and Heritage, the Health Service Executive (HSE)²⁸, the Atlantic Philanthropies and Genio²⁹, with a total combined investment of €45m. It was established to accelerate and enhance the implementation of models of support that place the choices of the person using the service at the core. The scaling of these innovations and reforms involved complex collaborations across government departments, national administrative systems, local and regional structures, and Non-Governmental Organisations (NGOs) involved in service delivery and advocacy. Previous partnerships between the HSE and Genio to demonstrate and test the effectiveness of person-centred approaches provided the basis for the SRF, but the focus of the SRF was on the scaling of models and approaches nationally.³⁰

The SRF took a very different approach to traditional top-down, policy-led reform. It was informed by evidence from implementation science, change management processes and the learning from policy implementation efforts in mental health and disability in Ireland and elsewhere. The SRF was fully aligned with policy but recognised the need for changes in the culture as well of the structures of care. The work in the SRF embraced the complex change processes that are required and supported adaptive change, which “is required when our deeply held beliefs are challenged, when the values that made us successful become less relevant, and when legitimate yet competing perspectives emerge”³¹. The SRF required a shift – sometimes radical, other times in small, incremental steps – to the deeply embedded, systemic ways of responding to homelessness, mental health, and disability in the Irish context. This was supported by an action research element which identified implementation challenges as they emerged

²⁶ <https://www.irishtimes.com/politics/2023/02/09/disability-committee-hears-of-inadequate-care-options/>

²⁷ This section of the paper draws heavily from: Lally, N., Sharek, D., Brennan, C., Cahill, L., O’Leary, C. (2022). A Study of the Service Reform Fund (SRF): Understanding Reform in National Systems. Dublin, Ireland: The SRF Action Research Team, Genio. <https://www.genio.ie/publications/a-study-of-the-service-reform-fund-srf-understanding-reform-in-national-systems-0> Hereafter referred to as the **SRF report**

²⁸ The Health Service Executive is the national agency responsible for providing health and social care.

²⁹ Genio is a non-profit European organisation based in Ireland working with philanthropy and government at national and EU levels on scaling social innovation.

³⁰ Keogh, F. (2014). Supporting people to live self-directed lives in the community—Learning from 54 Irish projects. GENIO Ireland. <https://www.genio.ie/our-impact/research-evidence/supporting-SSDL-54-projects> ; Healy, J. & Keogh, F. (2014) Exploring a model of public services reform: A case study of the Genio organisation, *Administration*, 62, 55-90

³¹ Heifetz, R.A., & Laurie, D.L., 1997. The work of leadership. *Harvard Business Review*, 75, pp.124-134.



in real time. The key findings from the action research are incorporated into the section below on what has been learned.

4. What can we learn?

Reviewing four decades of effort in deinstitutionalisation across mental health and disability, as well as more recent focused efforts of the SRF, there are some experiences and observations which are useful to consider.

4.1. Understanding the nature of ‘an institution’

The move to close large institutions that commenced in the 1950s in the US and elsewhere was at least partly motivated by a humane impetus, especially given the very overcrowded, poor physical environment, poor quality care and sometimes abusive conditions which began to be more widely reported and acknowledged as unacceptable. If the initial question is ‘how do we close our institutions?’, the focus is immediately on the new settings; how many places are needed, how many staff and so on. In mental health services in Ireland, and in other jurisdictions, at least three decades of effort, energy and resources was focused on changing the setting. This essentially resulted in ‘downsizing’ - the creation of smaller, more homely settings, but institutions nonetheless. The focus was on numbers – how many patients, how many beds, how many buildings, how many staff – what was the ‘ideal’ set of numbers to provide cost-effective care.³² There was a strong focus on rehabilitation, the need to train people to live outside the institution, informed by a medical model of deficits that could be addressed through training. There was no real consideration of the wishes of people using these services and what they might be capable of if given appropriate opportunities. There was a profound lack of attention to the human rights of these individuals.

The decades of deinstitutionalisation effort and research, and listening to the experiences of people using services, have led to a better understanding of the nature of an institution and have helped us to ask better questions. Rather than ‘how do we close our institution?’, we ask ‘how do we support people to live a life of their choosing?’ This question leads us away from the setting and towards a focus on the person; understanding their strengths, their wishes and the range of supports they might need to live a similar life to that of their peers.

A European Commission group produced a set of Guidelines to support deinstitutionalisation.³³ Instead of a focus on the size of an institutions, the Guidelines

³²Mansell, J., & Beadle-Brown, J. (2010). Deinstitutionalisation and community living: Position statement of the Comparative Policy and Practice Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities. *Journal of Intellectual Disability Research*, 54 (2), 104–12.

³³ *Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care (2009) Brussels: European Commission.* A group brought together by the European Commission to address the complexity of institutional care reforms.

had a very different and thought-provoking definition of an institution; any residential care where:

- residents are isolated from the broader community and/or compelled to live together;
- residents do not have sufficient control over their lives and over decisions which affect them; and
- the requirements of the organisation itself tend to take precedence over the residents' individual needs.

This definition highlights the centrality of the culture of the institution, segregation and lack of autonomy which are the less visible features of an institution than the number of beds, but which, nonetheless, exert a strong influence on the life that is lived by the residents. Using this definition, deinstitutionalisation is not about moving a person to a nicer place to live, it is about working with *each person* to intentionally build a life that is integrated, not segregated, where the person has control over their life and the decisions that affect them, and where their support arrangements are designed to enhance their life.

4.2. Moving from 'care' to 'support'

In order for this to happen successfully, a profound shift is required in how the person who needs support is viewed and valued, and in the language that is used. Staff in different care sectors have typically been trained to identify a person's needs or deficits and to address or ameliorate them through their professional skills. In residential care, the care providers are in charge, they make the decisions and determine what happens in a person's life, from the mundane such as what the person eats, what time they go to bed; to the more significant, such as who the person can see or have a relationship with, when they can go out and where; whether the person is, in their judgement, capable of working or living in their own home. Providing support is very different to providing care. The person receiving the support is 'in charge' – they make the decisions, with support if necessary. This quote from a key worker describing a person with intellectual disability who they had supported to move captures this:

*"She's in charge of a lot of things in her life. She's in charge of her medication now which she wouldn't have [had] any [control over] ... it would have been handed to her (...). Now she goes to the pharmacy and gets the drugs herself. She gets her prescription from the GP (General Practitioner) herself; she attends the GP by herself. And like appointments, she turns up herself. She would be doing her shopping herself which you know and having a choice on to what she eats, when she eats, how she eats."*³⁴

³⁴ P. 70 McConkey, R., Bunting, B., Ferry, F., Garcia-Iriarte, E. and Stevens, R. (2013) *An Evaluation of Personalised Supports to Individuals with Disabilities and Mental Health Difficulties*, University of Ulster and Genio. <https://www.genio.ie/our-impact/research-evidence/evaluation-of-personalised-support>



This is a huge cultural shift for staff who have been working in institutional forms of care; and demonstrates the need to ‘change hearts and minds’.³⁵ The evidence and experience from the Service Reform Fund in Ireland showed that providing training in a specific way (section 4.3) and a different approach to risk (section 4.4) were both successful in enabling this cultural shift.

4.3. Training

A training programme for staff is usually one of the first things to be considered in a deinstitutionalisation programme. However, the type of training and the way in which it is provided need to be carefully considered to maximise the potential change in practice and to ensure changes are embedded and do not fade over time. Training and capacity building were an important part of the service reform process and were viewed as enablers of change, to be carried out in parallel with other aspects of the change process. To avoid the possibility of a disconnect between the evidence base, the training and the practice, training was structured, with blocks of training and practice, to provide staff with the opportunity to continually apply what they had learned in their everyday practice. This allowed staff to witness the impact of the new practices on the people they support. This increased the possibility of practice change becoming embedded. Training participants emphasised the need for not just a once off, but “constant training” at all levels of the system, including those in senior management and decision-making positions:

“...its nice frontline staff are doing it [the training], but they don’t have the authority to influence the change. So, I would have ...made it mandatory for all our team leaders and managers to do it”³⁶.

This quote alludes to the need for everyone involved in service provision to change, not just front-line practitioners, where the focus usually is, but those involved in management and in other processes such as finance and recruitment.

The content of the training and capacity building provided through the SRF was based on approaches which underpinned the policy directions which services were moving towards, including Recovery and Individual Placement and Support in mental health, and Social Role Valorisation (SRV) and Supported Self-Directed Living (SSDL) in Disability. SSDL supports an individual to exercise choice and control over their own life and to become a valued, participating member of society. It is an approach to facilitating access to the places where ordinary, everyday life is conducted, in ordinary ways, doing ordinary things.

³⁵ McConkey, R. & Keogh F. (2014) Transforming organisations to deliver more personalised housing and accommodation supports in disability and mental health services, Administration, 62, 91-118

³⁶ p.26 A Study of the Service Reform Fund (SRF) <https://www.genio.ie/publications/a-study-of-the-service-reform-fund-srf-understanding-reform-in-national-systems-0>



4.4. Changing approaches to risk

A shift from providing care to providing support involves balancing risk-averse, clinician-led services with people's involvement in decision-making that affects their lives. 'Risk positive' practice by staff was supported, lessening the focus on risk-aversion and safeguarding. A staff participant in the SRF programmes described person-centred practice:

*"It is truly putting the person at the centre of every single thing that you do... It's about people being able to take risks and us supporting them in that, so really, it's about seeing what is possible for that person and holding onto it for them until they can see it for themselves."*³⁷ (Disability, De-congregation).

However, this approach often went against the training of staff in the services and was described as "completely counterintuitive to our training".³⁸

The move away from highly controlled, risk averse practice, and support for risk-positive everyday practice, allowed for the transformation of ingrained beliefs and practices when staff saw the people they support in a new light.³⁹ The new practices were described as bringing the voice of the people using services closer to staff, providing opportunities for staff to get to know people who use services in a different way, by focusing on people's capabilities and strengths, "letting the skills of the person shine".⁴⁰

4.5. Changing other processes

Institutions, whether large or small, are designed as the EU Commission definition describes, to suit the needs of the organisation. From an administrative or managerial point of view, it is easier to manage staff and residents in one building, which provides a 'one size fits all' service. The number of inputs (e.g. staff hours) and outputs (e.g. places provided) are easier to manage and funding allocations are generally one allocated sum for the facility.

The amount of flexibility required when moving to very individualised approaches is considerable and not to be underestimated. Rigid and inflexible organisational processes, for example staff rosters, can become a real barrier to moving someone and supporting them in the life of their choosing. Regulations and standards need to be

³⁷ pg. 27. *ibid*

³⁸ pg. 27. *ibid*

³⁹ A Study of the Service Reform Fund (SRF) <https://www.genio.ie/publications/a-study-of-the-service-reform-fund-srf-understanding-reform-in-national-systems-0>; McConkey, R., Bunting, B., Ferry, F., Garcia-Iriarte, E. and Stevens, R. (2013) *An Evaluation of Personalised Supports to Individuals with Disabilities and Mental Health Difficulties*, University of Ulster and Genio. <https://www.genio.ie/our-impact/research-evidence/evaluation-of-personalised-support>

⁴⁰ pg. 27. A Study of the Service Reform Fund (SRF) <https://www.genio.ie/publications/a-study-of-the-service-reform-fund-srf-understanding-reform-in-national-systems-0>

carefully designed so that they incentivise and support the deinstitutionalisation process and do not become another barrier. Changes in funding processes are covered in Section 8.

5. Leadership

A change process as complex and emotive as deinstitutionalisation requires strong leadership to motivate, drive and sustain the change required. Successful leadership is often characterised as top-down, with a strong charismatic leader ‘making things happen’. The experience in Ireland was that the most effective change was achieved by active engaged leaders, at all levels, who were prepared to face down the inevitable challenges to culture and practice.⁴¹ Multi-level leadership means there is ‘a champion’ at all levels of the organisation and in other key groups, who supports and drives the move to a new way of supporting those using the service.⁴² The importance of identifying, mentoring and supporting leaders and champions at all levels was also identified by the research from the SRF.⁴³

“Change champions and passionate believers in the reform programme purposefully and strategically convinced other staff to abandon deeply held beliefs and assumptions about the people they support”⁴⁴.

6. Co-production

The involvement of people with mental health difficulties or intellectual disabilities in policy development or service design has been a slow process and has been more evident in mental health policy and services. There was significant involvement of people with mental health difficulties in developing the *Vision for Change* policy and its successor policy *Sharing the Vision*.⁴⁵ Service users and family members have been involved in the development of mental health services through local committees called Area Forums. Peer support workers, family support workers, recovery education

⁴¹ McConkey, R. & Keogh F. (2014) Transforming organisations to deliver more personalised housing and accommodation supports in disability and mental health services, *Administration*, 62, 91-118

⁴² Keogh, F. (2014). Supporting people to live self-directed lives in the community—Learning from 54 Irish projects. GENIO Ireland. <https://www.genio.ie/our-impact/research-evidence/supporting-SSDL-54-projects>

⁴³ A Study of the Service Reform Fund (SRF) <https://www.genio.ie/publications/a-study-of-the-service-reform-fund-srf-understanding-reform-in-national-systems-0>

⁴⁴ A Study of the Service Reform Fund (SRF) pg. 33

⁴⁵ *Sharing the Vision: A Mental Health Policy for Everyone* (2020) <https://www.gov.ie/en/publication/2e46f-sharing-the-vision-a-mental-health-policy-for-everyone/>



facilitators are all people with lived experience who are now employed in mental health services in Ireland.

The SRF played a role in incentivising greater involvement of people using services, through specifying the need for the regional structures to consult with people using services. This was the most heavily weighted criteria to receive funding. The SRF was regarded as a catalyst for both introducing service user engagement, “forcing the agenda” to some extent, and in strengthening existing service user engagement. In some areas, the consultation required as part of the SRF application process was noteworthy as it was the first time service user engagement had been carried out formally. While the application process required agencies to engage with the people using the services at the initial stages, concerns were expressed regarding the continuation and sustainability of such engagement in the face of perceived tokenism, the strength of professional groups and how best to reimburse service users for their time.⁴⁶ One of the key findings of the SRF was the need to build strong mechanisms for the capacities and voices of those using services to be at the heart of the service reform efforts.⁴⁷

7. Integrated working

A successful programme of deinstitutionalisation requires close, cooperative working among a wide range of organisations and actors, including government departments, state agencies, NGOs, advocacy and representative organisations and, most importantly, the people using services and their families. The SRF was the impetus for creating more cohesive organisational structures among organisations and actors who did not have a strong record of cooperative working:

“The national implementation plan...brought in the health side, the local authority side, the voluntary sector, made it everybody’s business to work together to make this happen which is just a godsend.”⁴⁸

Some of the conditions around accessing the funding directly incentivised this cooperation. In effect, organisations had to work together to get new funding.

Another way to encourage or facilitate cooperative working is to develop shared strategies and structures. This occurred in relation to housing: Ireland is one of the few countries that has a specific housing strategy for disabled people. The development of the *National Housing Strategy for People with a Disability 2011-2016*⁴⁹ and its successor covering the period 2022 – 2027 signalled an important degree of cooperation across

⁴⁶ p 7 A Study of the Service Reform Fund (SRF) <https://www.genio.ie/publications/a-study-of-the-service-reform-fund-srf-understanding-reform-in-national-systems-0>

⁴⁷ A Study of the Service Reform Fund (SRF)

⁴⁸ A Study of the Service Reform Fund (SRF) p.21

⁴⁹ *National Housing Strategy for People with a Disability 2011-2016*



three government departments and their related agencies.⁵⁰ The strategic aim of the first strategy was “To develop national protocols and frameworks for effective interagency cooperation which will facilitate person-centred delivery of housing and relevant support services”. This led to the development of a *Housing and Disability Steering Group* in each local authority area to enhance the existing ad hoc interagency cooperation and to bring a more coordinated approach to the delivery of housing and related services. A high-level monitoring group, jointly chaired by the government departments oversaw the implementation.

The 2011-2016 strategy had a clear commitment to “promote and mainstream equality of access for people with a disability to the full range of housing options available suited to individual and household need.” The aim of the strategy for 2022-27 is:

“To facilitate disabled people to live independently with the appropriate choices and control over where, how and with whom they live, promoting their inclusion in the community”.

The language used here, with the emphasis on choice, control, and inclusion, demonstrates the progress that has been made in shifting the mindsets of these departments and agencies. The two strategies, and the structures and policies that have developed as a result, have been very important in enabling integrated or cross-agency working. In order to be as effective as possible, such structures need to have decision-making authority and power over budgets or resources. This is what makes the difference in inter-agency cooperation.

8. Funding deinstitutionalisation

The SRF used funding allocation as a lever to incentivise new ways of working. It provided some funding for the extra costs associated with deinstitutionalisation, such as training and support with change management. The funding was also used strategically to create a sense of urgency and to draw staff and people using services into conversations about the types of services to be provided.

Moving from the block funding of services, to funding which is tailored to individual support needs is an important mechanism to free up funds from institutional service models. There are many funding mechanisms to achieve this. A detailed review of individualized funding models suggests that scepticism about individualised funding among practitioners largely relate to their occupational role (e.g., job loss) and concerns for those they serve (e.g., safeguarding, risk aversion). Organisations responsible for delivering services sometimes perceive individualised funding as a top-down,

⁵⁰ The Department of Health and the Department of Department of Children, Equality, Disability, Integration and Youth

Government led cost-cutting measure. These concerns and other misconceptions (e.g., misuse of funds, recipients flooding the system), were not grounded in evidence.⁵¹

The planning process for deinstitutionalisation requires a necessary focus on funding and questions around how new models of service provision will be funded. Considerable time and energy can be expended identifying and modelling potential costs for deinstitutionalisation and future care based on current needs assessment profiles of residents. The recent experience of deinstitutionalisation and service reform in Ireland was that it was more useful to have a more dynamic modelling of costs. For example, there was a cohort of people who needed less support than suggested by a needs assessment conducted when they were resident in an institution. For these individuals, their skills and abilities increased as they began to develop a life outside of the institution⁵². For another cohort, the costs were calculated for staff who were not best suited to supporting people in developing a new life outside of the institution. Although there is an important role for clinical staff, non-clinical staff (called 'community connectors' in the innovative work in disability services in Ireland) were more appropriate for the day-to-day support provision.⁵³

9. Legislation

Legislation has not been a significant driver of deinstitutionalisation; there was no specific piece of legislation mandating the closure of institutions as happened in other countries. However, there is legislation which is relevant to the process. For example, the Mental Health Act 2001, which was a long-overdue updating of mental health legislation in Ireland, introduced mandatory tribunals to automatically review involuntary detention of patients and put in place mechanisms to regulate and monitor the standards of care and treatment in mental health services by the Mental Health Commission and the Inspector of Mental Health Services. This, in turn, served to reinforce the importance of moving from institutional mindsets in terms of service delivery practices.

⁵¹Fleming, P., McGilloway, S., Hernon, M., Furlong, M., O'Doherty, S., Keogh, F. and Stainton, T., 2019. Individualized funding interventions to improve health and social care outcomes for people with a disability: a mixed-methods systematic review. *Campbell Systematic Reviews*, 15(1-2). <https://onlinelibrary.wiley.com/doi/full/10.4073/csr.2019.3>

⁵² McConkey, R., Bunting, B., Ferry, F., Garcia-Iriarte, E. and Stevens, R. (2013) *An Evaluation of Personalised Supports to Individuals with Disabilities and Mental Health Difficulties*, University of Ulster and Genio. <https://www.genio.ie/our-impact/research-evidence/evaluation-of-personalised-support>

⁵³ Keogh, F. (2014). Supporting people to live self-directed lives in the community—Learning from 54 Irish projects. GENIO Ireland. <https://www.genio.ie/our-impact/research-evidence/supporting-SSDL-54-projects>



10. Conclusion

Much has been achieved in Ireland in terms of closing mental health and disability institutions, albeit over a very long timescale. There is still work to be done, both in terms of closing congregated settings, but more importantly in terms of changing culture and practice from an institutional mindset to one which is truly person-centred and provides support to live a full life.

Much remains to be done in terms of support for older people. In spite of the decades of effort to close institutions for people with mental health difficulties and disabilities, institutional care is often the only viable option for older people who need a high level of support. Nursing homes for older people are also being used for older people moving from institutions which are closing, and for younger people with disabilities. This demonstrates the sustained effort which is required to embed the changes that have been made and to ensure practices do not revert to institutionally based practices.

Given the scale of the changes involved, it is helpful to think of a deinstitutionalisation programme in terms of three stages and to ensure enough resource and energy remains for all three; (i) planning - which needs to be thoughtful, with people using services centrally involved; (ii) implementation which can begin on a small scale as planning is underway in order to demonstrate what can be achieved and (iii) embedding, which involves long-term and continuous monitoring and training to sustain the new practices.

