

From institutions to community living: drivers and barriers of deinstitutionalisation

Case study report: Ireland 2018

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INTRODUCTION

Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) sets out the right of all persons with disabilities to live independently and be included in the community. Although the CRPD does not specifically mention deinstitutionalisation (DI) or address the transition process from institutional to community-based support, the Committee on the rights of persons with disabilities (CRPD Committee) has underlined that it is an essential component of fulfilling Article 19.

Achieving deinstitutionalisation is not limited to phasing out certain living arrangements. It entails a profound shift from environments characterised by routine and an 'institutional culture', to support in the community where persons with disabilities exercise choice and control over their lives. Realising the right to live independently for persons with disabilities therefore stretches beyond closing institutions and requires development of a "range of services in the community [...], which would prevent the need for institutional care".¹

FRA's project on the right of persons with disabilities to live independently and be included in the community

To explore how the right to independent living is being fulfilled in the EU, the European Union Agency for Fundamental Rights (FRA) launched a multi-annual research project in 2014. The project incorporates three interrelated activities:

- Mapping types of institutional and community-based services for persons with disabilities in the 28 EU Member States.²
- Developing and applying human rights indicators to help assess progress in fulfilling Article 19 of the CRPD.³
- Conducting fieldwork research in five EU Member States – Bulgaria, Finland, Ireland, Italy and Slovakia – to better understand the drivers and barriers of deinstitutionalisation.

From institutions to community living – commitments, funding and outcomes for people with disabilities

In 2017, FRA published three reports exploring different aspects of the move from institutions towards independent living for persons with disabilities:

- [Part I: commitments and structures](#) highlights the obligations the EU and its Member States have committed to fulfil.
- [Part II: funding and budgeting](#) looks at how funding and budgeting structures can work to turn these commitments into reality.
- [Part III: outcomes for persons with disabilities](#) focuses on the independence and inclusion persons with disabilities experience in their daily lives.

The series complements the Agency's [human rights indicators on Article 19 of the CRPD](#).

Other relevant reports previously published by FRA include:

¹ European Expert Group on the Transition from Institutional to Community-based Care (2012), [Common European Guidelines on the Transition from Institutional to Community-based Care](#), p. 27.

² FRA (2017), [Summary overview of types of institutional and community-based services for persons with disabilities](#).

³ Indicators are available at: <http://fra.europa.eu/en/project/2014/rights-persons-disabilities-right-independent-living/indicators>. The indicators are based on the human rights model developed by the Office of the United Nations High Commissioner for Human Rights (OHCHR). See: UN, OHCHR (2012), [Report on Human rights indicators: A Guide to Measurement and Implementation](#), HR/PUB/12/5.

- [Choice and control: the right to independent living](#)
- [Involuntary placement and involuntary treatment of persons with mental health problems](#)

Reality check? Local-level research on drivers and barriers of deinstitutionalisation

FRA's fieldwork aimed to give actors involved in the deinstitutionalisation process the opportunity to share their knowledge, experiences and perceptions of what drives the process forward, and the barriers that hold it back. It focused in particular on implementation of deinstitutionalisation at the local level, an area little covered by previous research.

The fieldwork was conducted by FRA's in-country research network, FRANET,⁴ in five EU Member States that are at different stages of the deinstitutionalisation process. It was divided into two parts:

- In 2016, interviews and focus groups were conducted in each Member State with various stakeholders from the national and local level (municipalities or cities). The findings led to the identification of one case study locality in each Member State.
- In the first half of 2017, interviews and focus groups took place with a range of stakeholders in the selected case study locality.

This report incorporates findings from both parts of the fieldwork. More information on the research methodology is available in the Annex and the main report presenting the results of the research.⁵

Why this report?

This report presents the findings of FRA's fieldwork research in Ireland. Separate national reports capture the results from the four other fieldwork countries.⁶

The report starts by summarising the national context of deinstitutionalisation, including the legal and policy framework and funding, as well as how individuals involved in the deinstitutionalisation process understand some of the key terms and concepts. The rest of the report is structured according to five features emerging from the research as being essential for the deinstitutionalisation process (see table 1). Firstly, the report presents the drivers and barriers of the deinstitutionalisation process in Ireland, as experienced by participants in the research. It then looks at what participants believe is needed to make deinstitutionalisation a reality.

A comparative report bringing together the research findings from the five fieldwork countries was published in December 2018.⁷

Table 1: Key features of a successful deinstitutionalisation process

⁴ See: <http://fra.europa.eu/en/research/franet>.

⁵ FRA (2018), *From institutions to community living for persons with disabilities: perspectives from the ground*, Luxembourg, Publications Office.

⁶ The national case study reports are available at: <https://fra.europa.eu/en/country-data/2018/right-independent-living-case-studies>.

⁷ FRA (2018), *From institutions to community living for persons with disabilities: perspectives from the ground*, Luxembourg, Publications Office.

1.	Commitment to deinstitutionalisation
2.	Availability of guidance to support the deinstitutionalisation process
3.	Active cooperation between the people involved in the deinstitutionalisation process
4.	A change in attitudes towards persons with disabilities
5.	Practical organisation of the deinstitutionalisation process

Source: FRA, 2018

1. CONTEXT OF DEINSTITUTIONALISATION

1.1 Legal and policy framework for deinstitutionalisation

1.1.1 National legal and policy framework for deinstitutionalisation

Policy in Ireland has been moving towards providing residential services in the community for persons with disabilities rather than institutions over the last number of decades. Participants in this research pointed to the Centres for Independent Living movement in the 1990s, and the publication of *Needs and Abilities: A policy for the intellectually disabled in 1990*, as early moves towards community-based services.⁸ However, it was only in 2011 that a national strategy for deinstitutionalisation (DI) was established with the publication of *Time to Move On from Congregated Settings: A Strategy for Community Inclusion* by the Health Service Executive (HSE).⁹ The Time to Move On strategy sits alongside a number of cross-departmental national policies, including the broader 'Transforming Lives' programme and National Disability Inclusion Strategy 2017-2021 (the latter was adopted after the completion of this research).¹⁰

While the terms 'deinstitutionalisation' and 'institution' are not unheard of in this context in Ireland, most participants in the FRA research used the terms 'decongregation' and 'congregated settings' in line with the Time to Move On strategy. This report uses 'deinstitutionalisation' and 'decongregation' interchangeably.

The Time to Move On report looked at congregated settings for people with intellectual and physical disabilities. People living in mental health services were not included in the report, as their needs were due to be addressed under the national policy on mental health services.¹¹ This case study therefore looks primarily at deinstitutionalisation for people with intellectual and physical disabilities. However, mental health advocates have indicated that deinstitutionalisation has also not been adequately addressed for mental health services.

The Time to Move On report identified over 4,000 people still living in congregated settings, defined as settings with 10 or more individuals. 93% of those people had an intellectual disability, and 73% had been there for 15 years or more. Residents of congregated settings were typically older and had a greater level of impairment than the general population.¹² Just over half of all those with intellectual disabilities in some form of residential service were accommodated in congregated settings.¹³ The report set out a strategy to completely close congregated settings within a seven year timeframe; however, progress has been slow. The latest available figures show that, at the end of 2017, there were 2,370 people remaining in congregated settings.¹⁴

This slow progress has been attributed by some participants to lack of funding, owing to Ireland's financial crisis post-2008 and ensuing austerity measures:

⁸ Department of Health (1990), *Needs and Abilities: A policy for the intellectually disabled*.

⁹ Health Service Executive (HSE) (2011), *Time to Move On from Congregated Settings: A Strategy for Community Inclusion*. Report of the Working Group on Congregated Settings.

¹⁰ Department of Justice and Equality (2017), [National Disability Inclusion Strategy 2017-2021](#).

¹¹ Health Service Executive (HSE) (2011), *Time to Move On from Congregated Settings: A Strategy for Community Inclusion*. Report of the Working Group on Congregated Settings, p. 26.

¹² *Ibid.*, p. 36.

¹³ *Ibid.*, p. 38.

¹⁴ HSE (2018), [Progress Report on the Implementation of Time to Move On from Congregated Settings: A Strategy for Community Inclusion – Annual Report 2017](#), p. 28. This figure does not capture some people with disabilities living in some residential centre for people with Autism and mental health facilities, as well as people with disabilities placed in nursing homes.

"We set ourselves a seven year time frame... but obviously, Ireland Inc. was broke and there was no additional resources made available." (National official)

In addition, some participants in the FRA research highlighted that the policy is not clearly underpinned by a strong rights-based legal framework. While Ireland signed the CRPD in 2007, it did not ratify the convention until March 2018. The eleven year gap between signature and ratification was attributed to the need to put in place key legislative amendments to ensure compliance with the Convention. However, significant legislative gaps remained at the time of ratification, including the commencement of the Assisted Decision-Making (Capacity) Act.

In the absence of funding and a strong legal framework, a large number of participants pointed to the role of the Health Information and Quality Authority (HIQA) in shaping the DI process. HIQA was created under the Health Act 2007 and commenced its role as inspector of disability services in 2013.¹⁵ Their published findings of extremely poor conditions in some large institutions prompted urgent action, often towards decongregating the setting. However, under the current legislative framework, HIQA do not have a regulatory remit to specifically progress DI, making the role that they play in driving DI somewhat ambiguous (see Section 3.1.1). The National Standards for Residential Services for Children and Adults with Disabilities refer to promoting and protecting the rights set out in the CRPD "when ratified"; they are not binding, however.¹⁶

A renewed commitment to DI was given on the formation of a new government in May 2016. The Programme for Partnership Government states:

*"We will move people with disabilities out of congregated settings to enable them live independently and be included in the community. Currently 2,725 people live in congregated settings and our objective is to reduce this figure by at least one-third by 2021 and to ultimately eliminate all congregated settings. The movement of those with high dependency needs will start in parallel with that of others and will not wait until higher function people have been moved."*¹⁷

1.1.2 Local legal and policy framework for deinstitutionalisation

Ireland's Health Service Executive is divided into nine Community Health Organisations (CHOs), each of which are mandated to progress DI within their own region. They are tasked with implementing national policy, rather than setting policy regionally or nationally.

One of the distinguishing characteristics of the Irish system is that the majority of public services for people with disabilities are delivered by voluntary agencies. These are charitable bodies who have Service Level Agreements with the Government to provide public services. As a national official commented: *"one of the issues that we face within this country...is you have all different service providers who come with their own ethos, their own board of management, their own CEO and their own view of the world on this."* (National official) This contributed to wide regional disparities in terms of DI in the decade leading up to the publication of the Time to Move On strategy. Large numbers of people with intellectual disabilities transferred out of congregated settings in some regions, while

¹⁵ Health Information and Quality Authority (HIQA) (2013), *National Standards for Residential Services for Children and Adults with Disabilities*.

¹⁶ *Ibid.*, p. 64, Standard 1.1.1.

¹⁷ Government of Ireland (2016), *A Programme for Partnership Government*, p. 72.

in other regions, new admissions to institutions remained high.¹⁸ This regional disparity formed the basis for a major research study, *Moving Ahead*, published in 2015. It compared two regions with very different levels of DI, and found that both local and regional factors played a significant role in this.

At local level, the researchers found that the ethos of the larger service providers was particularly significant. At regional level, the study found the region which had achieved a much higher rate of DI had early on adopted a policy of no re-admissions to congregated settings, and no clustered developments. The HSE and voluntary services providers worked together on a regional referral committee which examined accommodation options for individuals leaving congregated settings.¹⁹ However, as the report also noted: “*In the light of the commentary from HSE commissioners participating in Moving Ahead, it seems that at regional level there is some motivation but little authority to drive reform*”.²⁰

1.2 Organisation of deinstitutionalisation

Responsibility for DI, therefore, has a national, regional and a voluntary service provider dimension. However, because some of these voluntary agencies are very large and may operate across several CHOs, the responsibility is not always neatly hierarchical. The voluntary agencies concerned with people with intellectual disabilities also engage at national level through the Federation of Voluntary Bodies, which is the national representative group of disability service providers.

At national level, the HSE established a National Implementation Group in 2011 to oversee the implementation of the *Time to Move on From Congregated Settings* policy. In 2014 this group was realigned as a sub-group under the “Transforming Lives” Programme, which was established to implement the recommendations of the *Value for Money and Policy Review in the Disability Services in Ireland 2012*.²¹ The Time to Move On sub-group produces guidance on community transition plans and accessing housing. It has also developed and revised a Master Data Set, which requires service providers to submit quarterly information on individuals making the transition to independent living directly to the HSE project lead for deinstitutionalisation. On the basis of this information, progress reports have been published for 2015, 2016 and 2017.²²

Since 2015, annual targets for transition of people from institutional settings to homes in the community have been set in the HSE Annual National Service Plans, growing more ambitious as further funding becomes available. The HSE National Service Plan for 2017 sought to complete the move of 233 people to community based settings, while the

¹⁸ McConkey, R., Kelly, F., Craig, S., & Mannan, H. (2013), A longitudinal study of the intra-country variations in the provision of residential care for adult persons with an intellectual disability, *Journal of Intellectual Disability Research*, 57(10), pp. 969-979.

¹⁹ Linehan, C., O’Doherty, S., Tatlow-Golden, M., Craig, S., Kerr, M., Lynch, C., McConkey, R., & Staines, A. (2015), *Moving Ahead. Factors contributing to the successful transition of people with intellectual disabilities from congregated to community-based residential options in two regions in Ireland*. Dublin, School of Social Work and Social Policy, Trinity College Dublin, p. 115.

²⁰ Linehan, C., O’Doherty, S., Tatlow-Golden, M., Craig, S., Kerr, M., Lynch, C., McConkey, R., & Staines, A. (2015). *Moving Ahead: Executive Summary*, Dublin, School of Social Work and Social Policy, Trinity College Dublin, p 19.

²¹ HSE (2016), *Time to Move On Bulletin*, July 2016.

²² HSE (2016) [Progress Report on the Implementation of the Time to Move On Strategy: Annual Report 2015](#); HSE (2017), [Progress Report on the Implementation of the Time to Move On Strategy: Annual Report 2016](#), HSE (2018), [Progress Report on the Implementation of Time to Move On from Congregated Settings: A Strategy for Community Inclusion – Annual Report 2017](#).

National Service Plan for 2018 commits to moving a further 170 individuals.²³ These targets are currently set in response to the findings of HIQA inspection reports,²⁴ and therefore relate to specific services in specific locations.²⁵ However, the Time to Move On progress report for 2017 indicates that only 144 transfers were completed, compared to the target of 223; the 2016 report indicates that only 74 transfers were completed that year,²⁶ compared to a target figure of 160.²⁷

At regional level, it is the responsibility of the Social Care Division within each CHO to support the transition of these individuals from the specific congregated settings into community living. In some cases, the individual may transfer from a HSE facility to the care of a voluntary agency or vice versa; in other cases, the care may be provided by the same agency in a community setting. Beyond these priority individuals, however, the voluntary agencies themselves may have their own plans to transition individuals into the community. For example, in the CHO covering the case study locality, the case study service is not listed on the annual target list. The service is nonetheless actively planning the DI of several individuals and the closure of a congregated unit.

1.3 Funding for the deinstitutionalisation process

The Time to Move On report concluded that the cost of HSE-funded supports for people transitioning to community-based living could be met within the current budget for disability services, by appropriate reallocation of funds. On the other hand, it highlighted that additional funding for the capital costs of new housing, financing transition supports, and 'bridging funding' (to meet the need to keep both old and new living arrangements open for a limited period of time) would have to be considered.²⁸ However, the Time to Move On strategy was put forward in a time of limited resources, and it was not until some years later that these additional funds began to materialise, with several participants citing developments in 2016 as a key turning point, as outlined below.

Many participants welcomed the commitment of the new government in 2016 to provide €100 million capital investment into disability services in a multi-annual programme, starting with €20 million in 2016. In the first year, this capital investment was specifically linked to the need to provide housing for those mentioned on the annual target list for transition to the community.²⁹ The Time to Move On 2016 bulletin refers to an exercise underway with service providers to identify future housing needs of those still to transition, according to the will and preference of each individual. This would then inform the disbursement of the remaining €80 million to 2021.

Also in 2016, a Service Reform Fund was established to support the implementation of reforms in disability and mental health services, including DI, supported by the Department of Health (contributing €30 million over three years) and Atlantic

²³ HSE (2018), [Progress Report on the Implementation of Time to Move On from Congregated Settings: A Strategy for Community Inclusion – Annual Report 2017](#), p. 60; HSE (2016), *National Service Plan 2017*, p. 32. In 2016, the target was 160.

²⁴ See, for example, HSE (2016), *Progress Report on the Implementation of the Time to Move On Strategy: Annual Report 2015*, p. 44.

²⁵ HSE (2017), *Social Care Division Operational Plan 2017*.

²⁶ HSE (2017), *Progress Report on the Implementation of the Time to Move On Strategy: Annual Report 2016*, p. 30.

²⁷ HSE (2015), *National Service Plan 2016*, p. 75.

²⁸ HSE (2011), *Time to Move On from Congregated Settings: A Strategy for Community Inclusion. Report of the Working Group on Congregated Settings*, p. 120.

²⁹ Department of Health (2016), [Minister Finian McGrath announces significant investment to support people with a disability to move into more suitable accommodation €100m funding for Programme for Government commitment from 2016-2021, including €20m in 2016](#), 20 June 2016.

Philanthropies (contributing €15 million).³⁰ This Service Reform Fund is supported by Genio, a not-for-profit organisation which brings together government and philanthropic funders in the area of disability and mental health.³¹ Genio has funded a number of projects on self-directed supported living.

In terms of providing individualised services, many participants noted the challenges in unbundling funding. Although some funding is now disbursed on an individualised basis, many of the large service providers are still awarded block grants to provide care. These block grants are disbursed annually to the service provider, and are generally based on a historical baseline, and on numbers of units and centres operated, not on the basis of individuals supported. The Time to Move On report in 2011 divided the expenditure data by centre by the number of residents to find an average per-person cost to the HSE of €106,000, of which 83% is made up of staffing costs. There is, however, a very wide variation between providers, from a high of €231,575 to a low of €37,394.³²

Many participants felt that establishing an individualised resource allocation model would be helpful, whereby budgets and support are assigned on the basis of individual need.³³ The Government put in place a Task Force on Personalised Budgets, which was due to report back with a suggested implementation strategy by the end of 2017.³⁴ Some participants, however, were of the view that this was unlikely to come into force in the near future, one citing lack of political will. The Task Force published its report in June 2018, after the completion of this research.³⁵ The report contained a number of recommendations to test and evaluate a system of personalised budgets.

In the majority of cases, the HSE funds service providers to provide assistance, or provides services directly themselves. However, there are a small number of broker-type services, such as [Possibilities Plus](#) and [Áiseanna Tacaíochta](#), facilitating direct payment schemes, allowing people with disabilities to hire their own personal assistant.³⁶

1.4 The status of deinstitutionalisation

“What’s been happening nationally to me seems to be very slow [...]. I’m looking at it thinking why are people just not grabbing it and going with it? [...] Because another year will have passed [...] and the people will be getting older and they’re still living in institutions.” (Service provider)

The latest available data indicates that numbers in congregated settings have diminished from 4,099 identified in the Time to Move On report in 2011 to 2,370 at the end of 2017.³⁷ While this is much slower than the original target of complete DI within seven years, it is an improvement over the preceding decade, where, while numbers in congregated settings

³⁰ Department of Health (2016), [Lynch welcomes collaboration with The Atlantic Philanthropies on Service Reform Fund](#), 16 June 2016.

³¹ For more information, see: www.genio.ie/.

³² HSE (2011), *Time to Move On from Congregated Settings: A Strategy for Community Inclusion. Report of the Working Group on Congregated Settings*, p. 47. See also: *Transforming Lives, Working Group 1 (2018), Report on future needs for disability services*.

³³ [Two projects by the National Disability Authority](#) investigated resource allocation in the Irish context.

³⁴ Department of Health, [Task force on personalised budgets](#).

³⁵ Department of Health, [Towards personalised budgets for people with a disability in Ireland: report of the Task Force on personalised budgets](#).

³⁶ These schemes and two other pilot programmes for younger people are evaluated by Fleming, P. (2016), *How personal budgets are working in Ireland: Evaluating the implementation of four individualised funding initiatives for people with a disability in Ireland*, National University of Ireland, Maynooth, Research brief.

³⁷ HSE (2018), [Progress Report on the Implementation of Time to Move On from Congregated Settings: A Strategy for Community Inclusion – Annual Report 2017](#), p. 28.

declined slightly due to natural attrition, new admissions exceeded transfers to the community between 1999 and 2008.³⁸

In 2017, the latest year for which data is available, there were 144 transfers to community living and 36 admissions or re-admissions. In addition, there were 103 deaths of residents of congregated settings in 2017.³⁹

As outlined in the introduction, this report covers both fieldwork done in 2016, comprising a range of interviews and focus groups with both national stakeholders and local services across Ireland; and the fieldwork done in 2017, in a selected case study location. The local case study part of the research focused on one particular voluntary body service and their efforts to decongregate a large institution for persons with intellectual disabilities. The institution is located in a small town, with a population of less than 4,000. The congregated setting is on the campus of a former religious order, with various units spread over the campus. People leaving the congregated setting continue to be supported by the voluntary service provider and are generally housed either in the town, or in the surrounding countryside or rural villages, in houses owned or rented by the voluntary body. The voluntary body was originally established by a religious order, and catered initially only for women and girls, who might have been sent there from all over the country.

The case study service is among those voluntary bodies who were early adopters of the principles and philosophy of DI, with the first community group home opening in the early 1980s. Houses in the community were opened gradually over the years, but a big push came a decade ago with a decision to close one of the large units on campus, where living conditions had become extremely run-down. According to one staff member, there were: *"18 people living there with one chair lift"* (Service provider). The pace of DI then accelerated, and today, there are two remaining campus units, home to slightly over 20 people. The service plans to fully de-congregate one of these units, catering for people with severe to profound disabilities, and to keep the other unit open as a convalescence/respite facility. The service continues to modify and innovate their approach to DI, viewing independent living as an evolving process rather than a process which ends once the institution finally closes its doors. Approximately 75 individuals are now availing of community-based services provided by the same voluntary body in the locality.

Initially, service users were mostly accommodated in group homes of up to six people, but have moved towards smaller numbers over the years. Now residential services generally accommodate between one and four persons, in keeping with the Time to Move On policy, and are regulated by HIQA. A government Housing Circular at the end of 2015 stipulates that homes funded through county councils for DI house no more than four individuals.⁴⁰ However, a housing official interviewed said that most applications he sees would not seek to house less than that, presumably for reasons of economy. Participants in the case study locality, in contrast, state that they strive towards two or three per house. Individualised arrangements – whereby a service member lives alone with staff support – are preferred for people with severe autism or challenging behaviours.

The case study service also has a smaller operation which facilitates people with disabilities to avail of more independent living arrangements. In these cases, they, usually supported

³⁸ HSE (2011), *Time to Move On from Congregated Settings: A Strategy for Community Inclusion. Report of the Working Group on Congregated Settings*, p. 3.

³⁹ HSE (2018), [Progress Report on the Implementation of Time to Move On from Congregated Settings: A Strategy for Community Inclusion – Annual Report 2017](#).

⁴⁰ Department of Environment, Community and Local Government (2015), [Supplementary Guidance for the Provision of Housing for Persons with Disabilities](#), Circular: Housing 45/2015, 21 December 2015.

by their family, have their own tenancy agreement with a private landlord. Support staff is provided through the service, but staff are recruited directly by and for each individual. This service does not fall under the remit of HIQA, who do not currently regulate home supports.

Key to understanding the Irish system is that local services are primarily run through voluntary agencies, which are commissioned by the HSE to provide public services. As such, each service has its own approach towards decongregation, and the case study service should not be taken as representative. This report incorporates research data from both the case study service and other services and stakeholders nationwide (see introduction); the analysis is disaggregated where appropriate.

Although services nationwide are at very different stages in the DI process, many participants from both the case study locality and others involved in the research referred to similar milestones in the DI process (see box).

Timeline of DI: Some key milestones

The first win: Many participants emphasised the importance of achieving a first success story, which would serve as a positive example for service users, families and staff.

The tipping point: Both HSE managers and CEOs of services mentioned that, after a number of successes, enough momentum would be generated to carry through the greater part of DI.

The hump: A final hurdle, however, often presents itself at the moment when complete closure of the institution is envisaged. A small but determined cohort of staff, family and service users opposed to DI may be challenging, as well as the issue of 'double staffing' a skeleton institution as well as new community houses.

The second wave: Several participants felt that community group housing was only the first step for some service users towards a more independent living arrangement, as illustrated by Cathy's story (see section 3.1.4).

2. UNDERSTANDING OF DEINSTITUTIONALISATION AND INDEPENDENT LIVING

2.1 Key terms and concepts

In *Time to Move On*, a congregated setting is defined as where 10 people or more live together. It recommended that, in undergoing DI, where residents choose to share accommodation, no more than four should be accommodated together.⁴¹ As some participants pointed out, this leaves something of a gap concerning larger group homes – they are not considered as a 'congregated setting', but neither are they an optimal arrangement.

Participants were generally in agreement that smaller numbers were better, as one participant with an intellectual disability commented: "*You must cut that down [to] one and two and...not five*".

However, while for the majority of participants across all groups, smaller living groups are a crucial prerequisite, they are not the only factor in community-based living. Many

⁴¹ HSE (2011), *Time to Move On from Congregated Settings: A Strategy for Community Inclusion. Report of the Working Group on Congregated Settings*, p. 17.

participants felt that even smaller group homes easily became 'mini-institutions' (see section 3.4.4). One participant emphasised that:

"I think unfortunately sometimes community-based is sometimes looked at in terms of bricks and mortar, as opposed to looking at it in the context of the individual. The word community means connecting with community, living in a community." (Representative of a NGO)

The issue of congregated day services was also mentioned as an issue by a small number of participants. The New Directions policy report issued in 2012 advocates a move away from segregated day services towards individualised support in the community. In the case study locality, the day service had been closed for some time, but other services are still grappling with this issue.

Several participants in different groups had some unease about the term independent living, feeling that it was easily misinterpreted as being able to live with minimal support, particularly for those with higher degrees of impairment. A sister of a service user with profound disabilities who remains in an institution recounted an earlier attempt at DI:

"I remember at the time that they were saying like with independent living they would be able to train her to look after herself and I remember mother coming home very upset from the meeting because...we knew that this wasn't possible at all." (Family member of a person with disabilities)

This experience reflects the findings of a 2014 Genio study on self-directed supported living, which found that: *"efforts from the past...relied on a perhaps naive assumption that those who moved would somehow acquire the skills they needed to participate in their community"*.⁴²

A senior manager of a voluntary agency working with people with an intellectual disability commented:

"It is interesting you say supporting people to living independently [...]. We would have moved a lot of people into community settings that have really very heavy support needs. So, obviously, you are trying to optimise independence but very often there isn't [...] marked evidence of [...] independence but there is very often an immediate improvement in terms of the personal stress levels." (Manager of a service provider)

A senior manager working with people with physical disabilities concurred, feeling that independence could be difficult to measure, but that stress levels had evidently gone down for people who had made the move to community.

One participant commented that those less in favour of DI could use independent living as a metric which is destined to fail:

"[the term independent living is] like a weapon or a stick that people use as well...you're expecting to take Johnny out here [to] community and you expect Johnny to be independent and six months later, 'sure I told you Johnny's not independent'." (Staff member)

⁴² Genio (2014), *Supporting People to live Self-Directed Lives in the Community: Learnings from 54 Irish Projects*, p. 8.

This contributes in part to the tendency to decongregate people with lesser support needs first (see section 3.6).

Many participants, therefore, favoured the terms supported living, self-directed supported living, or person-centred approach over independent living. Others felt that it was better to champion a clearer understanding of 'independent living', similar to that defined by Judy Heumann, US disability activist and early leader of the international Centers for Independent Living Movement: "*Independent Living is not doing things by yourself, [...] it is being in control of how things are done*".⁴³

2.2 Impact of deinstitutionalisation

"I've been in institutions since 35 years ago and I've seen a lot of changes. People give you more [in institutions] they don't let you speak up what kind of food you want and all that and run the place you want but I felt really lonely there because you couldn't speak up when you wanted and get mountains of food what you want. I came out [to community setting], [...] I'm a new girl now, I know what I want and everything." (Person with a disability)

The vast majority of participants, across all groups, felt that the impact of DI on people with disabilities was overwhelmingly positive. Service users themselves spoke principally of increased choice and control with regard to daily choices, such as food and routine. One service user, speaking of his staff said:

"They...help me go town, come home, do shopping, go out and [they don't say] what time are you coming back and what time you go bed, what time you get up. Yeah, [I] move out and make more friends. And go out come home late at eleven o'clock." (Person with a disability)

People with disabilities also spoke of greater space and privacy. The contrast between the congregated setting and community-based living in this latter regard was highlighted by a staff member:

"You go out to the units [in the congregated setting] and they're kept immaculately but you walk into the bedrooms and you have four beds. These are people's homes and some people have been living like that for 50 years or more here. You go into the dining room and it is like a canteen, it's a café. As opposed to where they have their own bedroom, the kitchen will have maybe one or two other people with them but you don't have the likes of me walking through the unit, you don't have the electricians, you don't have the maintenance, you don't have all of these outside people. It is their homes [...] whereas you go onto the unit and you have all that activity. At night time [...] there are lights on all the time, there are night nurses doing the rounds. You go out to community housing and [...] it is quiet, people get some, for the first time ever a good night's sleep." (Service provider)

Staff and managers also noted decreased stress levels for people with disabilities with community-based people enjoying their personal possessions and food without the fear that other residents would take them away. In many cases, decreased levels of medication needed or administered were noted. Staff also noted improved service user image and appearance once they were receiving more individualised attention. One elegantly dressed service user explained that when she wanted a new outfit, staff took her shopping, whereas in the congregated setting, she was reliant on staff to buy her clothes. Improved

⁴³ World Institute on Disability (1995), *Just like Everybody Else: the changing image of disability*, p. 8.

personal care and image was noted by at least one participant as key to integrating into community life and by another as linked to decreased levels of medication – because when the physical appearance of a service user improved, psychotropic medication was less likely to be prescribed.

Service users, staff and managers all spoke of better relationships between staff and service users, and between staff themselves. The staff: *“start looking at the [service users] as being individuals”* and took a more flexible approach to their work, *“whereas in the congregated settings ‘it’s not my job’, you know”*.

In some cases, family became more involved in service users’ lives following DI, feeling freer to visit in a home-like setting.

Negative impressions of the impact DI could have were much rarer, and generally expressed by those staff or family members who had not experienced DI. Concerns for people’s safety and security were expressed (see section 3.4.5), and staff and family members who had not experienced DI sometimes had fears that the care would not be as good in community settings. Others felt that, without the necessary resources and supports, people risk being segregated or lonely in the community.

A number of self-advocates expressed concern with regard to the transition process, which they felt was not always adequately resourced. Without an adequate transition process, people could feel anxious or ill-prepared. However, others favoured a shorter transition period, arguing that a person’s full potential did not show until they were already living in the community (see section 3.2).

3. ESSENTIAL FEATURES OF THE DEINSTITUTIONALISATION PROCESS

Essential features	Key drivers	Key barriers
3.1 Commitment to deinstitutionalisation	<p>3.1.1 Role of the Health Information and Quality Authority (HIQA)</p> <p>3.1.2 National strategy on DI: The Time to Move On from Congregated Settings report</p> <p>3.1.3 Voluntary agency management commitment to DI</p> <p>3.1.4 Persons with disabilities themselves are empowered to achieve DI</p>	<p>3.1.5 Funding is insufficient, ineffectively spent or opaquely awarded to support the DI process</p> <p>3.1.6 Reluctance on the part of some voluntary agencies</p> <p>3.1.7 Limited political will at national level</p>
3.2 Availability of guidance to support the deinstitutionalisation process	<p>3.2.1 Pilot projects showcasing how DI works in practice are implemented</p> <p>3.2.2 Staff working with and for persons with disabilities receive (re-) training on how to implement the DI process</p>	<p>3.2.3 Insufficient preparation for DI for the persons concerned</p>
3.3 Active cooperation between the people involved in the deinstitutionalisation process	<p>3.3.1 Avoidance of large-scale comprehensive consultation</p> <p>3.3.2 Active engagement with families of persons with disabilities on an individual basis</p> <p>3.3.3 Co-operation between HIQA, HSE and service providers</p>	<p>3.3.4 Unhelpful 'co-operation' between staff and families</p> <p>3.3.5 Lack of co-ordination on housing for people with disabilities</p>
3.4 A change in attitudes towards persons with disabilities	<p>3.4.1 Individual stories of people with disabilities successfully transitioning to living in the community and shared with people involved in the process</p> <p>3.4.2 Committed community based staff</p> <p>3.4.3 Local communities show their support for the DI process</p>	<p>3.4.4 Persisting 'institutional culture' in community-based services</p> <p>3.4.5 People fear for the safety and security of persons with disabilities moving to live in the community</p> <p>3.4.6 Learned dependence among persons with disabilities</p>

<p>3.5 Practical organisation of the deinstitutionalisation process</p>	<p>3.5.1 Facilitating independent living skills for persons with disabilities</p> <p>3.5.2 Person-centred planning</p>	<p>3.5.3 Insufficient suitable housing</p> <p>3.5.4 The rules and regulations on provision of services to persons with disabilities are inflexible</p> <p>3.5.5 Staff working conditions</p> <p>3.5.6 Community-based services responding to the different support needs of people with disabilities are lacking</p> <p>3.5.7 Too few employment opportunities for persons with disabilities</p>
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3.1 Commitment to deinstitutionalisation

Drivers and barriers around commitment to deinstitutionalisation, particularly at national level, featured very strongly in the research. As outlined in the introduction, however; many participants felt that while policy had been put in place in 2011, with the publication of the Time to Move On report, it took the establishment of HIQA and some damning public reports on life in institutions to provide momentum to the decongregation process.

3.1.1 Driver 1: Role of the Health Information and Quality Authority (HIQA)

Many participants pointed to the role of HIQA in providing momentum to the DI process, including national and local public authorities, HIQA inspectors themselves, and some employees of voluntary bodies.

HIQA began its inspection of disability services in 2013, with a view to ensuring that each residential setting for people with disabilities would be registered as compliant with regulatory standards by 2016 (see section 1.1). This deadline has now been extended to 2018. Their findings of extremely poor conditions in some of the larger congregated settings prompted action in two ways. Firstly, HIQA's refusal to register unsuitable centres served to fast-track existing DI plans:

"[Management will say] 'we know this is a terrible place for people to live, we know people are not safe [...] we've a plan here and it's a lovely plan' and the plan has been there for the last five years, 'and we're going to move people out into these houses' and nothing happens. And then [HIQA] cancel registration and all of a sudden, boom, people are moved out within days, weeks." (National official)

Secondly, their published reports are often picked up by the media, creating a public outcry and, in the view of many participants, forcing government to act. Capital funding for DI is now linked to a priority list of residents moving from specific congregated settings, which is determined by funders on the basis of HIQA reports.

However, many participants also pointed to difficulties in the way in which HIQA were shaping the DI process. As stated above, HIQA's standards for residential services cover congregated settings, clustered housing and dispersed housing in the community and they do not have a regulatory remit with regard to the DI process.⁴⁴ Thus while in many cases, unsatisfactory findings prompt a move towards dispersed settings, in other cases, participants pointed out that money has been put into improving congregated settings to meet the standards instead. It is possible for a congregated setting to meet the legal requirements set out in the Health Act 2007 and in the associated regulations. If providers meet these requirements, including in residential settings for more than four people, HIQA are required to register them. The fact that the standards are not tailored towards community-based living can also act as a barrier to independent living (see section 5).

Even where the HIQA process has led to a move towards DI, some national stakeholders were uneasy about the reactive nature of this process. They questioned whether it would lead to quality outcomes, and felt that money for community services would only be made available where residential institutions fail to meet the standards. In their view, this sometimes meant that funding was awarded to some of the services who were least willing or less well placed to provide good individualised services. In this regard, the indication that the remaining capital funding will be disbursed on the basis of a comprehensive review

⁴⁴ HIQA (2013), *National Standards for Residential Services for Children and Adults with Disabilities*, p. 6. For a discussion of the HIQA inspection process, see: National Disability Authority (2015), [Review of the implementation of regulations and inspections in residential services for adults and children with disabilities](#).

of the housing preferences of those remaining in congregated settings is encouraging (see section 1.3).

3.1.2 Driver 2: National strategy on DI: The Time to Move On from Congregated Settings report

"HIQA are really putting a spotlight on these larger settings. So the HSE and therefore government, have really had no choice but to really pick up [The Time to Move On Report] again and say, 'we'd better get out and implement this'." (Representative of a disabled persons' organisation)

Participant views were mixed as to whether the national strategy on DI was a major driver of the DI process. It was rarely mentioned in the interviews with stakeholders in the case study location, where the service in question has been implementing DI for far longer than the national policy had been in place. At national level, some cited it as a significant driver, or just a report *"sitting on the shelf"*.

Many participants felt that it took the HIQA inspections to put the Time to Move On strategy into action; however, the fact that there was strategy in place to put into action was seen by some as crucial. There is some evidence that the findings of the Time to Move On report are now being used to implement evidence-based policy in specific areas. For example, the Time to Move On recommended dispersed housing in the community, as opposed to housing clusters, on the basis of an expert report commissioned by the National Disability Authority (NDA).⁴⁵ This was then reiterated in a Housing Circular in 2015, which stipulated that ring-fenced housing funding should be used for dispersed housing only.⁴⁶

However, while this circular was being implemented by local authorities, the rationale behind it was not universally accepted. One local housing official interviewed sought an exemption for a specific campus-based cluster accommodation:

"Sure it was lovely out there, they had all the activities, the pottery and everything. It was in a very rural setting, where would you move them to? And you couldn't move those people out, they wouldn't be used to it at all." (Local official)

3.1.3 Driver 3: Voluntary agency management commitment to DI

In Part 1 of the research, many interviewees pointed to the role of CEOs of voluntary bodies as key to implementing DI successfully, and in Part 2, almost every interviewee cited the role of senior management in the organisation as a key driver behind DI in the locality. Most viewed this as a top-down process, starting with the CEO, who then brought in committed individuals, so that DI became a priority across all departments for senior management. This then led to what one interviewee described as the *"only show in town"* attitude towards DI – meaning that staff at all levels of the organisation understood that DI was a reality, whether they liked it or not.⁴⁷

However not all voluntary agencies display the same enthusiasm for DI, and the proactive nature of certain voluntary bodies can in some ways be seen as complementing the reactive response to HIQA findings at the other end of the scale (see section 3.1.6).

⁴⁵ Mansell, J. and Beadle-Brown, J. (2008), *Dispersed or clustered housing for disabled adults: a systematic review*, Canterbury, Tizard Centre.

⁴⁶ Department of Environment, Community and Local Government (2015), [Supplementary Guidance for the Provision of Housing for Persons with Disabilities](#), Circular: Housing 45/2015, 21 December 2015.

⁴⁷ The importance of multi-level leadership was also emphasised by Genio (2014), *Supporting People to live Self-Directed Lives in the Community: Learnings from 54 Irish Projects*, p. 10.

3.1.4 Driver 4: Persons with disabilities themselves are empowered to achieve DI

"[T]here was a decision by somebody that he would engage with this and move out and he then packed his bag and there are the bags sat, packed...Then it was everybody else scrambling around saying we have to do this...and we had to do it quickly." (National official)

There were many examples of persons with disabilities being strong self-advocates and then playing an important role in setting an example for other service users throughout the research. One service user, Cathy, followed the lead of her friend who had achieved DI to campaign for a home of her own. In another example, one staff member described how a group of self-advocates were encouraged to take taxis to attend evening classes. All of the members of the group were initially fearful, seeing drivers as a potential danger, but once one person had done it:

"Well if [names service user] can go and do that, maybe I can get into one'. [...] It might sound simple but they were the stuff that you had to break down." (Staff member)

However, participants also felt it was important to pay attention to those who might not be considered such strong drivers of DI:

"For some people, they're chomping at the bit to actually be gone but there's some people with very significant disabilities who, as to say, they themselves don't know that there may be a better way that they could live." (National official)

For those with severe disabilities, knowing how they might respond to DI is challenging. One mother, speaking of her daughter's transition explained:

"It is a huge, fantastic change in her. She is a much happier girl now. When she was in [the congregated setting] she had big patches, bald patches from twisting her hair out and I didn't realise that that was saying she was unhappy. I thought that was just what she did. And she would box herself. And like, I didn't know that she was unhappy." (Family member of a person with disabilities)

This then raises the question around 'will and preference' and how best to respect a service user's wishes. In one case recounted by a senior manager, a service user's transition to community living was vehemently opposed by her family. The service employed a personal advocate in an effort to move things along, but while the service were expecting that this advocate would assess the situation and decide whether or not the move was in the 'best interests' of the service user, the advocacy service were adamant that they did not "*do best interests*" (Service provider). This is because the remit of the advocacy service, following best practice, is to follow the will and preference of the service user. But the service provider felt that the service user had been unduly influenced by her family.

"She did say at the start that she wouldn't mind living in the community house. But the advocate was kind of saying, 'But she didn't repeat it more than two times.' I suppose. And it was so difficult at the time, because you had the family saying, 'Absolutely not'." (Manager of a service provider)

Several participants in the case study locality also highlighted that it was not until a person underwent the transition that their full potential emerged:

"[P]art of our rationale would [be] really creating a context in which a fuller version of the person can emerge because you typically find a very one-dimensional

expression of the person in the congregated setting. That would be one of the reason why we wouldn't waste much time on doing detailed assessment in the congregated setting." (Manager of a service provider)

In some cases, this led to persons with disabilities, sometimes having initially been hesitant about community living, deciding to go one step further and campaign to live by themselves. One participant described how a service user she was close to had been persuaded to leave the congregated setting and move into a community group home. After a couple of years *"she completely shocked us all because she decided, out of the blue, she wanted to live on her own with nobody"* (Staff member of a service provider). A similar story is told by Cathy, a research participant with an intellectual disability.

Cathy's story

I come from a large family. I was at home till I was eighteen, going to a normal school – well, I didn't go all that often! When I was 18, I was sent to [congregated setting]. I don't know why; my mam just told me it would be better for me.

I was up in the main house at first, it was big dorm rooms up there. Eventually I moved down to [Unit C], and I got my own room. The staff were still on duty at night though, they used to open the door at night, checking you were OK. There would have been a lot of people in that house.

When they first started talking about moving out into the community, I wasn't too sure about it. I didn't know what I was going to face. But I said, sure, I'll give it a go.

I moved into a house with four other girls. That didn't suit me at all, though, they expected me to do everything. I said, I have to get out of here. I saw my friend [Bernadette], she was in [Unit C] with me. She got to move out on her own, in a house on her own. I said, that's what I want. I used to go up to [congregated setting] every day after work, I was telling [the manager in charge], "I have to move out, I want to move out".

My family didn't let it happen for a long time, though, they were dead set against it. They didn't think I'd be able for it, living on my own. In the end, [a support worker] came down with me to [the family home] and I told my sister: 'That's it, I'm moving out, I need my own space.' And so they said: 'Well, alright then Cathy.'

I went and viewed apartments myself, with [the support worker] and my younger sister. I saw this apartment and I said: yes, this is the one. I have my own balcony, with a few plants, and I can see over to the river from the balcony. I have a spare room, and my sisters come and stay. My name is on the lease, and if I have any problems, the landlord comes, no hassle.

I go to work from 10-2, three days a week, but I get the bus so I'm out from 8.30 to 4. I go to the local day service on Wednesday mornings, and I'm into all the community activities here, the youth club, the ladies' group. The neighbours are friendly, they called over when I first arrived, to see if I was ok, like.

I don't mind being here on my own in the evenings, I'm tired, I'll watch a bit of telly. I don't stay here on my own on the weekends, though, it might be a bit lonely. So every second weekend, I go to [Louise, her care worker]'s house, she lives with her partner on a farm. Every other weekend, I go and stay with my friend [Bernadette, another service user] in [principal town]. There's no staff member there, just the two of us for the weekend.

What else do I need in my life? Nothing, I'm happy the way I am.

3.1.5 Barrier 1: Funding is insufficient, ineffectively spent or opaquely awarded to support the DI process

Lack of funding was probably the most cited barrier across all participants. Given that the 2011 Time to Move On strategy had little dedicated funding until 2016, this is not surprising. It is in itself also an indicator of limited political will to some extent. However, many participants also cited a lack of transparency and efficiency around funding and how it is awarded, as illustrated by one person with a physical disability:

"I mean you're not entitled to anything... One person gets, one person doesn't get, there doesn't seem to be no rhyme or reason as to why one person get and one person doesn't get it." (Person with a disability)

A service manager recounted that he was offered a sum so large he *"would be embarrassed to tell you"* by the HSE to provide an individualised service to one person.

Several others also pointed to inefficiencies in the way some large voluntary services spent their funding. The awarding of funding to date has been channelled towards the services which fall short of HIQA standards (see section 3.1.1). Some participants suggested that unreasonably large sums were requested by services to undertake DI because of their unwillingness to engage with the process.

Many participants felt that the lack of a standard resource allocation model, taking into account different levels of impairment was part of the problem. However, some service providers felt that the block grant system had actually been helpful in their move towards DI. They pointed out that it was very hard to predict what funding one person would need in a community based service before transition, and that block funding permitted them to move funding quickly to where it was most needed.

3.1.6 Barrier 2: Reluctance on the part of some voluntary agencies

"I'm sure it's to do with the agencies themselves. I mean not wanting to do it. That's the biggest block." (Person with a physical disability)

While some voluntary agencies have been early champions of the DI process, the influence of these large voluntary bodies on the DI process has not been universally positive (see section 3.1.3). One interviewee stated that there had been significant lobbying on the part of some service providers during the drafting of the Time to Move On report, arguing for campus-based accommodations for those with high levels of impairment, for example.

While all of the voluntary agencies who agreed to take part in this study were committed to DI, both HSE managers and voluntary agency managers pointed to the challenges of simultaneously running a large institution while trying to undertake DI. In the case study locality, this was achieved by separating the campus based operation from the community based operation, and by further establishing a quasi-autonomous independent living service.

3.1.7 Barrier 3: Limited political will at national level

Many participants very clearly thought that it took the negative findings of the regulator, HIQA, to generate momentum behind the DI process, and that the reaction was sometimes knee-jerk rather than well thought through for best outcomes. HSE managers also

mentioned that, in some cases, local members of parliament spoke out against the closure of institutions because of the job losses it might entail.

3.2 Availability of guidance to support the deinstitutionalisation process

Although there are now a number of toolkits and guidelines which have been prepared by the Time to Move On working group,⁴⁸ these were rarely mentioned by the participants in the research. Part of this may be to do with the relative newness of some of these tools, and part of it may be attributed to the very different systems which each voluntary service operates, making a 'one size fits all' system difficult to achieve. Secondly, rather than close down institutions in one go, Ireland has espoused a 'one person at a time' approach to DI which, while this has involved a very slow pace of change, it has perhaps meant that there are less observations of insufficient preparation for DI. Certainly, some participants felt it was preferable to the rush to 'de-designate' mental health institutions in the early 2000s. Finally, many participants, particularly in the case study locality, were wary of "going down the road of a system to put in place" feeling that the essence of a person-centred approach was that there was no single approach that suited everyone, and that over-reliance on standard systems and guidance would impede that. However, some potential drivers and barriers around guidance and preparation for DI are briefly mentioned below.

3.2.1 Driver 1: Pilot projects showcasing how DI works in practice are implemented

Several participants mentioned the work done by the Federation of Voluntary Bodies 'Next Steps' project through case studies of ongoing work to identify supports and barriers in moving towards more individualised supports.⁴⁹ Others were either managing or service users in a pilot DI project funded by Genio. Clearly, many of the participants were familiar with these projects and were well-networked with each other in a variety of fora. However, one national stakeholder commented: "there's some very good stories out there but we don't seem to have them in places where people are hearing them often".

3.2.2 Driver 2: Staff working with and for persons with disabilities receive (re-) training on how to implement the DI process

Many participants, particularly in the case study locality, explained that they tried to recruit afresh for staff in community-based settings, to avoid bringing institutional habits into the community (see section 3.4). However, in the case study locality, re-training was offered to service staff, such as canteen or maintenance staff, to become community care workers, and several took it up. This was a way of recruiting staff who would be familiar with service users, but not necessarily influenced by models of institutional care, while ensuring jobs for those who might otherwise be without a job as the institution grew smaller.

3.2.3 Barrier 1: Insufficient preparation for DI for the persons concerned

There was a divergence of views as to the level of preparation for DI that is necessary and useful, particularly for the service user concerned. In Part 1 of the research, both a peer advocate consulted and a service user felt that it was crucial to prepare people well in advance for DI, by providing extra individual support while still in the institution:

"What's happening now is that these people are setting us up to fail... after 40 years in an institution, they can't just all of a sudden overnight throw you out say off you"

⁴⁸ The full set of document is available at: www.hse.ie/eng/services/list/4/disability/congregatedsettings/. See also: www.hse.ie/eng/services/list/4/disability/newdirections/.

⁴⁹ See: National Federation of Voluntary Bodies, [Next steps community of practice and learning](#).

go in the morning on your own. There has to be a good six to nine months lead-in time where they teach you these life skills.” (Service user)

Another self-advocate felt that the transition needed to be properly resourced.

However, in the case study locality, very short transition periods were generally favoured, partly in order to avoid prolonged conflict with staff, and partly because management felt that it was only after a move to community group housing that the person’s true potential was revealed. Key to the success of this approach was the organisation’s willingness and ability to move an individual to another living arrangement within a short space of time if necessary – three out of four persons with disabilities interviewed in the locality had moved several times. In general, the approach appeared to have worked well, although one staff member who remained in the campus-based setting provided a dissenting view:

“If [the transition] had have happened over eight weeks, you could tell then possibly someone’s not really going to make this and then you could actually delay it.” (Staff member)

3.3 Active cooperation between the people involved in the deinstitutionalisation process

Active co-operation between persons involved did not feature very prominently in the discussions with participants in the research. Where it did, it was sometimes the inverse of what might be expected. Cooperation between stakeholders including staff, family and local communities was seen more often as reinforcing resistance to DI, and therefore long and comprehensive consultative processes were often avoided. This was particularly true in the case study locality.

3.3.1 Driver 1: Avoidance of large-scale comprehensive consultation

One service attributed part of their success in achieving DI to avoiding a large-scale consultation approach.

“We would have pursued very much guerrilla tactics, seriously, we would say ‘these three or four people’ and then let’s move really fast and move faster than the unions you know, before they start ‘oh no we have to meet everybody and we have to’ you know you really have to be a kind of moving target, harder to hit, if you operate on the basis of ‘we need all the stakeholders in the room, we need to agree with all the families and all the unions and all around the table’, [forget] it.” (Service manager)

As well as avoiding comprehensive downward consultation, this service minimised top-down control by funding DI out of their block grant:

“the greatest benefit we had was we had no contact with HSE, they just kept out of the way and we didn’t go to them for funding”. (Service manager)

3.3.2 Driver 2: Active engagement with families of persons with disabilities on an individual basis

While the approach of avoiding large-scale consultations was informed by early experiences of meeting families as a group, which proved to be “a disaster”, another senior manager in the case study organisation described the sometimes very long process by which families of individuals would be consulted about the possibility of DI.

"[S]ome other families are great, they're in every week, have a conversation and it's so much easier if you can have a conversation, 'I was wondering about, you know, would you consider it?' plant the seed, 'no, no wouldn't consider it' then, a couple of weeks later you're kind of back and say, 'Well look would you talk to another family that somebody has moved out, see what you think, even go see the house', you know so it's nearly like a sales person to actually get them to commit a little bit, you're on a road to selling it, in that sense, you know what I mean?" (Senior manager)

Such a process might involve as many as ten meetings, and in some cases, the manager would travel to other parts of the country to meet less engaged family members. Another senior manager in the service mentioned that, in some cases, she had given written assurances to families that their family member could return to the institution if they were not happy – this had only ever been taken up in one case.

3.3.3 Driver 3: Co-operation between HIQA, HSE and service providers

A HIQA participant noted that meetings with the HSE are organised every second month to use the information HIQA has to drive improvements in the disability sector. One HSE manager commented that *"we used HIQA to enable us to push the [DI] agenda much further"*. This was echoed by a senior manager in the case study locality, who used HIQA findings of poor person-centred planning in one house to improve staff practices: *"People put it [implementing person-centred plans] on the long finger, I was ready to take that one on the chin and use it you know"*. HIQA also organise annual seminars for service providers. However, as pointed out above, HIQA do not have a remit to seek DI, which somewhat skews the cooperation.

3.3.4 Barrier 1: Unhelpful 'co-operation' between staff and families

"What really amazes me is how quickly families who have been dyed in the wool, 'over my dead body are you moving out of here,' and within a week [of DI] often are saying 'Jesus Christ' and when you go back you find that they were being spun all kinds of things by staff who had an interest in sustaining a particular arrangement." (Service manager)

This type of resistance fuelled by different stakeholders, particularly staff and families, was mentioned by a number of participants in the case study locality, including the HSE manager for the region. It appears that, having initially relied upon the line managers of the units to work with families of service users in transition, it was then seen that this was unhelpful and so the bulk of the work with families was done by a fully committed senior manager for the organisation, as described above. While this overcame a good deal of resistance, this became more challenging as the institution nears final closure:

"And that's why, I think, we're coming to the end now because we've a cohort of staff here who won't want to move. We've a cohort of service users who won't want to move and sometimes you'll have the staff getting to the families and so you have to unpick all of that." (Service provider)

Staff resistance can also feed into service user concerns because service users felt the need to *"please and appease staff; the power we hold is huge [...] so they would very much want to stay with the staff they were obviously familiar with and happy with."* (Service provider)

3.3.5 Barrier 2: Lack of co-ordination on housing for people with disabilities

Lack of suitable housing for people with disabilities was a major issue across the country, but some participants also felt that it was compounded by a lack of clarity on how and by whom housing should be provided for people moving to live in the community (see section 3.5.3). The Housing Options Guidance document for people with disabilities moving to the community recommends that people with disabilities should be provided for by local authorities as with anyone else with a housing need.⁵⁰ However, the €100 million capital investment announced in 2016 for decongregation is administered through the HSE. Many of those interviewed felt that houses owned either by service providers or the HSE were a better option, as they were better placed to understand persons with disabilities' accessibility needs. Moreover, given the current severe homelessness crisis, local authorities are simply not in a position to provide suitable housing. Service providers can apply, as approved housing bodies, for funding from their local authorities through the Capital Assistance Scheme. While service providers applauded the fact that some funds in this scheme have been ring-fenced for decongregation in 2016 for the first time, they felt that there was a lack of understanding of accessibility issues and the expense involved.

3.4 A change in attitudes towards persons with disabilities

Accepting and welcoming attitudes towards persons with disabilities was for many participants key to ensuring success in community living. While many felt that Ireland had come a long way in this respect – an observation supported by survey evidence⁵¹ – others felt that more could be done. They particularly highlighted the importance of converting the moral outrage felt by many on conditions in congregated settings, to a deeper understanding of how people with disabilities can be integrated into their communities.

The National Federation of Voluntary Bodies Providing Services to People with Intellectual Disabilities has an ongoing 'Next Steps' community of practice which provides leadership and support to services progressing with providing individualised services. One of the key findings in a report on progress to date was that *"having valued roles in your family and community are vital building blocks that support community inclusion"*.⁵² This might include employment or volunteer roles, but also includes roles which many people take for granted, like being a valued 'sister', 'neighbour' or 'friend'. In other words, it is not so much about a change in attitudes towards persons with disabilities by 'the community', as an understanding of people with disabilities as engaged members of the community in their own right.

3.4.1 Driver 1: Individual stories of people with disabilities successfully transitioning to living in the community are shared with people involved in the process.

"As [people with disabilities] began to agitate and feel, yeah I could do this, I could live, why couldn't I, so and so has gone to live. [...] And the more they see people starting to move out, [...] they began to think, yeah, this is for me. Once the person themselves, the service user, once they can see it happening for others, then, that's a life that can happen for me too." (Service provider)

⁵⁰ HSE (2016), *Supporting People with Disabilities to Access Appropriate Housing in the Community: A guidance document developed by the housing work stream of the Time to Move On (from Congregated Settings) subgroup under the Transforming Lives programme.*

⁵¹ See, for example, the National Disability Authority's [Public attitudes to disability in Ireland](#) surveys.

⁵² Harnett, A. and Greaney, K. (2015), *Next Steps: The Journey so Far: Sharing learning to inform the movement to individualised supports*, National Federation of Voluntary Bodies Providing Services to People with Intellectual Disability, p. 59.

Participants regularly referenced the success stories as key to convincing other stakeholders. This held true for service users, as in the quote above, for staff and most particularly for families. As one HSE manager commented:

"Like everything else you have to find a champion. [...] I got a family that said 'I want to move' and they influenced the rest of them." (National official)

Getting that crucial first win could be challenging, because people wanted to hear local success stories:

"Families were a bit like that's grand in America like and it's grand in Australia but this is Ireland." (Service provider)

However, as the process progressed, this became easier, and one HSE manager described being actively contacted by families who want to share their success stories with other families in the process. As one participant put it, the power of personal stories is that:

"Any argument with a [Chief Executive Officer] or a funder or a department, or a government representative], [...] it just cuts through all of it because they are saying: 'my life is better'." (National official)

3.4.2 Driver 2: Committed community based staff

While front line staff were not generally cited as a driver in the DI process itself – and indeed, frontline staff in the congregated settings were very frequently cited as a barrier to DI – it is clear that frontline staff in the community play a key role in helping people undergoing DI to integrate into the community. Many frontline staff and managers underlined the importance of treating service users as friends, or even family, and several frontline staff participating in the research had clearly built up close and caring relationships with the service users with whom they worked. Families also praised the work of the carers:

"I just think it's such a difficult job to be a carer that they have to be good. I wouldn't stick at it, you'd go pack boxes, you'd do anything instead of it." (Family member of a person with disabilities)

Senior managers in the locality felt that this was achieved largely by recruiting new staff, often with little or no background in care, to work in community settings. As one manager explained:

"I'm not caught under looking for huge qualifications or anything. I'm looking for what's in your heart and [...] what your skills are and what your life experience is." (Service provider)

3.4.3 Driver 3: Local communities show their support for the DI process

"Communities are a bit like hitchhiking you know, you don't need a lift from everybody you just need one or two." (Service provider)

Members of local communities could be either a huge help or a considerable hindrance in the DI process, but as the above quote illustrates, considering 'the community' as a block is not always possible or helpful. On balance, however, the majority of participants considered that community attitudes towards persons with disabilities had changed for the better over the last few decades in Ireland. Some participants felt that this was linked to DI – as service users became more visible in the community, people became more

accepting of them. Another felt that the public scandals around how some people in institutions were treated have heightened public awareness, citing two instances where members of the public registered concern around how staff members were interacting with service users in public. However, for some older parents of service user, the stigma associated with their service user relative sometimes caused a family member to oppose DI.

One difficulty mentioned by a number of participants at national level was where service users were housed in low-cost social housing in disadvantaged areas: *"we are already putting people who are devalued into devalued areas you know"*. Others mentioned the current requirement that developers allocate a number of houses in each estate for social housing as a positive step towards more mixed social groups.

In the case study locality, community interaction was on balance extremely positive, and many attributed this to the small, rural nature of the town and surrounding villages, and the fact that so many local people would have worked in the institution and with people with disabilities. People with disabilities would have come to the congregated setting from all over the country, but most naturally chose to remain close by when moving to the community. As a result, a couple of service managers expressed the view that the principal town was saturated with service users, and that service users were better integrated in some of the surrounding villages. This was not, however, the view of the community members from the town who participated in the research, who felt that the visibility of service users in the town contributed to greater respect for them as community members.

Staff members highlighted that the general public were sometimes uncertain as to how to engage with service users. Some outlined how they tried to educate waiters to take the order from the service user directly, rather than referring to the support worker. Another said that a community member was unsure whether they could accept an invitation from a service user to have a cup of tea in her house without the permission of staff. Where possible, allowing service users the space and freedom to develop their own relationships in the community often yielded a greater benefit to the individual than if always accompanied by a support staff member. However, committed and imaginative staff could play a vital role in integrating the people they support into local communities as illustrated below.

Promising practice: Shopping like the French

Many staff and managers felt that shopping locally, even if no longer the norm for most people, was key to integrating people into the community. In one case, a staff member explained that the person with autism she supported got very upset if other shoppers wouldn't shake her hand, and so she always shopped in the local supermarket, where people were well used to meeting service users and *"I know that the butcher will shake her hand"*. (Service provider).

A CEO went into more detail on how a team of two staff helped the two men they support settle into their new community:

"We have two guys in a tiny little village and we have a staff who have no [previous] involvement [in care] and like within days they decided...we are going to split the shops, so this is John's shops and these are Mark's shops and...we are going to be like the French, we are going to shop every day for the meal, right, because we are going to be generating opportunities to be bumping into people."

He continued: *"John who has autism and no language...he gets involved in...graveyard maintenance...and he takes on the role of maintain the graves for people who have nobody"*

left, you know and suddenly there is a space for him and like the person that led out on that [the staff member] before he came to us, he was a builder, you know, and you just can't inject that kind of imagination into people" (Service provider manager).

3.4.4 Barrier 1: Persisting 'institutional culture' in community-based services

The creation of 'mini' or 'micro' institutions in community group housing was very frequently cited across all participation groups, and attributed to a number of factors. Staff with ingrained habits and practices were the most commonly cited factor. The action many had taken was to recruit externally where possible, rather than bringing staff out from the congregated settings – or to ensure that at least the lead staff in the house was externally recruited. In this regard, training and qualifications were usually regarded as less important than personality:

"If you get the right person coming in the door, you can always give the training but it's very hard to do the other way round. [...] You cannot train the personality, you cannot change the empathy or how they view the situation." (Service provider)

Institutionalisation of service users was also a common factor cited, in particular with regard to early bedtimes or a rigid schedule of medication.

Lack of staff to facilitate individual activities could also contribute to an institutional like culture, with service users sometimes constrained to do all their activities together, including shopping, activities and medical appointments. A number of actions had been taken in the case study locality and elsewhere to alleviate this situation including: building up a service user's independence so that they could undertake activities or stay at home on their own; incorporating activities supervised by external facilitators into a service user's day, such as a mainstream day service for older people; adding extra staff hours for certain times of the week; and enlisting volunteers, as described below.

Promising practice: volunteers

The Best Buddies programme was founded in the U.S. and helps to connect people with intellectual disabilities into their communities 'one friendship at a time'.⁵³ This was introduced into Ireland in 2002/3 and is currently run by several services throughout the country. Volunteers are matched with persons with intellectual disabilities, spending time with that person both in and out of their home.

A piece of action research by KARE and the Muiriosa Foundation found that participating persons with disabilities gained in confidence and that friendships often developed naturally from the programme.⁵⁴ One participant told the researchers that since she joined the programme four years ago, there is a "*big difference in me. I'm happier in myself; I'm enjoying myself more since I met my friend Cathy and I'm getting to know more people in my local community.*"⁵⁵

The programme was being run in the case study locality where the FRA research took place, and family members spoke highly of it: "*Oh yeah [my brother] had I think it was called a 'Best Buddy' thing and I thought that was so effective. [...] It was where he came and sort of brought [my brother] places where [my brother] was interested in. Like I said*

⁵³ See: [Best Buddies friendship programs](#).

⁵⁴ Frontline, [Best Buddies friendship programme: fostering, sustaining and enriching lives](#).

⁵⁵ Ibid.

[my brother] loved machinery and he'd bring him out the bog to the tractor and look at the turf being cut and he was in his element." (Family member of a person with disabilities)

3.4.5 Barrier 2: People fear for the safety and security of persons with disabilities moving to live in the community

Fear for the safety and security of service users in the community was another very frequently cited barrier to DI, and the various discussions threw some light on this issue.

Firstly, many of the fears were bound up in a commonly held view of service users as children, as typified by this remark by a service user's mother:

"[The discussions around DI were] going on for a long, long time before I would agree to it, before I'd let go! He's still a baby, he's forty there two weeks ago!" (Family member of a person with disabilities)

This was perhaps compounded with the service users having been frozen in time by going into an institution at a young age, as another mother's comment illustrates:

"I was afraid she would run away [if she lived in the community].....because when she was three she had escaped.... But the psychologist said to me you know...she doesn't do that now, she is 39 now so she doesn't run away now. (Family member of a person with disabilities)

One staff member felt that service users themselves had never moved on from childhood lessons on safety:

"The safety was [...] ingrained as well with people we support because you couldn't go out to town because someone might jump on you, someone might grab you, someone would take you. The 'stranger danger' obviously was very good, you do that with your child of a certain age, then you have to say, well, just be careful." (Staff member of a service provider)

Finally, the issue of what might be termed the dignity of choice regularly arose, with both staff and community members exploring the limits and possibilities of service users making potentially unhealthy or unsafe choices for themselves. One staff member of a service provider applauded the initiative of a woman with a supposedly severe intellectual disability who snuck out of the house on New Year's Eve to buy a bottle of wine, and regretted the inflexibility of a system which held her to have absconded and confiscated the (unpaid for) bottle of wine.

Many participants felt that staff tended to be overly protective and risk averse in these situations, often more for fear of procedural consequences than because they genuinely feared for the service user's danger. On the other hand, the community focus group in particular highlighted a number of instances in which they felt service users were engaging in unhealthy or risky behaviour, underlining the difficulties in balancing personal safety with personal choice. For example, one community member recalled that:

"The [police] said they'd often got a phone call because the same girl could be in [nearby town], thumbing a lift at the weirdest of hours. And I wouldn't do it myself. [...]Like if she was my sister, [...] I'd give out to her, I'd be like don't do it. But she just, I think she's very headstrong too." (Community member)

3.4.6 Barrier 3: Learned dependence among persons with disabilities

"All services talk about creating independence and no matter what, all services struggle with it. Actually what they create is dependence. We deskill people, you know, we were so obsessed with risk, we protect them with everything. We don't allow them to make the cup of tea and then all of a sudden we realise [...] we need to start trying to teach them how to make a cup of tea again." (National official)

Learned dependence of service users was also cited as a major barrier, going hand in hand with risk aversion. Many participants highlighted the fact that in previous generations, it was common practice for people with epilepsy to be sent to institutions and that those people now facing DI had an environmental rather than any other kind of disability.

A number of services deliberately frontloaded staff hours for persons with disabilities when they first went to live in the community, in order to teach them to become more independent, as described in the text box below.

Promising practice: undoing learned dependence

Several services had the flexibility to assign extra hours to those just leaving an institution, in order to help them acquire the life skills they need for community living. One participant described this in practice.

"We have two men and [...] their apartment [...] is in the middle of [...] town and the day service is about five or six minutes' walk but they have to negotiate crossing the road twice and two streets [...] and it's totally new to them [...]. So it took us months and months and months [of training and risk assessment], but eventually we got there. And those men now get up [...] independently and we give them a ring in the morning and say 'listen, how are things?' [...] and they just walk up and they know the route. But the amount of hours that went into that to get them right." (Service provider)

But now, not only can they walk to the day service, but they can independently go to the local shop which is on the same route.

The staff hours which were used to help these men walk independently through town: *"are switched to somebody else [...] getting him to use the train [...] to go for a weekend at his sister's".*

3.5 Practical organisation of the deinstitutionalisation process

More barriers than drivers could be identified under practical organisation of the process in the research, with accessing suitable housing at the forefront of many discussions.

3.5.1 Driver 1: Facilitating independent living skills for persons with disabilities

In order to combat the learned dependence outlined above, many services had put in place measures to enable persons with disabilities to live more independently. In one case, extra support by an external agency had been provided to one individual before undergoing DI to facilitate the discovery process. In some cases as highlighted in the text box above, staff hours were front-loaded at the outset of DI to enable a person to develop independent living skills.

In the case study locality, in addition to the more mainstream community group housing, a more independent living arrangement was available, with service users supported to

recruit their own staff and have their own tenancy agreements. However, this was dependent on either the service user being capable of taking on a tenancy agreement themselves, or having a family member who was willing to take on this role. There are a number of such arrangements in various localities, which currently are not regulated by HIQA – providing for adequate, but not overly prescriptive, regulation of such accommodation is the subject of a position paper by Inclusion Ireland.⁵⁶ A HIQA participant in the research confirmed that there had been discussions on regulation of home support services under the last government (2011-2016) but as yet, no plans have been announced publically.

3.5.2 Driver 2: Person-centred planning

Person-centred plans (PCPs), also called person-centred support plans have been used in disability services for some time⁵⁷, but are now a statutory requirement under the remit of HIQA. While not specifically linked to DI, several participants pointed to their importance in either helping to achieve greater independence in community living, or in some cases, to hold it back. While some participants saw the system as a useful way of discovering the individual's wishes and desires, others felt it was sometimes unrealistic or overly rigid. As one participant put it:

"How do we get a good life for people, rather than getting a good PCP? That would probably be it in a nutshell really, isn't it? And we struggle with it all the time, really."
(Service provider)

3.5.3 Barrier 1: Insufficient suitable housing

The lack of suitable housing was mentioned by a large number of participants, including staff, CEOs and HSE managers. Availability and affordability is a major issue for everyone right across Ireland at the moment, and Ireland is (still) experiencing a serious homelessness problem.

This is compounded for persons with disabilities in terms of accessibility. Participants in the case study locality outlined how, while a town-based location would be preferred in terms of facilitating community integration, most of the houses large enough and accessible enough would be rural and very isolated. Sourcing housing for people with severe disabilities was next-to-impossible, and this was the major barrier to the closure of the second-last unit remaining in the campus facility.

As mentioned at the outset, €100 million in capital expenditure in a multi-year programme has been committed by government to fund housing for DI through the HSE. This money will be spent in the first instance on DI for those on the priority list. Even with this injection of funds, sourcing suitable housing can be difficult, and the necessary modifications can be expensive. The fact that the HSE could not fund alterations to rented stock was cited by some participants as another difficulty. From late 2017, however, the HSE has sought to overcome this by facilitating funding of adaptations to rented stock. In the case study locality, a large proportion of the homes for persons with disabilities are rented, with the service resigning themselves to paying for alterations when necessary. Long leases are usually sought, both for the economic value of the alternations, and for security of tenure, although the CEO did indicate that being able to change rented accommodation quickly at

⁵⁶ Meagher, M. (2016), *The New Obvious: Regulatory Concerns for Person-centred supported living arrangements*, Inclusion Ireland [unpublished]. See also: National Disability Authority (2015), [Review of the implementation of regulations and inspections in residential services for adults and children with disabilities](#).

⁵⁷ National Disability Authority (2005), *Guidelines on Person Centred Planning for the Provision of Services for People with Disabilities in Ireland*.

a time when the market was less tight was a key factor in the flexible, iterative approach which they have taken to DI.

A welcome development in 2016 was funds were ring-fenced for DI for the first time within the Capital Assistance Scheme (which allows a local authority to advance money to an Approved Housing Body in the form of a loan/mortgage which is not recouped unless the property is sold). The case study service got approval for one build under this scheme, although frustration was expressed that a second plan for rehousing four service users from Unit A under the Capital Assistance Scheme was rejected because of the expense of the build. The facilities manager felt that not enough consideration was given to the fact that this build was to house service users with very high dependencies, which necessarily entailed greater expense.

One of the major difficulties in DI is giving service users true choice and control over whom they live with, which can be curtailed by housing options. Some service users moved several times before finding a living arrangement that suited them, as Paul's story below illustrates.

Paul's story

Paul came from a residential facility for persons with intellectual disabilities, which was in the grounds of a psychiatric hospital. He describes the stressful conditions there:

"It was very rough. I lived in a big dormitory first. Later I had my own room, with my own TV and my own wardrobe but [another service user] broke into my wardrobe and stole my clothes, put them all out on my bed. I was crying. [Somebody] was hitting me while I was in the bath, and people used to bang on the table when we were having dinner. I like to have some quiet when I am eating."

The institution was finally closed down, and Paul was transferred to the care of the case study service. Paul lists off the houses he has lived in since leaving Institution B – five in total, all shared with between one and three other people. He left the first because 'a young family wanted to move in.' This is one of the difficulties with using rental accommodation to provide homes for service users. About another house, he explains that he left because of his housemates, one of whom "pinched me". "Mary [his current housemate] still goes to visit people in [that house]. I don't go in, I stay in the car."

Support staff spent some time to work out if Paul and Mary would be a good match as housemates. "I got to meet Mary before moving in with her. We got to look around a few houses together and then we went to buy plates and stuff like that together." When asked about his relationship with Mary, Paul says Mary is "nice in her own way. We sometimes have an argument, and I don't like some things about her. I don't like it when she roars at me."

Paul seems to prefer quieter activities and is happier spending time at home: *I am planning to have a garden this year. I will grow carrots, potatoes, and maybe peas. [The service gardener] will help me.* He points out his artwork, which are framed paintings, some on canvas and all interesting and well executed. Sitting on a comfortable couch in his sunny living room with his dog curled up beside him, Paul is firm that his current living arrangement is definitely the best.

3.5.4 Barrier 2: The rules and regulations on provision of services to persons with disabilities are inflexible

HIQA has played a major role in shaping the provision of community-based services in Ireland. A frequent complaint is that its standards are not sufficiently tailored towards smaller residential settings. In some cases, however, participants attributed requirements attributed to HIQA that are actually set by other bodies. For example, participants noted how residential services seek to comply with standards by indicating fire exits, and displaying complaints procedures, staff lists and menus on the walls.

Irrespective of the source of these requirements, they contribute to a less than homelike atmosphere, and many participants considered that this indicated a 'tick-box' procedure rather than a true measure of quality of care. Proponents of the independent living model felt that one of the advantages was that visitors were not required to sign in and sign out, and permission was not needed for overnight guests, leaving the service user more in charge of their own home.

HIQA itself has flagged this in a report which outlines some of the flaws of the current regulatory model: *"It can be argued that the current regulations of relevance to disability services are not best suited to this service model [community/residential care]. There are certain elements of the regulations which are in conflict with the idea that these houses are a person's home."*⁵⁸ The report goes on to recommend a model, used by many other regulators, of registering or certifying a service provider as opposed to the physical location at which it is based.

3.5.5 Barrier 3: Staff working conditions

"Absolutely staff would have been and still would be our greatest barrier." (Manager of a voluntary service)

Resistance by staff in campus-based settings was frequently cited by management and public authorities as a barrier to deinstitutionalisation, largely in terms of resistance to change in their terms and conditions. In the individual interviews in the case study locality, it was cited as a significant barrier in every interview except for one with a local housing official.

'Sleepovers'— where there is a staff bedroom and staff are expected to sleep during their night shift - were mentioned by several as a flashpoint. While staff in the campus settings did a waking night and were paid accordingly, sleepovers which are the norm in community are paid at a lesser rate. There was also an apparently well-founded fear that staff might be reassigned from one community house to another more frequently, making for a less settled working environment than the campus setting. This staff resistance to DI often had a negative influence on families of service users (see section 3.3.4).

Nevertheless, not all staff resistance could be attributed to working conditions. Some staff were concerned by a genuine fear that service users would not receive as good care in the community:

"We definitely felt a bit sad when they all left, you know. And thinking maybe that nobody else would look after them as good as we did." (Staff member of an institutional service)

⁵⁸ HIQA (2017), *Exploring the regulation of health and social services: disability services*.

While staff in the community-based settings clearly had built up close relationships with the people they support, they sometimes felt that this was being taken advantage of by management. When discussing the fact that staff would not be paid for all their hours when accompanying service users on holidays, for example, one staff member said that she would do this task *“because I like the woman that I support”*. Another added, however, that management *“do prey on staff that way”* (Staff-member of a community-based service).

Finally, there could be a tension between what was good for the service user and what was good for the staff. As one community-based staff member commented:

“The less hours we have with them the more they were growing independently. Which was terrible for us but better for them. So, the less they needed us, the more they went on, the better for themselves. And then we were shifted on to the next [person].” (Staff member of a community-based service)

3.5.6 Barrier 4: Community-based services responding to the different support needs of people with disabilities are lacking

“You can move out...into normal society but societies are not ready for people to live in. Basically from the transport service...to accepting people into the workforce and suitable accommodation... So lots of things in society is not suitable to integrate people with disabilities as... equal members of society.” (Person with a physical disability)

In order for people with disabilities to live ordinary lives in ordinary places, they need not just appropriate supports, but for general community-based services to be more mindful of people’s differing needs. One staff member described a recent visit to the GP with her client, who has severe autism, where she had to wait for almost an hour. By the time she saw the doctor: *“The staff were stressed, she was stressed, the doctor was afraid of her because she’s so wound up. It benefited nobody”*. The staff member concluded: *“she never had that stress in [the institution], because the doctor came in to see her.... Some of the things that happened [in the institution] weren’t all bad. They weren’t all bad, it benefited a lot of people”*. However, a simple solution is suggested by the *New Obvious* report, which highlights a case study where the client is offered the first appointment after lunch to avoid the distress of queues in the waiting room.⁵⁹

Several family participants described difficult experiences which their family members had had in accessing medical and dental services. The sister of a non-verbal service user with a severe disability described a particularly traumatic incident where her sister was taken ill. The hospital maintained that this was a progression of her illness and would have sent her home to die if the family had not insisted on them doing more tests, eventually discovering that a wisdom tooth was the root of the problem. This incident clearly factored in to the participant’s reluctance to see her sister undergo DI, as she was concerned that new staff members might not correctly interpret her sister’s non-verbal communication.

In contrast, several participants highlighted positive interactions with local services. For example, the local hairdresser was cited by staff as being particularly accommodating of a particular service user:

⁵⁹ Meagher, M. (2016), *The New Obvious: Regulatory Concerns for Person-centred supported living arrangements*, Inclusion Ireland [unpublished].

"She knows that she will have five minutes with this girl in the chair... she knows she can't stand near her toes, she knows the razor can't go anywhere near her... And then she'll come out and wave to us when we can come in because she [the service user] can't sit." (Service provider)

3.5.7 Barrier 5: Too few employment opportunities for persons with disabilities

The importance of employment and barriers to accessing employment were discussed by several participants at both national and local level. In the case study locality, however, it was primarily an issue for participants living in independent living arrangements. In those housed in residential services, very few had any sort of employment – in part because they were a relatively elderly population, but possibly also to do with a difference in service ethos.

For those living more independently, both in the case study location and nationally, working was a financial imperative, as rent supplement is usually not adequate to cover actual rental costs. However, only a certain amount could be earned before the disability allowance would be affected, creating a welfare-to-work trap.

The social benefits of work were discussed at the local level with both staff and community members, many of whom were employers of persons with intellectual disabilities. The majority of participants viewed employment as vital in terms of community integration. One staff member argued that even largely tokenistic work was important:

"Some people though in the independent sector where we're kind of making up jobs for them, we'll go clean your house, we'll do your gardening if you give us a tenner like, you know, but that's great for them though as well because they're meeting other people and they're getting out and about." (Staff member of a community-based service)

Lack of employment opportunities was seen as a major, but not the only barrier to persons with disabilities taking up employment. Others included bureaucracy and regulation, including lack of qualifications among service users. Distrust of service users by clients and indeed inspectors were mentioned by two service user employers, who both run services for children. However, sometimes prospective employers were more responsive to appeals to employ the person as an individual, than if they thought it was a request from an organisation. The need for adequate supervision of service users at work was raised as a potential barrier, but several employers felt that service user employees tended to do better when their support worker was not present.

3.6 Cross-cutting issues

3.6.1 Impact of different types and degrees of impairment on the deinstitutionalisation process

The Time to Move On report identified that people with the most severe disabilities can make the most gains from community settings.⁶⁰ However, it was clear from participants that this had not always been translated into actions to decongregate this group. In the case study locality, a facilities manager expressed his frustration with the under-resourcing of this group, meaning that people with less severe impairments get to transition first because they have fewer physical requirements: *"So, what happens is the people with the*

⁶⁰ HSE (2011), *Time to Move On from Congregated Settings: A Strategy for Community Inclusion. Report of the Working Group on Congregated Settings*, p. 72.

higher needs are left and left and left and left". This is echoed by a national level stakeholder: "people with higher needs of support are resource intensive and until we come to the point where we accept that, we're always going to have problems".

Another issue raised for those with higher levels of impairment, particularly with non-verbal service users, was around really understanding their wishes in undergoing DI and ensuring that they are happy in their new living arrangement. One staff member in a congregated setting, who had seen some of her clients with severe and profound disabilities undergo DI was unsure whether the move had been good for them:

"[Patrick] looks really sad when he sees [his former housemates from the residential unit]. You'd just love to kind of get into his head, because he could kind of look at you and you could say 'what is wrong with you'." (Staff member of an institutional service)

However, many participants emphasised that the gains in quality of life for those with higher levels of impairment are huge in undergoing DI. Although their physical independence may be limited, their choice and control over their lives is greatly expanded. Pam's story below gives some insight.

Pam's story

Pam came to [the congregated setting] when she was a teenager. She suffers from epilepsy, and it seems that her severe intellectual and physical disability is largely acquired. She tells me that when she was a child, she saved her granny from falling into the fire (and asked me to include this in her personal story). At the time when I meet her, however, she cannot move independently and has issues around swallowing and eating. She speaks with difficulty, and can be hard to understand. Despite all of this, she has a bright, engaging personality, and is not afraid to speak her mind.

She recounts her experiences in [congregated setting] with less inhibition than some other service users. *"You won't believe what I will tell you."* she says, describing the conditions in [congregated setting]. At first, she was in the main house. There, the beds were all right next to each other, with personal space delineated just by a small locker for personal effects, like in a dorm room. Later, she was moved to [Unit D], where the doors would have been locked, to prevent service users from wandering. She describes an act of aggression by another service user: *"I was kicked in the stomach by [service user]."* She remembers the food with particular distaste. *"It was always porridge for breakfast, always",* she says. "Could you ask for anything else?" I ask. *"No. 'Why not?' You wouldn't have been given it!"*

She moved from the congregated setting to her current home in May 2013. She would have been among the last in her particular unit, which was closing, to undergo DI. *"When they told me I was moving out, I was overjoyed",* she says. She lives with two other service users – [Emily], who has Down's syndrome and is non-verbal, and [Catherine], who has clear but limited speech. When I visit, the housemates all gather around the table and they seem happy together.

When I ask Pam what it is like living in her new home, she says: *It is terrific, I have my own freedom.* She describes in detail what she likes to eat – the support worker explains that they ask each service user at each meal what they feel like eating, because they all have issues around swallowing. They each have their own bedroom, and there are two sitting rooms in the large bungalow. Pam can choose what she wants to watch on TV – she likes to watch the rugby and the horse racing. She enjoys welcoming guests to the house – when the neighbour calls over, she tells me, she says: *"Come in, Mr. [Corcoran]."*

When I asked her if there is anything she misses about the congregated setting, she says emphatically: *"Not at all. [Congregated setting] was nobody's favourite."*

3.6.2 Impact of age on the deinstitutionalisation process

"We should have done it 20 years ago. For many of our folk, it has been too late."
(National official)

While most of those in positions of authority interviewed expressed their commitment to DI across the board, a couple made an exception for the very elderly:

"The only people that it's probably not for are the very aging population who in a natural environment may well end up in a nursing home type environment anyway because that's the natural progression." (Local official)

However, as a service provider in the case study locality pointed out, the majority of the population undergoing DI are relatively elderly:

"[National policy doesn't] take into consideration the fact that it's an aging population and we certainly advocate ageing-in-place. [A] number of our ladies will ask us [...] 'you won't send me back in', and it's awful really." (Service provider)

There is an unresolved policy question around older people with disabilities. Given that Ireland is currently embracing a largely nursing home model of care for older people, that question becomes whether persons with disabilities will be accommodated in mainstream nursing homes, or accommodated in specialised nursing homes for people with disabilities. This is an issue because, as one participant pointed out, people with intellectual disabilities often develop dementia earlier than the general population. This means that people with intellectual disabilities risk being put into nursing homes at a much younger age than is the norm, effectively being 're-institutionalised'.

4. MEASURES TO ACHIEVE SUCCESSFUL DEINSTITUTIONALISATION

4.1 Commitment to deinstitutionalisation

"I think, well what we don't need is more policy and what we don't need are more discussions about what the solution is. All we need is the will and the resource to implement what we've signed up for." (Representative of a NGO)

Many participants considered that greater commitment to DI at the political level was needed to progress the DI process. One HSE manager commented: *"I think we have to hope this research will bring the message...to government because it has to be government led. This can't be HSE led because there is too much pressure."*

Several people felt the need for a more clearly rights-based approach to DI. At the time of the research, the CRPD had yet to be ratified, and two national stakeholders expressed similar hopes that once ratified, the Convention would drive the DI agenda forward by providing a proper legal basis for DI.

"[The Convention] should stop any further debate about what is the right response. [...] Article 19 is the right response, Article 12 is the right response. So it's all there and it's supposed to be legally binding in all states." (Representative of a NGO)

More funding was another frequently raised issue, to fund both housing and staff, although some participants in the case study locality thought it was perhaps assigned too great an importance: *"Everyone says, money can help but we've done a lot of work without the extra money"*. In particular, the need for bridging funding to maintain parallel systems (community housing and a much reduced institution) for a period of time was raised. Progressing a systematically allocated individualised funding model was mentioned as an important factor by a number of national level stakeholders; less so at regional level and very rarely at local level.

4.2 Availability of guidance to support the deinstitutionalisation process

As above, this was not one which many participants commented on extensively, although some self-advocates spoke with conviction of the need for transitions to be better resourced. Many participants agreed that taking time and a person-centred approach during the initial move towards DI, sometimes known as the 'discovery phase' of DI, was crucial:

"It's really about getting to know the individual, respecting their needs and looking at their history." (Service provider)

Opinions differed as to whether this was better done before or after an initial transition. In the case study locality, sufficient flexibility was built into the DI process that service users could change their living arrangements, although was often easier in theory than in practice. Another participant mentioned an arrangement in another congregated setting where persons scheduled to complete DI were first moving to four-person dwellings on campus, to trial compatibility before a definitive move to the community. This, however, has cost implications and perhaps overly prolongs the DI process.

4.3 Active cooperation between the people involved in the deinstitutionalisation process

One staff member felt that HIQA should spend more time working with service providers to achieve quality outcomes, rather than overly complicating service provision with rigid accountability structures:

"Instead of an inspection though, HIQA should come out and... give you some advice first. [That] could save [the service] fifty grand instead of us going over the top, have to have a team leader, have to have all of this". [HIQA] should be there in an advisory role or you should have somebody in your area [to whom you could turn], saying "Look, we're going to set up this innovative service, we want to trim it down a bit, help us out". (Staff member)

4.4 A change in attitudes towards persons with disabilities

"What is going to drive [DI] is you have to catch the imagination of the families who will drive the political agenda as well, who will be on their local TDs [members of parliament] saying 'I want this for my son or daughter'." (National official)

Public outcry regarding the findings of HIQA in some congregated settings, followed by a televised and widely watched investigative report into one setting, raised awareness of conditions in some institutions. But as one community member succinctly put it: *"There's never a report on good stuff"*. So, while the general public have become aware of the need to treat people differently, they have not generally been given a picture of the alternative.

Several participants across a variety of groups felt that television reports featuring positive stories of people with disabilities living in the community would go a long way towards changing attitudes. As one participant commented, such positive stories, including televised stories, do exist, but are not generally featured in the mainstream media. Some positive video testimony of decongregation is available from the FEDVOL Next Steps project,⁶¹ and Inclusion Ireland are currently undertaking participatory research – funded by the NDA – on social inclusion for people with disabilities, which will include filmed stories. Another community member suggested that a video message or a module that could be completed by secondary school students would also help, and said that it should convey “*an awareness of their abilities rather than disabilities*”.

Some references were made to the long-awaited Assisted Decision Making (Capacity) Act coming into force, with one participant feeling that it would assist in changing families’ mind set with regard to how they treat their adult children.⁶² Others felt that the DI process as currently implemented did not give people with disabilities sufficient choice and control over their lives:

“[W]e should say to a person with an [intellectual disability] ‘what is it you want?’, in order for them to tell us we have to be able to nurture them and develop that within them. We haven’t done that, we have put them in an institution or a community group home with four others.” (Service provider)

4.5 Practical organisation of the deinstitutionalisation process

The most frequently cited actions which participants felt should be taken in this category concerned housing. This includes the need to acknowledge that housing persons with high dependencies was expensive, and the need to guarantee stability for the service user. One participant highlighted that having either the service or the HSE own the house would be the ideal scenario, although this diverged somewhat from the CEO’s admission that rental properties had given DI a certain amount of flexibility in the early days of the transition process.

Participants also saw the need for funding and the flexibility to frontload staff hours to combat learned dependency, as outlined above.

4.6 More general considerations

Constructing a national policy around ageing and disability was a clear missing piece for some participants. Participants were, however, divided as to what that might be, with some favouring nursing home style facilities for elderly people with disabilities and others advocating ageing-in-place – that is, facilitating people to remain at home as they grow older.

Finally, a few participants felt that most of the necessary steps to achieve DI were in place, and that what was mostly needed was time:

“I suppose the ingredients are kind of all there but I think what it is going to take though is time, it’s breaking it down into the small pieces to get the wins, you know.” (Service provider)

⁶¹ See: National Federation of Voluntary Bodies, [Next steps community of practice and learning](#).

⁶² This Act was signed into law on 30 December 2015, but has only been partially commenced. The new National Disability Inclusion Strategy (July 2017) states that it will be commenced in early 2018. Assisted Decision-Making (Capacity) Act 2015 (Commencement of Certain Provisions) (No. 2) Order 2016 S.I. No. 517 of 2016.

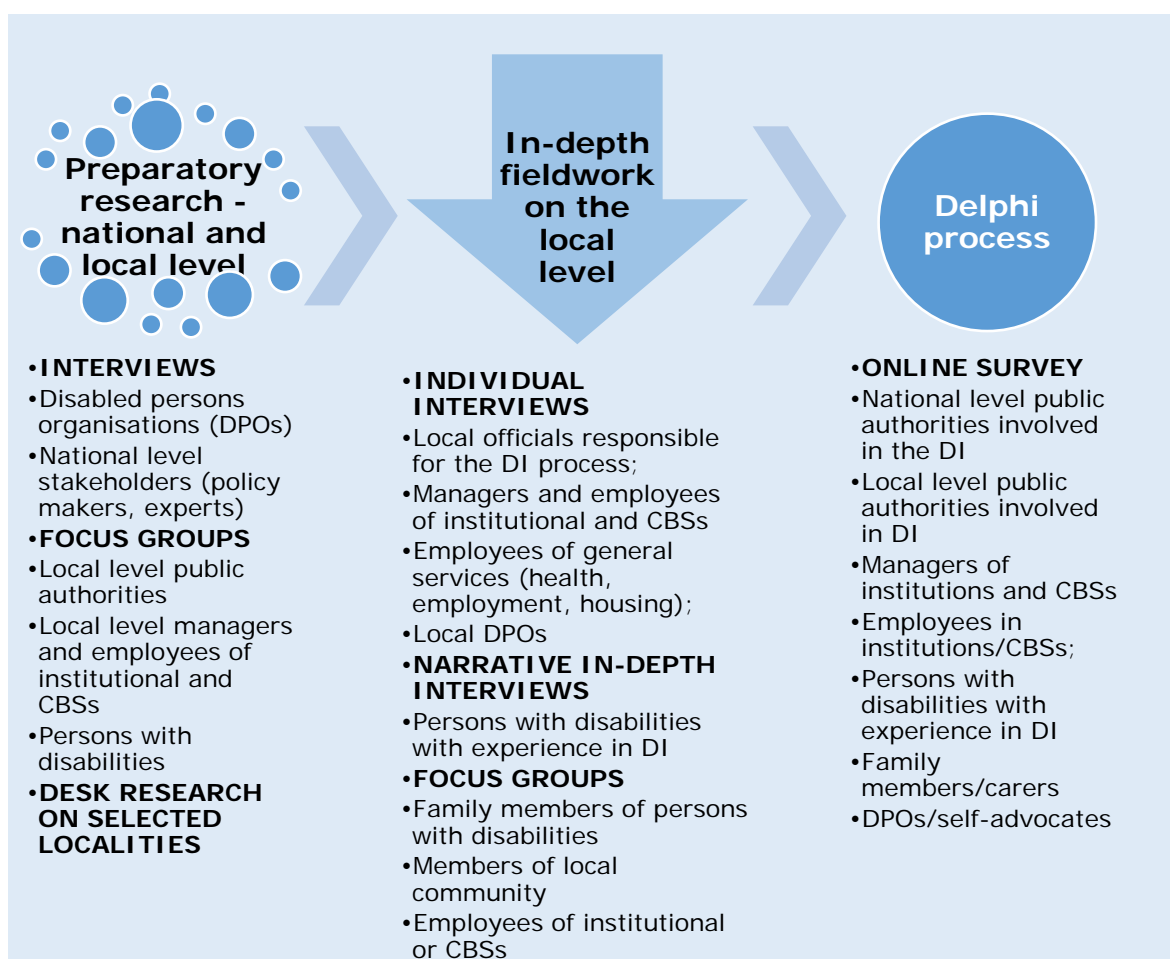
ANNEX: RESEARCH METHODOLOGY

The fieldwork employed several common qualitative research methods to capture the views of a variety of different stakeholders. These included participatory research methodologies enabling full participation of persons with disabilities:

- Preparatory **semi-structured interviews** with selected national stakeholders to gather contextual information about the status of the national deinstitutionalisation process and to identify key themes to be explored in later interviews.
- **Focus group discussions** to explore differences and commonalities in the experiences and perceptions of groups of participants with similar roles in the deinstitutionalisation process.
- **Face-to-face semi-structured interviews** with individuals involved in the deinstitutionalisation process in the case study locality to gather their views about what works and what does not work regarding policies and practices.
- **Narrative interviews** giving persons with disabilities the opportunity to share their experience of the deinstitutionalisation process and how it affects their lives.

Much more information on the design and methods of the fieldwork research is available in the main report '[From institutions to community living for persons with disabilities: perspectives from the ground](#)'.

Figure 1: Research methods and target groups



Source: FRA, 2018

Inclusion of persons with disabilities

Participatory research principles guided the development of the research design. Particular attention focused on ensuring that persons with disabilities are active participants at all stages of the research.

In preparation for the research, FRA held an international expert meeting with representatives of disabled persons organisations (DPOs) and experts with experience of conducting research with persons with disabilities. This was complemented by a similar process at the national level, where researchers in the fieldwork countries conducted consultations and interviews with national DPOs and experts.

FRA ensured the preparation of easy-read research materials and reasonable accommodation in all activities part of the research.

The names of persons with disabilities telling their personal stories of deinstitutionalisation are pseudonyms.

Delphi process

To validate the results of the fieldwork research at both the national and local levels, FRA carried out a Delphi survey. Delphi is a participatory group communication process which aims to conduct a detailed examination of a specific issue, bringing together a range of stakeholders in a time-efficient way. The process enabled FRA to assess areas of consensus and disagreement between and across stakeholder groups and countries.⁶³

FRA's Delphi survey included almost all those who had participated in the fieldwork. Participants were presented with a summary of the key findings and asked to identify the most important drivers and barriers of the deinstitutionalisation process.

Peer review meeting

In addition, FRA organised in-country peer review meetings in each of the five fieldwork countries between January and February 2018. These meetings allowed a small number of research participants to reflect on the findings emerging from the research. Discussions at these peer review meetings fed into the revision of the national case study reports and informed the drafting of the main report bringing together the findings from the five countries where the research took place.

⁶³ Hsu, Chia-Chien and Sanford, A., Brian (2007), [The Delphi Technique: Making Sense of Consensus](#), Practical Assessment, Research and Evaluation, No. 10/12; Cuhls, K. (2005) [The Delphi Method](#), Fraunhofer Institute for System and Innovation Research ISI.