National Advocacy Service

For people with disabilities

Have things moved on?

Examining the lived experience and quality of life of disabled people who continue to live in congregated settings



Coimisiún na hÉireann um Chearta an Duine agus Comhionannas
Irish Human Rights and Equality Commission

Deontas-mhaoinithe
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Foreword



This paper is, ultimately, about people and the lives they want to live.

The evidence and experiences shared throughout these pages are more than statistics, policy findings or examples of service provision. They are stories of disabled people, people who want what we all want: a place they can call home, relationships that matter to them, choices about their everyday lives, and the opportunity to be part of their community.

As NAS National Manager, I have seen the difference that the right support can make. When people are supported to live in their own homes, make their own choices and participate in their communities, the possibilities for a good life can change profoundly. It is a powerful reminder that people should never be defined by their disability or by the service in which they live.

Ireland has made important progress in moving away from institutional models of disability support. But progress is not the same as completion. There are still people living in congregated settings, waiting for the opportunity to live differently. We should not lose sight of them, nor should we accept further delay. The transition to ordinary community life cannot be allowed to continue indefinitely, and there must be clear accountability for delivering it.

Government must now give renewed priority to bringing this work to completion. The remaining institutions must close, and this must be backed by a clear plan, defined timelines and accountability for delivery. This requires political leadership, sustained investment, clear accountability, and a coordinated effort across Government and services.

But closing institutions is only part of the story. Deinstitutionalisation must never simply mean moving people from one form of service to another. It must mean supporting each person to build a life of their own choosing, with a home, with relationships, with meaningful activities, opportunities and the support they need to exercise choice and control over their lives.

The people whose experiences inform this paper have waited long enough. Their lives cannot be put on hold while we wait for the system to change. The evidence is clear. The ambition must now match it.

Ireland has made a commitment to move away from institutional living. That commitment now needs to be delivered, not deferred. Government and services must be accountable for ensuring that every person with a disability has the opportunity to live a good life, in a place they call home, as an equal and valued member of their community.

The time has come to finish what we started.

I would like to acknowledge and thank everyone who contributed to this paper. In particular, I want to thank the people with lived experience who shared their experiences, views and aspirations. Their voices are at the heart of this work and should remain at the heart of the change we are seeking. We are grateful also to the many key stakeholders who gave of their time and experience to input to this paper.

We are grateful to the Irish Human Rights and Equality Commission (IHREC) for its support and for providing the grant that enabled this work to be undertaken. This support has provided an important opportunity to listen to the experiences of disabled people and to consider what is now needed to ensure that the transition to community living is completed.

I also want to thank the author of the paper, policy writer Dr Paul Dunbar, our contributors and colleagues across the NAS Social Policy team, capably led by NAS Regional Manager – Micheál Walsh for the time, expertise and commitment they have brought to this work. Their contribution has helped to bring together the evidence, experience and perspectives that underpin the case for change.

Thank you,



Joanne Condon
National Manager
The National Advocacy Service for People with Disabilities

Easy-to-Read

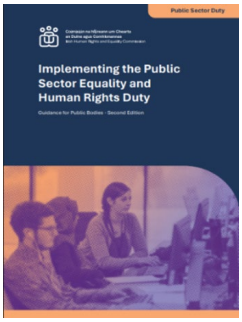
	**Words We Use In This Paper:**
	**Social Policy Paper:** This is a report that talks about an issue that affects a lot of people.
Feidhmeannacht na Seirbhíse Sláinte Health Service Executive	**HSE:** The **H**ealth **S**ervice **E**xecutive is in charge of all health services in Ireland. They call themselves the **HSE** for short.
	**Congregated Settings:** A **Congregated Setting** is where 10 or more people live together in one big house, or in smaller houses in the same place.
	**UNCRPD:** UNCRPD stands for the **U**nited **N**ations **C**onvention of **R**ights for **P**eople with **D**isabilities. The **UNCRPD** is a set of legal rules that Ireland agreed to follow to make sure people with disabilities enjoy the same rights as everyone else.

Coimisiún na hÉireann um Chearta
an Duine agus Comhionannas
Irish Human Rights and Equality Commission

IHREC is the **I**rish **H**uman **R**ights and **E**quality **C**ommission. They call themselves **IHREC** for short.

IHREC makes sure that everyone in Ireland is treated equally and that their human rights are respected.





Public Sector Duty:

This is a legal rule that says public services must treat everyone the same.









Communicate Differently:

Some people do not communicate using words.

Some people use other ways to communicate their wishes and needs. People can use movement, sounds, pictures, or technology to communicate. This way of sharing is called **communicating differently**.





Introduction:

National Advocacy Service
For people with disabilities

This **social policy paper** was made by the **N**ational **A**dvocacy **S**ervice for People with Disabilities. We call ourselves **NAS** for short.





This is the easy read section which will tell you about our ***Social Policy Paper.**

We will call it **'paper'** for short.







This **paper** is about where people with disabilities live.





The Key Message Of This Paper:



People with disabilities should be supported to live a good life, with the right support, in the community they choose.



People with disabilities should feel like where they live is their home.



About This Paper:



Some people with disabilities live in **congregated settings.**

	This **paper** looks at what life is like for people who live in **congregated settings**.
	This **paper** also looks at what needs to change about where people with disabilities may live.
	**NAS** made this **paper** to listen to what people with disabilities think.
	**NAS** made this **paper** to listen to the wishes of people living in **congregated settings.**
	**NAS** made this **paper** as the **HSE** said it was not a good idea for people to live in **congregated settings**, away from the community.

	**NAS** works with a lot of people who still live in **congregated settings.**
	In 2011, a **policy** called "Time to Move on from **Congregated Settings**" was made by the HSE.
	This policy talked about how people with disabilities should live in the community, like everyone else.
	This policy talked about how **congregated settings** are not the best place for people with disabilities to live.
	This means that everyone living in **congregated settings** should be supported to move to smaller homes in the community.

	The **HSE** said they would support people to move out of **congregated settings.**
	The **HSE** have not supported as many people living in **congregated settings** to move as they said they would.
	When **NAS** spoke with people living in **congregated settings**, they told us that they would still like to move to the community.
	When **NAS** spoke with people living in **congregated settings**, they told us that they feel like the HSE has forgotten about this policy.
	**NAS** has created this **paper** to remind everyone about this **policy.**

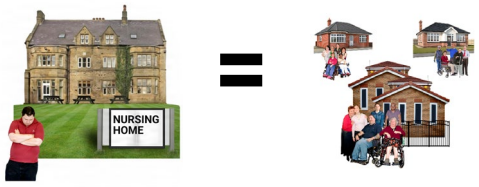


What Is A Congregated Setting?



A **congregated setting** is where many people with disabilities live together in one big house, or in smaller houses in the same place.

This is sometimes called a campus.



Some young people with disabilities live in a nursing home. For them, living in a nursing home feels the same as living in a **congregated setting**.



Some of these young people do not have any nursing needs, and do not need to live in a nursing home.



In Ireland, a **congregated setting** usually means 10 or more people living together.



Some people living in **congregated settings** were not given a choice about where to live.



Some people living in **congregated settings** were not given a choice about who they live with.



Some people have lived in **congregated settings** for most of their lives.





What Younger People Living In Nursing Homes Told Us:



Some younger people with disabilities live in nursing homes.

	If a young person is under 65 years old, it usually means that they are too young to live in a nursing home.
	In July 2025, too many young people were living in nursing homes.
	A nursing home may not be the right place for a younger person to live.
	This is because nursing homes were made to support older people.
	Younger people can feel lonely in a nursing home.



Younger people living in nursing homes may be far away from family or friends.



A younger person should not have to live in a nursing home just because there is nowhere else for them to live.



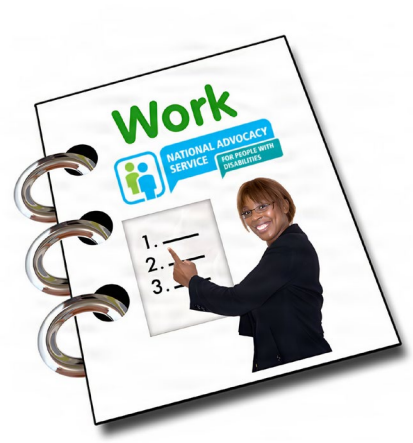
What Else People Told Us:



When **NAS** made this **paper**, we listened to what people with disabilities had to say about living in **congregated settings**.



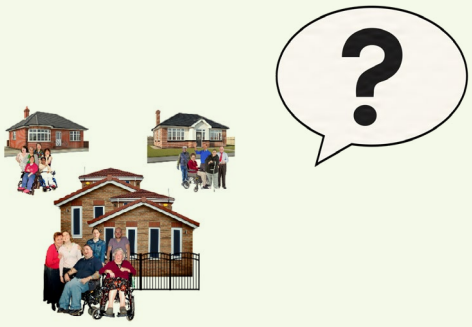
When **NAS** made this **paper**, we also listened to **NAS** Advocates, organisations that work with people with Disabilities and other groups.



When **NAS** made this **paper**, we looked at examples from our own work with people with disabilities living in **congregated settings**.



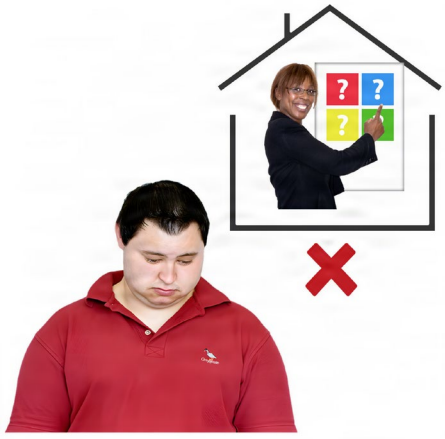
NAS thinks it is important to listen to what people want for their own lives.



What People Living In A Congregated Setting Told Us:



Some people told us that living in a **congregated setting** does not feel like home.

	Some people living in **congregated settings** may have little control over their daily lives.
	Some people living in **congregated settings** may not be able to choose what or when they eat.
	Some people living in **congregated settings** may not be able to choose when they go out or what they do.
	Some people living in **congregated settings** may have little privacy or private space.



Everyone should be able to feel that where they live is their home.





Everyone Has The Right To A Good Life:

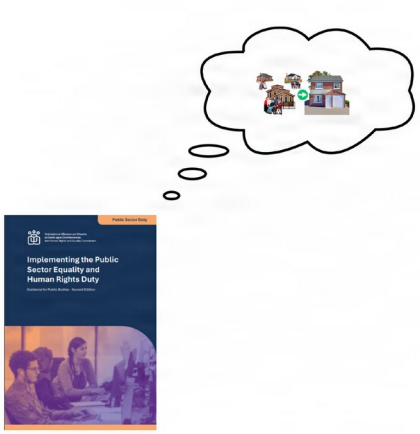


The **UNCRPD** says people with disabilities have the right to live in the community.



People have the right to choose where they live.

	People have the right to choose who they live with.
	People have the right to privacy and to feel safe.
	People have the right to take part in their community.
	People with disabilities have the same rights as everyone else.



Public Sector Duty also supports people to choose where they want to live.



What Is Public Sector Duty?



Public Sector Duty is a legal rule that says public services must treat everyone the same. An example of a public service is the **HSE**.



This rule means services, such as the **HSE**, must think about equality and human rights when making decisions.



This is important because these decisions can affect where people with disabilities live and what supports they receive.



NAS thinks it's important to tell everyone about this rule because:

- **IHREC** helped us to be able to do this **paper.**
- Everybody should protect people's choice, privacy, dignity and rights. An example of this is living in the community.



What Did Other Places Outside Of Ireland Tell Us?



NAS wanted to know what people with disabilities who live in places outside of Ireland thought of **congregated settings.**



NAS looked at studies that were done with people with disabilities in these places.



Some of the places **NAS** looked at are:

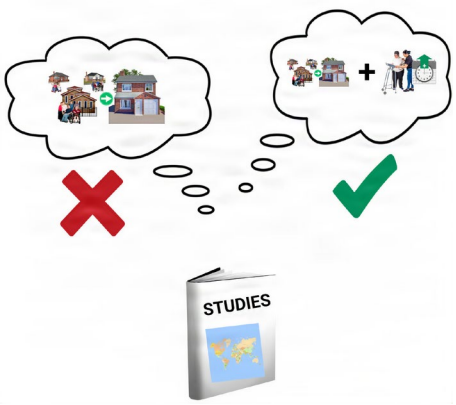
- The United Kingdom
- Europe
- Australia
- New Zealand

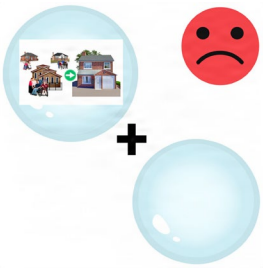


The studies found that people had a better quality of life after moving into the community.



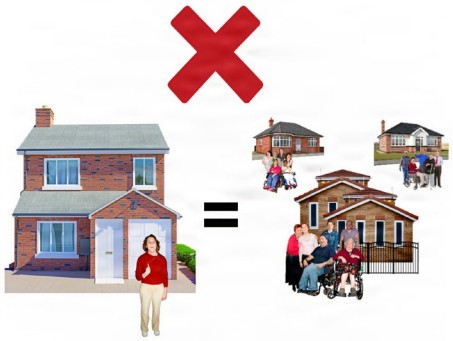
The studies found that people usually had more freedom, choice and control over their everyday lives.

	The studies showed that moving house on its own is not enough.
	The studies showed that when moving, people also need the right support to make choices and take part in everyday life.
	The studies showed that overall, when given the right support, people with disabilities were happier after they moved from a **congregated setting.**
	For example, in a study, one person who moved to a community house with supports said: **"My life is better; it's changed a lot because I have much more freedom"**

	**The Right Support:**
	Moving to a smaller house in the community does not make life better on its own.
	People must also have the right support.
	This support should be based on what the person needs.
	For example, some people may need support with communication, cooking or travelling.



Everyone should be supported to make their own choices.



A smaller house in the community should not become the same as a small, **congregated setting**.



After Moving To The Community:



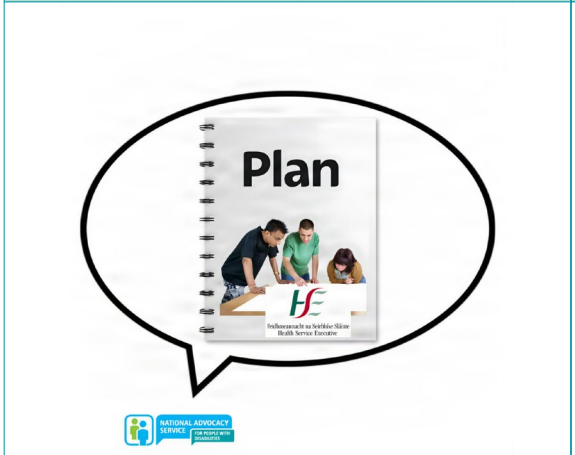
NAS spoke to people who had moved to the community with the right supports.

	**NAS** heard many good stories from these people.
	A lot of these people said they have more freedom since they moved to the community.
	A lot of these people said they have more choice and independence.
	A lot of these people said they can make friends, for example, with their neighbours.

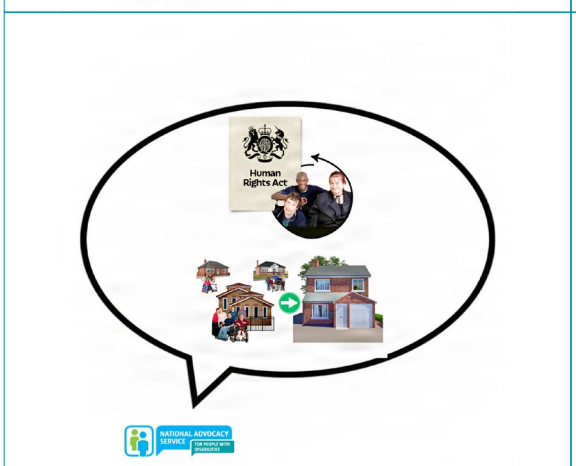
	A lot of these people became healthier and more active.
	Most importantly, a lot of these people said they had more control over their own lives.
	After hearing how happy people were after moving to the community, **NAS** would like this to happen for more people.



What NAS Wants To Happen



NAS wants the **HSE** to make a better plan to help people move out of **congregated settings**.



NAS wants the **HSE** to see people with disabilities living in the community as a human right.



NAS wants the wishes of people with disabilities living in **congregated settings** to be heard, including the wishes of people who **communicate differently.**

	**NAS** wants people with disabilities living in **congregated settings** to be supported to find a good home in the community.
	**NAS** wants people with disabilities to have the right support when moving to the community.
	**NAS** wants this to happen as soon as possible.
	**NAS** wants to make sure the **HSE** do not make any new **congregated settings**.

	**NAS** wants to make sure the **HSE** stops moving people into **congregated settings.**
	**NAS** wants people to have access to independent advocacy.
	**NAS** wants to make sure as many people as possible can have an Advocate if they need one. Advocacy services need more Advocates to do this.
	**NAS** wants to see the human rights of people living in **congregated settings** reviewed regularly by the proper services.

	**NAS** wants to see the organisations that represent people with disabilities be given more money to help them to do their job**.**
	**NAS** wants to see people with disabilities leading decisions on changes in the future.
	**NAS** wants to see a proper process in place to check in on people who have moved to the community. The **HSE** must make sure there is enough money given to do this.

Acronyms, Abbreviations and Terminology

The table below lists acronyms and abbreviations that appear in the paper, including those used only in case studies, international comparisons or references.

Acronym / abbreviation	Full term / meaning
ADHD	Attention Deficit Hyperactivity Disorder
ÁT / ÁT Network	Áiseanna Tachaíochta (the name used in the draft for the ÁT Network)
ATUs	Assessment and Treatment Units
BMJ	British Medical Journal; appears in the reference to BMJ Open
DFI	Disability Federation of Ireland
DPO / DPOs	Disabled Persons' Organisation / Disabled Persons' Organisations
EGL	Enabling Good Lives
GPs	General Practitioners
HIQA	Health Information and Quality Authority
HSE	Health Service Executive
IHREC	Irish Human Rights and Equality Commission
ILF	Independent Living Fund
ILMI	Independent Living Movement Ireland
NAS	National Advocacy Service for People with Disabilities
NDA	National Disability Authority
NDIS	National Disability Insurance Scheme
NPMs	National Preventive Mechanisms
OPCAT	Optional Protocol to the United Nations Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment
RA	Rehabilitative assistance
SDS	Self-Directed Support
TV	Television
UK	United Kingdom
UN	United Nations
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities

Terminology note:

The original HSE *Time to Move on* report uses the term 'decongregation'. However, engagement with a number of key stakeholders who inputted to this paper identified 'deinstitutionalisation' as a more appropriate term, reflecting that the objective extends beyond relocating people from congregated settings to encompass the development of person-centred, rights-based supports that enable people with disabilities to live ordinary lives in the community, in line with the principles of the UNCRPD. Accordingly, this paper uses the term deinstitutionalisation throughout.

Methodology



This social policy paper examines the continued use of congregated settings for disabled people in Ireland, the barriers to deinstitutionalisation, and the impact that congregated settings have on people's rights, wellbeing, and quality of life. Consistent with the values and advocacy approach of NAS, the central aim of this work was to ensure that the voices, experiences, aspirations and preferences of disabled people remained at the heart of the analysis.

While policy, legislation and research evidence are important components of understanding the issue, **this paper is grounded primarily in the lived experiences of people who have resided in congregated settings and those who have been supported through deinstitutionalisation processes.** The intention was not simply to examine systems and policies, but to understand how those systems are experienced by people in their everyday lives.

A qualitative, rights-based methodology was adopted, drawing on four principal sources of information: stakeholder engagement, advocacy practice experience, case study analysis, and desk-based policy and literature review. These sources should be read according to their distinct evidential status: direct testimony, Advocate observation, third-party account, case study material, policy and legal analysis, and published literature are not interchangeable forms of evidence. **Direct testimony, Advocate observations, case study material and third-party accounts are used throughout the paper to give voice to people living in congregated settings and to convey their lived experiences.** Legal and policy analysis, as well as published research material, are used to contextualise various aspects of the debate around deinstitutionalisation and are also used to demonstrate the consensus across many key stakeholders that congregated settings should be discontinued as a form of residential care for disabled people.

A total of 14 people were interviewed as part of this research. Selection criteria (focused on knowledge of lived experience of congregated settings) were devised by NAS management, with an emphasis on Advocate testimony as well as representation from Disabled Persons Organisations (DPOs) and other relevant key stakeholders - these inputs are shared throughout this paper. Fieldwork took place from June to September 2026. Interviews were conducted online via Microsoft Teams and were recorded for the purposes of producing transcripts. Recordings were destroyed on completion of transcripts. Consent of interviewees to use quotations or material from interviews was sought and obtained in advance of publication. Case study material (referred to hereafter as 'lived experience examples') was sourced by NAS management through engagement with their advocacy staff.

Listening to the Experiences of People Supported by NAS

The primary focus of this paper is the experience of disabled people. Much of the evidence presented throughout the report is drawn from the experiences of individuals supported through NAS advocacy interventions. These experiences were captured through advocacy engagement, casework, and reflective discussions with NAS Advocates who have supported people living in congregated settings and other institutional environments.

Particular attention was paid to ensuring that the voices of people who may communicate differently were represented. Many people living in congregated settings communicate through non-speaking means, gestures, behaviours, assistive communication methods, or through long-standing relationships with those who know them well. Consequently, the paper seeks to reflect not only what people said directly, but also their expressed wishes, preferences and experiences as understood through advocacy relationships and person-centred engagement.

Throughout the paper, the experiences of individuals are presented through anonymised case studies. Names and identifying details have been altered to protect privacy and ensure confidentiality.

Stakeholder Engagement

Recognising that deinstitutionalisation is a complex policy and practice issue, a range of individuals and organisations with expertise and experience relevant to disability services, independent living, housing, advocacy, regulation and human rights were engaged with in the development of this paper.

Semi-structured interviews and discussions were conducted with NAS Advocates and 14 key stakeholders. These conversations explored experiences of congregated settings, barriers to community living, examples of successful deinstitutionalisation, and opportunities for policy reform. Stakeholders were selected based on their knowledge of residential disability services, rights-based practice, housing policy, disability advocacy, regulation, and service provision.

Representatives from the following stakeholder organisations were interviewed:

- Disabled Women Ireland (joint interview with two representatives)
- Health Information and Quality Authority
- Inclusion Ireland (interviews with two representatives)
- Independent Living Movement Ireland
- NAS Advocates/Senior Advocates
- National Disability Authority
- Social Health and Education Project (Cork)

The purpose of this engagement was not to establish consensus but to gather a broad range of informed perspectives. Quotations drawn from these interviews are included throughout the paper to illustrate key themes and ensure that the views of contributors are reflected in their own words.

Analysis of NAS Advocacy Case Studies

A key component of the methodology involved the review and analysis of advocacy case studies drawn from NAS practice experience. These cases, all of which were active within the 12 months prior to publication, provided insight into the realities faced by people living in congregated settings, as well as the challenges encountered by those seeking to move into community-based housing and supports.

Case studies were selected because they illustrated recurring themes emerging across advocacy work, including issues relating to autonomy, privacy, safeguarding, communication, choice and control, social inclusion, access to housing, and the exercise of rights under the UN Convention on the Rights of Persons with Disabilities (UNCRPD).

The analysis also examined examples of positive outcomes where people had successfully transitioned to more independent living arrangements. These examples highlighted the practical and personal impact that deinstitutionalisation can have when appropriately planned and supported.

Policy Review and Desk-Based Research

The paper was informed by a comprehensive review of Irish and international policy, legislation, research literature and public reports relating to congregated settings, deinstitutionalisation, housing, independent living and disability rights.

The Irish review examined relevant legislation, policy frameworks and guidance documents, including those relating to disability services, housing, decision-making, regulation and human rights. Particular attention was given to Ireland's obligations under the UNCRPD, especially Article 19 on living independently and being included in the community.

Internationally, the review explored approaches to deinstitutionalisation and community living across a number of jurisdictions, including the United Kingdom, Scandinavia, Canada, Italy, Australia and New Zealand. The purpose of this comparative analysis was to identify common themes, examples of good practice, and lessons that may be relevant to the Irish context.

In addition to academic literature and policy documents, relevant reports from advocacy organisations, regulators, human rights bodies and disability organisations were reviewed to provide a broader understanding of current challenges and developments.

A Person-Centred and Rights-Based Approach

Throughout the development of this paper, every effort was made to ensure that the experiences and perspectives of disabled people remained the primary lens through which the issue was examined. The paper is therefore informed by a rights-based understanding of disability that recognises people as experts in their own lives and emphasises their right to choice, autonomy, dignity, participation and inclusion within their communities.

Engagement with DPOs formed part of the interview process for this paper, as well as the drafting and feedback process. In addition, one person with direct experience of living in a congregated setting was interviewed for the paper, alongside the voice of people through the Advocates that supported them.

The findings and recommendations that emerge from this paper are grounded not only in policy analysis and research evidence, but in the voices and experiences of people whose lived experiences demonstrate the continuing impact of congregated settings and the importance of creating opportunities for people to live ordinary lives, in ordinary homes, as equal members of their communities.

Executive Summary

The National Advocacy Service for People with Disabilities (NAS) commissioned this social policy paper to examine the continued use of congregated settings in Ireland and their impact on the lives of disabled people. This is an Advocate-informed policy analysis grounded in NAS practice, stakeholder engagement, case-study material and desk-based research. **Fundamentally, however, this paper is not about buildings, services, policy frameworks or regulation. It is about people.**

It is about individuals whose voices are too often absent from discussions about where they live, how they live, and the choices available to them. It is about people who continue to reside in congregated settings and whose experiences challenge us to reflect on whether current arrangements are consistent with a modern, rights-based approach to disability or more importantly a good life for people.

A focus throughout this paper is the importance of listening to and respecting the voice of the person. The experiences relayed by NAS Advocates, disabled people and key stakeholders repeatedly demonstrate that people want the same basic things: a home of their own, meaningful relationships, privacy, opportunities to participate in their communities, and genuine choice over how they live their lives. Yet many of the people whose experiences informed this paper continue to live in environments where those ordinary aspirations remain difficult to achieve.

The findings presented throughout this document draw on advocacy case studies, stakeholder engagement, policy analysis and international evidence. Together, they point to a consistent conclusion: **Ireland has made significant policy commitments to deinstitutionalisation and independent living, but implementation remains too slow, too uneven and too dependent on local circumstances.** As a result, many disabled people continue to live in settings that restrict choice, autonomy and participation in community life.

Fundamentally, however, this paper is not about buildings, services, policy frameworks or regulation. It is about people.

Congregated settings have been a longstanding feature of the Irish disability services landscape. Historically, they emerged from a model of care that viewed disabled people primarily through a medical lens and emphasised care, protection, control and segregation rather than rights, autonomy and inclusion. **Although services and supports have evolved over time, many people still reside in settings characterised by institutional routines, limited personal control, and separation from the wider community.** The experiences documented in this paper suggest that, despite the dedication and commitment of many staff working within these services, the congregated model itself often restricts opportunities for people to live self-directed lives.

The testimony gathered from disabled people living or who have lived in congregated settings through this research highlights **recurring concerns regarding privacy, dignity, autonomy, communication, safeguarding and community participation.** Advocates described environments that were often institutional in design and atmosphere, characterised by communal living arrangements, regimented routines and limited opportunities for people to make meaningful choices about their daily lives. Participants spoke about people having little control over fundamental aspects of ordinary living, including what they eat, what activities they participate in, who they spend time with, and how they access their community.

Particular concerns are voiced regarding people who communicate differently. Many individuals living in congregated settings communicate through non-speaking means, gestures, behaviour, assistive communication methods or other forms of expression. Contributors to this paper raised concerns that the voices of these individuals can sometimes be overlooked or misunderstood, with decisions being made about their lives rather than with them. **The findings reinforce the importance of ensuring that all people, regardless of communication style or support needs, are afforded equal opportunities to express their will and preferences and to influence decisions that affect them.**

The paper also identifies concerns relating to personal safety and wellbeing. Many contributors described situations where people experienced fear, intimidation or distress arising from incompatible living arrangements within congregated settings. While these issues are often managed by staff in challenging circumstances, they nevertheless highlight the inherent difficulties associated with large group living environments where individuals have little choice regarding who they live with.

The findings suggest the lives of disabled people living in congregated settings can be improved by placing greater emphasis on compatibility, rights, choice and individual preferences rather than organisational convenience.

Importantly, the experiences documented throughout the paper are not presented as isolated incidents. Instead, they illustrate broader systemic issues that continue to affect people's quality of life. These issues include the overarching state approach to supporting disabled people, housing shortages, staffing challenges, delays in implementation of deinstitutionalisation initiatives, reliance on block funding models and a lack of available community-based alternatives. Together, these factors contribute to a situation in which people remain in congregated settings for years, and in some cases decades, despite policy commitments to support a move to more community-based living.



At the policy level, the paper finds that Ireland has developed a substantial framework supporting deinstitutionalisation and independent living. Key policy initiatives such as Time to Move on from Congregated Settings, the National Housing Strategy for Disabled People and the Assisted Decision-Making (Capacity) Act 2015 reflect a growing recognition that disabled people should enjoy the same opportunities as others to choose where and how they live. Ireland's ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2018 further strengthened this position by establishing clear international human rights obligations, particularly under Article 19, which affirms the right of disabled people to live independently and be included in the community.

However, despite these commitments, the paper finds a considerable gap between policy ambition and people's lived reality. The evidence suggests that implementation has been inconsistent and that significant numbers of people continue to live in congregated settings many years after commitments to deinstitutionalisation were first made. **Housing shortages, insufficient community supports, workforce challenges and competing policy priorities all continue to impede progress.** As a result, the right to live independently and be included in the community remains unrealised for many people.

The Irish and international evidence reviewed as part of this paper provides important context. While countries such as the United Kingdom, the Scandinavian nations, Italy, Australia, Canada and New Zealand have followed different pathways towards deinstitutionalisation, the **evidence consistently suggests that people experience better outcomes when they live in homes embedded within their communities and when they receive personalised supports tailored to their individual needs and aspirations.** These are findings echoed in Irish research. Equally, international experience demonstrates that deinstitutionalisation is not simply a matter of relocating people from one building to another. Successful outcomes depend on access to housing, person-centred supports, opportunities for community participation and genuine respect for personal choice.

One of the most striking findings of this paper is the transformative impact that can occur when people move from congregated settings into smaller homes in the community. Contributors repeatedly described improvements in people's confidence, independence, physical health, mental wellbeing, social participation and overall quality of life following successful transitions. People developed stronger connections with their local communities, exercised greater control over their daily routines, and experienced a renewed sense of pride in their homes and personal identities. These stories serve as powerful reminders of what can be achieved when support systems are organised around the person rather than the service.

The paper also highlights the importance of independent advocacy in supporting these outcomes. NAS Advocates frequently work alongside people who may have limited opportunities to express their wishes or challenge decisions that affect them. Through advocacy, people are supported to articulate their views, understand their rights, participate in decision-making and pursue lives that reflect their own goals and aspirations. Furthermore, information gained through advocacy with disabled people should be used as an evidence base of the issues on the ground to push for changes in housing conditions for disabled people, something that is critical to the effective implementation of the Public Sector Human rights and Equality Duty. **The experiences documented throughout this paper demonstrate that advocacy is often a critical safeguard against institutional practices and an important mechanism for ensuring that people's voices remain central to decision-making.**

Ultimately, this paper concludes that congregated settings are fundamentally inconsistent with a rights-based vision of disability grounded in dignity, autonomy, equality and community inclusion. While significant progress has been made in recognising this principle within Irish policy, the pace of implementation must accelerate considerably if Ireland is to fulfil its commitments under national policy and international human rights law.

NAS recommends that the Government and HSE develop a new national deinstitutionalisation delivery plan with clear targets, accountability, resourcing, and transparent reporting. Renewed commitment is particularly important considering Ireland's UNCRPD obligations, the Public Sector Human Rights and Equality Duty and the need to improve the quality of life of people living in congregated settings,

Most importantly, the paper concludes that discussions about deinstitutionalisation must always begin and end with the person. The central question is not where services can accommodate people, but how society can support people to live the lives they choose. The voices contained within this paper demonstrate that **disabled people do not seek special treatment or extraordinary opportunities. They seek what every person seeks: a home, a sense of belonging, meaningful relationships, autonomy, and the freedom to participate fully in the life of their community. Ensuring that these voices are heard, respected and acted upon is both the central message of this paper and the challenge it presents to policymakers, service providers, public bodies and society as a whole.**

The central question is not where services can accommodate people, but how society can support people to live the lives they choose.

Case Study:

Lived experience example
Francie

Context

The advocacy enquiry came to NAS from a Mental Health Social Worker who stated that Francie was inappropriately placed in her residential service and had been for many years. Francie was 42 years old when the Advocate met her first. She had a mild intellectual disability. Seventeen years before the Advocate met with her, she had a short-lived mental illness, which resulted in her being placed in an institutional setting as a temporary measure. But she is still living there.

There were 12 other people in the institution. Francie told the Advocate that they are all "old" and the place is too "noisy" for her and she asked could the Advocate come and see it to help her get out and live a meaningful life. The Advocate met with Francie in the institution, and this was her experience, alongside Francie's description:

> I [The Advocate] noted that the building was a large, single story one and on entering I was met with a large glass-sided room where a nurse was seated. It appeared more like a clinic than a home. Long gloomy corridors led to the bedrooms. People wandered around, slowly and aimlessly. More sat on chairs outside, smoking. There was no life about the place, no laughter or busyness.
>
> Francie's bedroom is small, containing a single bed, a locker, a small built-in wardrobe and many stuffed animals. The floor is tiled, the paintwork institutional green, pictures cut from magazines of cats and dogs line the walls. The shared bathroom is down the hall.
>
> There are two bare TV rooms, devoid of any homely touches and a canteen more akin to a school lunchroom of old. The whole place and the people living there seemed to be forgotten in time, and I felt empathy for Francie, and the others who lived there, housed together in this building. Occasionally, the bright spark of a friendly carer lit the space, momentarily, always short lived, but many of the staff seemed as institutionalised as the people living there.

When I first met with Francie she was supported by a manager in the centre to meet with me. During the conversation, Francie often asked if she had done anything wrong. Francie told me that she didn't like living there and wanted to move and had wanted to for many years, but nobody listened to her. There were too many people, they were all old and the place was too noisy. She missed people and being able to go to the shop and do things freely. She told me that she wanted to have a cat or a dog.

Over the years, advocating for Francie's right to be supported according to her needs, and her wishes, she has come to trust me. However, if I touch her accidently, or absent-mindedly lay my hand on her arm in comfort, she recoils as if she received an electric shock, trauma still evident, and it breaks my heart.

Francie is impatient for change. And so am I. But change is slow in coming because Francie has said she feels like a nobody, overlooked and forgotten. She is not big or important; she doesn't shout loud enough, and, in her words, she has been hidden away so long, nobody wants to help her…but I am determined to continue to work towards proving that wrong. Every day reminding her of her own strength of character as we advocate for her to get a home to live an ordinary life where she can have friends, pick her activities, and enjoy the company of a pet.

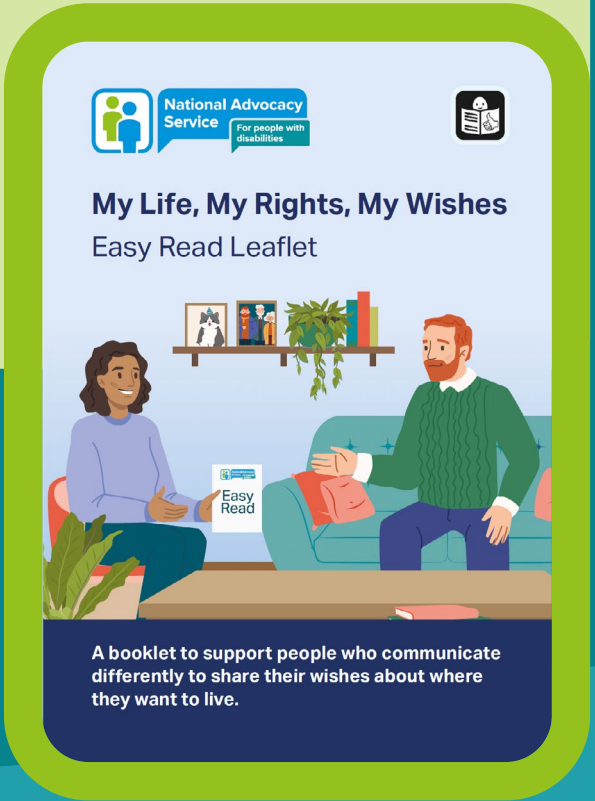


NAS Practical resource

Easy to Read Toolkit to capture will and preference for future living arrangements

NAS has alongside this social policy paper also produced an easy-to-read toolkit intended to support the identification and ongoing representation of a person's will and preferences in relation to their current and future living arrangements.

The first half of the toolkit outlines NAS advocacy work with people who communicate differently and explains how their wishes can be captured through 4 ways, namely "What matters to you", "Your life and your choices", "How you show us what you want" and "Your rights are important", which are all based on a person-centred approach, ordinary life principles, witness-observer practice and a rights-based framework. The second half of the toolkit is intended for staff to use when documenting a person's will and preferences. The expectation is that it will be used regularly as a working document to support deinstitutionalisation when it occurs. The central purpose of the toolkit is to ensure that a person's will and preferences are recorded on an ongoing basis and remain central to any future move.



1. Introduction: Congregated Settings, Disability Policy and the Right to Community Living

This paper proceeds in four parts. It firstly explains the policy, legal and human-rights context for deinstitutionalisation in Ireland. It then presents evidence from NAS advocacy practice and stakeholder engagement about the lived experience of congregated and de facto congregated settings. The paper next considers the outcomes associated with community living and the structural barriers that continue to slow progress. It concludes by setting out policy recommendations intended to move deinstitutionalisation from policy commitment to rights-based delivery.

1.1 Policy Purpose and the Role of Independent Advocacy

NAS commissioned this social policy paper to amplify the voices of people living in congregated settings. A core responsibility of NAS is to listen to disabled people and advocate with and on behalf of them. This includes supporting people to express their views, helping them to resolve problems, and assisting them to communicate with organisations and services. **In 2024 and 2025, a significant proportion of NAS advocacy work related to housing, living arrangements, residential services and healthcare settings.**



NAS places particular importance on supporting people who may be isolated from their communities, have no natural supports or communicate differently, as they may require additional support to advocate for themselves. This is especially relevant to disabled people living in congregated settings. People living in these centres are sometimes isolated from their surrounding communities. They may also have cognitive or communication differences that can sometimes make it difficult for them to understand their rights and entitlements, or to self-advocate.

Through many years of advocacy with people living in congregated settings, NAS Advocates have developed a detailed understanding of recurring structural and experiential problems. These include the institutional layout and design of some of these centres; the lack of person-centred care; a failure to provide for the privacy and dignity of people; a lack of access to the wider community; limited opportunities to participate in employment and education; and denial of day-to-day experiences, choices and freedoms that most of us take for granted, like ordinary routines, relationships and meaningful roles within our communities.

It was once noted that "The tragedy is not that people live in institutions, but that institutions live in people." This quote speaks powerfully to what NAS Advocates have witnessed over many years of visiting congregated and institutional settings. Spending time alongside people living in these settings can be a profoundly emotional experience.

"The tragedy is not that people live in institutions, but that institutions live in people."

The impact extends beyond the visible restrictions of the environment. It is felt in **the loss of autonomy, the absence of ordinary rhythms of life and the erosion of individuality that institutional living can produce.** Witnessing people living in environments where routines are determined by the needs of the institution rather than the individual can leave a long-lasting impression on advocates. Seeing people denied the everyday choices, relationships, privacy and freedom that most citizens take for granted makes clear why institutional living remains a pressing human-rights concern.

The dehumanising effects of institutionalisation are not confined to those who live within these settings; they are also recognised by those who bear witness to them. Many NAS Advocates who contributed to this paper described shock at the lack of choice and control, anger at failures in care, and frustration at delays and barriers placed in people's way. These experiences strengthen NAS's conviction that **institutional models of care are fundamentally incompatible with the right, recognised in Article 19 of the UN Convention on the Rights of Persons with Disabilities, to live independently and be included in the community.** Every person should have the opportunity to live an ordinary life, with the same dignity, choice, belonging and opportunities as every other member of society.

As shown in this social policy paper, progress in moving people out of congregated settings and into smaller, more person-centred homes in the community has been limited. **This slow pace of change is having a sustained negative impact on people living in congregated settings and raises serious human-rights concerns. NAS Advocates have repeatedly heard from people living in these centres that they do not like their living arrangements, that they are afraid of some of the people they live with, and that their choices and daily routines are restricted.** Their stories and voices are amplified in this paper, with names changed to protect privacy.

While Advocates work to support and resolve these issues at the level of the individual, it has become increasingly clear that there is an onus on NAS, as an organisation, to raise these matters at a national level and shine a light on an often-forgotten population. It is for this reason that NAS has undertaken to develop and publish this document, to amplify the voice of the person who continues to reside in a congregated setting.

Public Sector Equality and Human Rights Duty

Under Section 42 of the IHREC Act 2014, public bodies must have regard to the need to eliminate discrimination, protect human rights and promote equality in all aspects of their work. For people living in congregated settings, this means ensuring that services support people's dignity, autonomy, participation and inclusion in community life, rather than simply providing care and protection.

1.2 Congregated Settings: Definition, Structure and Policy Context

Congregated settings have been a longstanding feature of the disability services landscape in Ireland. This is particularly true for people with intellectual and physical disabilities who have high or complex support needs. These settings typically involve groups of disabled people living together in shared accommodation, often on a purpose-built campus or re-purposed health facility, rather than in homes of their own or of their choosing within the wider community. While the size and form of congregated settings can vary, they are commonly characterised by shared living arrangements, limited personal choice regarding daily routines, and service delivery that is task-oriented and focused on medical or care needs rather than empowerment and individual autonomy.[1]

Wolf Wolfensberger, a German-American academic well known for his work on disability policy, summarised the negative aspects of institutions well:

"The term institution refers to a deindividualising residence....in which people are congregated....highly regimented...and in which all or most of the transactions of daily life are carried out under one roof."[2]

1 Health Service Executive, *Time to Move on from Congregated Settings*, 2011

2 Wolf Wolfensberger, *The Principle of Normalization in Human Services* (1972).

Case Study:

Lived experience example
Róisín

Context

Róisín is a woman in her early thirties who has lived in a residential service for all of her adult life. She has an intellectual disability and is non-speaking. She loves fun, noise, banter and gossip and to be stuck in the middle of it all. A NAS Advocate was contacted as those supporting Róisín were concerned as she would sometimes vocalise very loudly. She had multi-disciplinary team reviews which concluded that she might not be very happy. The NAS Advocate reviewed Róisín's situation. She was living in a very old-style unit on a campus that is a congregated setting. There were approximately ten people living there and she was sharing a dormitory-style bedroom. She had no day service either on or off campus and when she was brought off campus her presentation was pointing to possible unhappiness. Those living with her were all significantly older than her and some with a lot of healthcare and ageing needs.

Actions by Advocate

The Advocate sought to raise concerns regarding Róisín's quality of life with management, the service's Rights Committee, and HSE Disability Services. However, whilst there was a lot of interest and intent on doing everything possible to support Róisín, the overall solution was and still is that Róisín would move as part of deinstitutionalisation. The service was earmarked for deinstitutionalisation and at one point a Transition Co-ordinator was appointed. However, over several years the progress was extremely slow with only a very small minority of people being moved off campus. Instead, efforts were focused on improving the quality of life for people currently living there, such as trying to create more privacy and give more comfort in the bedrooms. In time, Róisín got her own room. However, this only happened when the overall numbers reduced, mainly due to the deaths of others living there. Nicer furniture was provided. More technology was made available and efforts were made to create sensory spaces within and outside the building. However, staffing remained a challenge, limiting the opportunities for Róisín and others to

leave the campus for activities. The HSE then funded a specific social programme to provide supports for people to get off campus and Róisín benefitted from supports under that scheme by doing some activities she absolutely loves. She now also gets to attend a day service (external to where she lives) a couple of days a week.

Outcome

The next progression for Róisín is that when some other people move off campus to a community setting, she will eventually get to move to a house on the campus which would have smaller numbers but be livelier and more age appropriate. Unfortunately, she is down the list of priority for people to move off campus given the large amount of people who are waiting to exit the congregated setting and are seen to have a more immediate need to move. The NAS Advocate cannot do any more at this point. However, it must be said that Róisín is a much happier person due to the improvements in her quality of life. This is very evident when meeting Róisín. However, there is still a strong sense of the missed opportunity for Róisín to be out there having a fuller life in the community and also a concern that by the time she eventually gets to move off campus, that she may not have the same level of health to fully enjoy it.



In Ireland, congregated settings are generally defined by the number of people living there and the nature of the accommodation and supports provided. National disability policy has historically described congregated settings as being where ten or more disabled people live together in a single location or where the living arrangements are campus-based. People living in congregated settings are predominantly adults with intellectual disabilities, often with additional physical, sensory, or communication needs. Many individuals have resided in such settings for long periods, sometimes for most of their lives as children and into adulthood, reflecting past service models that prioritised segregation and isolation from the community over inclusion.

"What strikes me when I go into these places is the physical environment. So, you're going into a campus and there's usually big gates that are locked. And even for the Advocate to get in, I find it's quite difficult, you know? I'm ringing the buzzer, nobody's answering. It's a very…restrictive environment".

NAS Advocate

Funding for congregated settings in Ireland is provided through the state, distributed via service-level arrangements with the HSE. The majority of service providers are non-profit or voluntary organisations, many of which have religious or charitable origins and operate as Section 38 or Section 39[3] bodies. **Increasingly, private providers are being contracted to provide residential disability services.** Funding typically covers residential care, staffing, day services, and clinical supports, and is largely allocated on a block-funded basis rather than being directly tied to the needs of individuals using the service. **This funding model has historically reinforced provider-led service configurations as opposed to genuine person-centred care.**

All residential disability services in Ireland, including congregated settings, are subject to statutory regulation and oversight by HIQA under the Health Act 2007 and associated regulations and standards. Providers must register designated centres, comply with regulations and national standards, and undergo regular inspections. Regulation and HIQA as regulators have played a positive role as catalysts for deinstitutionalisation, while driving up standards of care, quality and person-centred practice across services. Regulatory findings over time have highlighted recurring issues in congregated settings, including

3 Section 38 and Section 39 organisations are types of non-HSE bodies funded by the Health Service Executive (HSE) under the Health Act 2004. The terms come directly from the sections of the Act that legally underpin how these services are provided and funded.

restricted choice and control for people, limited access to community life, and challenges in safeguarding, privacy, and governance.[4]

"It's stark…I think that's the thing. I think for me the piece that was shocking is the fact that the people are living there since there were probably four or five, they're now in their late 50s, 60s. It's almost as if they're waiting for everybody else to notice them and actually provide them with something that all of their peers have moved on to. But these people would have an absence of people who would speak up for them".

NAS Advocate

The current picture of remaining congregated settings in Ireland

The most recent data supplied by HIQA shows the number of people still living in congregated settings across Ireland in both January and as recently as July 2026. (*The data presented is indicative of a moment in time, rather than a definitive representation of the issue over time). What is apparent is that the number of people moving out of congregated settings is minimal over the past number of years, given the commitments as outlined in this paper, as illustrated in the following table;

Congregated Settings (National Figures)	Jan 2024	Jan 2025	Jan 2026	July 2026
Registered providers	33	32	29	29
Registered centres	212	208	198	196
Residential places	2254	2111	1941	1889

What is also noteworthy about the prevalent ongoing use of congregated settings is that they are in existence across such a high number of counties in Ireland, as illustrated in the following data supplied by HIQA (*covers period up to January 2026).

4 Health Information and Quality Authority, 10 Years of Regulating Designated Centres for People with Disabilities, 2024

County	No. of Congregated Settings - Centres	No. of Congregated Settings - Places	No. of Providers operating Congregated Settings - County
Carlow	1	8	1
Cork	32	408	6
Donegal	10	58	2
Dublin	68	626	10
Galway	4	26	1
Kerry	5	68	3
Kildare	14	168	5
Kilkenny	8	72	5
Limerick	21	224	5
Louth	2	16	1
Mayo	1	8	1
Meath	8	51	2
Monaghan	1	17	1
Sligo	2	17	2
Tipperary	5	50	3
Waterford	7	53	3
Wexford	5	35	2
Wicklow	4	36	3
Grand Total	**198**	**1941**	**Note: As per above data, some of the 29 providers nationally provide services in more than one county**

Another area not accounted for in the above figures is nursing homes and the number of people under 65 who are living in them who have no nursing needs or requirement. Although nursing homes are not typically classified as congregated settings, a substantial number of younger disabled people continue to live in them due to a lack of appropriate community-based alternatives. According to official parliamentary figures as of July 2025, more than 1,200 people under the age of 65 were residing in nursing homes. The Ombudsman's Wasted Lives[5] report highlighted how these placements can amount to a de facto (unofficial/in all but name) congregated setting, with younger people often living in environments designed for the needs of an older population.

Over the past decade, Irish disability policy has increasingly recognised that congregated settings are inconsistent with a rights-based approach to disability and with Ireland's obligations under the UN Convention on the Rights of Persons with Disabilities (UNCRPD). Policy initiatives, most notably the Time to Move On policy from 2011, have promoted a transition away from institutional-style congregated settings toward a more community-based, person-centred model of care. The National Disability Authority has also published a number of important reports on the transition away from congregated settings. However, despite the policy commitment and weight of evidence, a significant number of people continue to live in congregated and institutional forms of residential care. The next section explores in more detail the various policy and legislative frameworks that contributed to the development and evolution of residential care for disabled people in Ireland.

Problems with congregated settings are not always confined to practical concerns around the provision of care or the lack of support. The problems sometimes run deeper and reflect society's attitudes towards disabled people:

"You can break it down into two main chunks. So, one I would call an insufficiency of supports right? So, you talk about the staffing levels, the lack of choice for people being able to move around, peer-to-peer violence is a massive thing…but I also think there's a second area which is around ambition, and seeing people in a holistic light as full, complete human beings entitled to the full complement of human rights…What does it look like to have many people to help you and support you in making decisions? There's no ambition in the system. There's no aspiration."

Amy Hassett – Disabled Women Ireland

5 Office of the Ombudsman, Wasted Lives: Time for a Better Future for Younger People in Nursing Homes, 2024

As described above, congregated settings are typified by attitudes and assumptions just as much as they are by the buildings, locations and the number of people who live there.

1.3 The Evolution of Irish Policy and Law on Deinstitutionalisation

Read chronologically, Irish policy reveals a gradual but incomplete movement from institutional care towards rights-based community living. The sequence matters: each reform has widened the formal recognition of autonomy, equality and inclusion, while implementation has continued to lag behind the normative standard. The following section therefore treats deinstitutionalisation as a policy trajectory, moving from service administration, through community-inclusion policy and equality duties, to supported decision-making and binding UNCRPD obligations.

For much of the late twentieth and early twenty-first centuries, Irish residential disability policy was organised primarily around service provision, system coordination and clinical or custodial responses, rather than around citizenship, equality, autonomy and enforceable rights. This policy architecture reflected the continuing influence of the medical model of disability, in which impairment was treated principally as an individual condition to be managed through care. Within that framework, congregated and institutional living became normalised as a default response, particularly for people with intellectual disabilities and for people described as having high or complex support needs. A disability-rights analysis requires a different starting point: the policy question is not how efficiently a setting can care for a person, but whether public systems enable that person to exercise choice, control, dignity, relationships and equal membership of the community.

The Disability Act 2005 remains a central component of Ireland's disability-services framework, but its contribution to deinstitutionalisation is indirect and limited. The Act established statutory processes for assessments of need and service statements and therefore created an administrative infrastructure for identifying and coordinating supports. It did not, however, establish a right to housing, independent living or community inclusion; nor did it prohibit institutional or congregated living or articulate the rights of people living in residential services. In policy terms, its design belongs to a pre-UNCRPD settlement: **it is concerned principally with administrative process rather than with the redistribution of power, choice and control to disabled people.** Accordingly, while the Act forms part of the bureaucratic system within which disability services operate, it does little to dismantle the structural conditions that sustain congregated settings or to secure the material conditions of a good life in the community.

The decisive policy shift came in 2011 with the HSE report ***Time to Move on from Congregated Settings – A Strategy for Community Inclusion***, the first explicit national commitment to deinstitutionalisation. The strategy marked a significant departure from earlier service-led approaches by identifying congregated settings as incompatible with contemporary understandings of quality of life and by committing the State to support people to move into dispersed housing in ordinary communities. "Dispersed housing" referred to apartments or houses of the kind used by the general population, while "supported living" described the individualised, person-centred supports required to make community living sustainable. The significance of the strategy therefore lay not simply in proposing different buildings, but in reframing deinstitutionalisation as a question of community inclusion.

The strategy referenced a range of research studies that supported the concept of deinstitutionalisation. The research was predominantly international and assessed the impact of deinstitutionalisation on a range of indicators such as mortality, health, community involvement and quality of life. In addition, the strategy also referenced studies on the costs of various residential care models and found that a process of deinstitutionalisation towards community-based living would be neutral in terms of the cost to the state.[6]

The strategy identified approximately 4,000 adults living in settings of ten or more people and envisaged their relocation to dispersed housing, typically shared by no more than four people, with personalised supports.

Importantly, the strategy framed deinstitutionalisation as a matter of community inclusion rather than merely service modernisation.

Despite its importance, *Time to Move on* was **never placed on a statutory footing which may have aided implementation.** Its original completion target date of 2018 was missed by a substantial margin, and progress has varied widely by region, provider, and level of support need. The most recent data from the regulator of disability services, the Health Information and Quality Authority, stated there were 212 congregated settings in 2023, where 2,256 people lived.[7] Given that there were 9480 residential places at the end of 2025, this means approximately one fifth of disabled people living in residential care were living in congregated settings, underscoring the slow progression of the deinstitutionalisation strategy.

6 Health Service Executive, Time to Move on from Congregated Settings, 2011
7 Health Information and Quality Authority, Annual Report 2023, 2024

It should be acknowledged that there is a discrepancy between the figures outlined above and those provided by the HSE. According to the HSE, 1,335 individuals remained living in HSE-tracked congregated settings at the end of April 2025. The discrepancy is likely due to the HSE counting people rather than available beds. Moreover, there may be differing interpretations of what services are included as congregated settings.

"Somebody received the keys to their home from the council in June 2025 and they still haven't moved in one year later. And [the provider] is saying this is due to staffing. So, although that is a positive step, they've been helping the person buy furniture for the house…the person's still living in the congregated setting, … that's a year. So, I'm still pushing for this and just being told its staffing."

NAS Advocate

The wider policy trajectory both preceded and followed this shift. The **National Disability Strategy (2004)** established an early cross-government framework; the **Disability Act (2005)** formalised aspects of assessment and service planning; **Time to Move On (2011)** made deinstitutionalisation an explicit policy objective; the **Public Sector Equality and Human Rights Duty** in section 42 of the **Irish Human Rights and Equality Commission Act (2014)** introduced a statutory equality and human-rights obligation for public bodies; the **Assisted Decision-Making (Capacity) Act (2015)** strengthened the legal status of will and preferences; the **National Disability Inclusion Strategy 2017–2022** reaffirmed community participation; Ireland's ratification of the **UNCRPD** in 2018 transformed the normative framework; and the **National Human Rights Strategy for Disabled People 2025–2030** now locates disability policy more explicitly within human rights. Across these successive frameworks, the recurring policy commitment is that disabled people should live as part of their communities, access mainstream services and exercise their human rights. Yet deinstitutionalisation has too often remained one objective among many rather than a time-bound structural reform programme. The result is alignment at the level of values and intent, but continued dependence on goodwill, cross-sectoral cooperation and incremental implementation rather than binding obligations, measurable targets and clear accountability.



Housing policy has increasingly been recognised as one of the principal constraints on deinstitutionalisation. This recognition is reflected most clearly in the National Housing Strategy for Disabled People 2022–2027, which represents a significant evolution in Government thinking. For the first time, housing for disabled people is framed explicitly within a human rights context, with direct reference to Ireland's obligations under the UNCRPD, particularly Articles 19 and 28. The Strategy acknowledges that the absence of accessible, affordable housing in the community is a primary driver of ongoing congregated living, delayed transitions, and inappropriate living arrangements.

The strategy also recognises that the successful transition from congregated settings requires more than the availability of suitable housing stock. It emphasises the **need for coordinated planning between housing authorities, health services and disability service providers to ensure that individuals can access both appropriate accommodation and the supports necessary to live independently in the community.** Through local Housing and Disability Steering Groups, local authorities and the HSE are expected to work collaboratively to align housing allocations with the provision of care and support packages, thereby reducing the risk that individuals secure housing without the supports required to sustain community living. This reflects a broader policy shift in which responsibility for securing housing solutions increasingly rests within mainstream housing systems rather than disability services alone.

Article 19 – Living independently and being included in the community

States Parties to the present Convention recognise the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

a. Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

b. Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

c. Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

Article 28 – Adequate standard of living and social protection

1. States Parties recognise the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions, and shall take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability.
2. States Parties recognise the right of persons with disabilities to social protection and to the enjoyment of that right without discrimination on the basis of disability, and shall take appropriate steps to safeguard and promote the realization of this right, including measures:

a) To ensure equal access by persons with disabilities to clean water services, and to ensure access to appropriate and affordable services, devices and other assistance for disability-related needs;
b) To ensure access by persons with disabilities, in particular women and girls with disabilities and older persons with disabilities, to social protection programmes and poverty reduction programmes;
c) To ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses, including adequate training, counselling, financial assistance and respite care;
d) To ensure access by persons with disabilities to public housing programmes;
e) To ensure equal access by persons with disabilities to retirement benefits and programmes.

Crucially, the Housing Strategy treats deinstitutionalisation not as a narrow disability service issue, but as a whole-of-government responsibility, requiring coordination between local authorities, health services, local government, and disability providers. It recognises disabled people living in congregated settings, in nursing homes, and in family homes without choice as distinct groups whose housing rights must be addressed. While its ambitions are considerable, its impact ultimately depends on wider housing supply, capital investment, and the prioritisation of disabled people within competitive housing markets.

Incorrect or inconsistent implementation of housing guidelines and legislation can also delay disabled people's access to housing. Where this occurs, people may remain in congregated or inappropriate settings not because their will and preferences are unclear, but because administrative systems fail to translate housing rights into timely, practical outcomes.

Broader policy and legislative developments outside the housing sphere have also reshaped the landscape surrounding deinstitutionalisation. In March 2023, responsibility for specialist disability services was transferred from the Department of Health to the Department of Children, Disability and Equality. This transfer was intended to contribute to a broader programme of reform designed to promote a more holistic and rights-based model of disability support. Additionally, **the establishment of a dedicated Disability Unit within the Department of the Taoiseach marked the first time that disability policy was placed at the centre of government coordination in Ireland.** The Unit was created to drive cross-government action, accelerate reforms, and support implementation of the National Human Rights Strategy for Disabled People 2025-2030, reflecting a rights-based approach grounded in Ireland's commitments under the UNCRPD.

The **Assisted Decision Making (Capacity) Act 2015**, following its commencement in 2023, has profound implications for where and how disabled people live. By embedding a presumption of capacity and prioritising a person's will and preferences, the Act challenges established practices where decisions about care and accommodation were made by service providers or families, often with little or no input from the person themselves. **The Act, therefore, addresses one of the subtle enablers of institutionalisation: the exclusion of disabled people from decisions about where, and with whom, they live. While the Act does not guarantee access to housing, it strengthens the legal basis on which individuals can direct how they wish to live their lives.**

Ireland is a signatory to the Optional Protocol to the United Nations Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (OPCAT). A key feature of OPCAT is that it requires participating countries to establish National Preventive Mechanisms (NPMs), which are independent bodies empowered to inspect certain services and make recommendations to improve conditions and safeguard human rights. OPCAT principles apply to any setting where people may be deprived of liberty, including some disability services, mental health facilities, nursing homes, and children's residential centres. **The focus is not solely on preventing torture, but more broadly on preventing abuse, neglect, degrading treatment, and infringements of people's rights through independent oversight and regular inspection.**

Ireland's ratification of the **UN Convention on the Rights of Persons with Disabilities in 2018** has fundamentally altered the context within which all Irish legislation, frameworks and strategies now operate. Article 19 of the Convention establishes a clear benchmark: disabled people have a right to live in the community, with choices equal to others, and States must take effective measures to end segregation and institutionalisation. Since ratification, Irish Government policies on deinstitutionalisation can no longer be understood as aspirational or discretionary. They must be assessed against clear human rights obligations, monitored domestically by IHREC and internationally by the UNCRPD Committee.

Ireland's Initial State Report to the UNCRPD was submitted in 2021. In August 2026, the Irish Government responded to the committee's 'List of Issues' arising out of the 2021 report. Ireland is now preparing for its first formal UNCRPD Committee review to assess compliance with the Convention. This is due to take place in 2027. Monitoring reports and independent analysis have repeatedly highlighted the gap between Ireland's policy commitments and lived realities for people in residential care. **Persistent reliance on congregated settings, slow transition rates, shortages of community-based housing, and the continued placement of younger disabled people in nursing homes are increasingly framed not as implementation difficulties, but as potential violations of binding human rights obligations.** This marks an important conceptual shift: deinstitutionalisation is no longer simply about service reform or modernisation, but about the realisation of basic human rights.

"So, an ultimate challenge is people being fully integrated with active lives in their local community. At present, much of the activity tends to be in the congregated setting. Congregated settings, the way they're set up, will have possibly a gym and a swimming pool and the multidisciplinary team and a canteen and day services. So, people tend to go to those areas within the congregated setting as opposed to accessing a similar service in their local community. So, we still do see that but not as much as in the early days of regulation where it was prevalent across the majority of congregated settings".

Regional Manager – Health Information and Quality Authority

Taken together, the Irish policy and legislative landscape is not characterised by an absence of commitments, but by a persistent implementation deficit. Over two decades, policy has moved from service coordination towards equality, supported decision-making, community living and human rights. Yet a sizeable number of disabled people continue to live in congregated settings. The central policy challenge is therefore one of translation and accountability: converting strategies, statutory duties and international obligations into a durable system in which housing,

funding, staffing and individualised supports follow the person. A rights-based approach must be judged by outcomes: whether disabled people can live in ordinary homes, exercise meaningful choice over where and with whom they live, participate in community life and pursue lives they themselves value.



Public Sector Duty in Practice

Policy publication, by itself, does not discharge the State's obligations. The Public Sector Equality and Human Rights Duty (as derived from Section 42 of the Irish Human Rights and Equality Commission Act, 2014) requires public bodies to assess whether their decisions, funding arrangements, commissioning practices and service models advance or restrict equality and human rights, to address identified inequalities, and to report on that work. Applied to deinstitutionalisation, the duty turns implementation into an institutional responsibility rather than an optional expression of good practice. It requires public bodies to examine whether resource allocation, housing decisions and service arrangements are perpetuating segregation and to take demonstrable action where they are.

1.4 The UN Convention on the Rights of Persons with Disabilities: A Rights-Based Framework

Ireland's ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) on 19 April 2018 fundamentally changed the policy context for congregated settings. The Convention creates an international legal obligation on the State to respect, protect and fulfil the rights it recognises. Although the UNCRPD has not been directly incorporated into Irish law, it has a central interpretive and policy role and is independently monitored under Article 33 by IHREC, supported by the National Disability Authority (NDA). The effect is to move deinstitutionalisation beyond the language of service improvement: the continued segregation of disabled people must now be assessed against explicit human-rights standards.

Housing sits at the intersection of several UNCRPD provisions, most notably Article 19 (Living independently and being included in the community) and Article 28 (Adequate standard of living and social protection). However, Article 19 is generally regarded by the UN Committee, Irish monitoring bodies, and disability organisations as being central to Ireland's deinstitutionalisation and disability housing obligations.

1.4.1 Article 19 – Core content and binding obligations

Article 19 recognises the equal right of all persons with disabilities to live in the community, with choices equal to others, and imposes positive duties on signatories to make this right real for disabled people. It requires signatories to ensure three closely aligned outcomes:

Choice of where to live: Disabled people must have the opportunity to choose where, how, and with whom they live, on an equal basis with others, and must not be obliged to live in any particular type of residence or accommodation.

Access to supports: Disabled people must have access to a sufficient range of home, residential, and community-based supports (including personal assistance) necessary to enable community living, prevent isolation and promote inclusion.

Equal access to mainstream services: Community services and facilities available to the general population must be accessible, inclusive, and responsive to the needs of persons with disabilities.

The UN Committee on the Rights of Persons with Disabilities has made clear that institutionalisation and segregation are incompatible with Article 19, regardless of the size or modernity of the setting, and that small group homes or campus style developments may still constitute institutions if choice, autonomy, and community integration are constrained.

1.4.2 Housing and the right to independent living

In the Irish context, housing is not simply a social policy lever but a structural precondition for compliance with Article 19. **Without access to appropriate, affordable, and accessible housing in the community, the right to independent living cannot be fully achieved.** The National Disability Authority explicitly recognises that Ireland's Article 19 obligations require the State to deliver housing options that enable real choice, including for people moving out of congregated settings and for those seeking to leave the family home.[8]

Irish research and rights monitoring consistently identify four housing-related barriers to the realisation of Article 19: insufficient supply of accessible and universally designed housing; long waiting times for social housing for people with needs related to a disability; lack of portable and individualised supports linked to housing; and continued reliance

8 National Disability Authority, Overview of UNCRPD Article 19 in Ireland - Living Independently and Being Included in the Community, 2022

on congregated or transinstitutional settings (settings that are in the community yet retain institutional characteristics), including nursing homes, residential centres, and disability-specific clusters.

These barriers mean that many disabled people in Ireland do not meaningfully exercise choice over where or with whom they live, thereby undermining Ireland's compliance with Article 19.

1.4.3 Deinstitutionalisation and the Duty to End Institutional Models of Care for disabled people

Ireland's obligation under Article 19 extends beyond improving conditions within services; it requires the State to actively dismantle institutional models of housing and support. This obligation has been acknowledged in national policy, most notably through *Time to Move on from Congregated Settings* and the *National Housing Strategy for Disabled People 2022–2027*.

However, evidence from academic research, advocacy organisations, and international monitoring indicates that progress has been slow and uneven. Individuals leaving large institutions have often been relocated to other congregated arrangements rather than to dispersed homes in the community, undermining the core purpose of Article 19.

The UNCRPD framework regards continued institutionalisation not as a policy choice or one of several potential service models, but as a rights violation. Article 19, therefore, imposes an obligation on Ireland to develop mainstream housing options, rather than parallel disability housing systems, and to ensure that housing policy across Government is aligned with independent living outcomes.

1.4.4 Interaction with Article 28: Adequate Housing and Social Protection

While Article 19 focuses on community living and inclusion, Article 28 underpins Ireland's housing obligations by recognising the right of persons with disabilities to an adequate standard of living, including access to housing. In practice, Articles 19 and 28 can be read together: adequate housing under Article 28 must be accessible, affordable, secure, and compatible with independent living, as required by Article 19.

Irish human-rights monitoring bodies and advocacy organisations have stressed that housing shortages, rising homelessness, and inaccessible housing stock disproportionately impact disabled people, further constraining Article 19 compliance even where formal deinstitutionalisation policies exist.

1.4.5 Monitoring, Accountability, and Evolving International Scrutiny

Under Article 35 of the UNCRPD, Ireland is subject to periodic review by the UN Committee on the Rights of Persons with Disabilities. Ireland submitted its first State report in 2021 and is currently within its first review cycle. Ahead of formal examination, IHREC and civil society organisations have warned that acute shortages of community-based housing and supports amount to a de facto policy of institutionalisation, particularly for people with high support needs. These critiques underscore that Article 19 compliance is increasingly understood as a whole-of-government housing obligation, not one confined to disability services alone.



Connecting Rights and Action

Article 19 of the UNCRPD establishes the right to live independently and be included in the community. The Public Sector Duty provides one practical mechanism through which public bodies can demonstrate how they are advancing this right in their everyday decision-making.

1.5 Congregated Settings and the Public Sector Equality and Human Rights Duty

The Public Sector Equality and Human Rights Duty (Section 42 of the IHREC Act 2014) legally obligates Irish public bodies, like the HSE, to proactively eliminate discrimination, promote equal opportunities, and protect the human rights of people that use services. In the context of congregated settings **this duty necessitates a transformation from an institutional, rigid routine to a person-centred, rights-based approach to care provision.** The public sector duty aligns with the state's Time to Move On policy, forcing public sector bodies and organisations to actively plan, fund, and transition people out of isolated settings and into independent community housing where they can exercise choice and autonomy. It is important to note, however, that this important piece of legislation only applies to public sector bodies. While the HSE is a provider of many congregated settings, a significant portion of these settings are provided by voluntary organisations. Obligations under the Public Sector Equality and Human Rights Duty do not apply to all of these organisations.

For people remaining in or transitioning from these settings, the Duty requires service providers to systematically protect fundamental rights

like personal liberty, privacy, and bodily integrity by eliminating restrictive practices. The Duty also requires that management must actively consult with people using accessible formats, train staff on the social model of disability, and ensure equal access to mainstream community health services like local GPs. Ultimately, public bodies must publicly report on these actions in their annual reports, transforming human rights from abstract concepts into transparent, mandatory targets and goals that promote people's rights.

Congregated settings often come into direct conflict with core human rights principles such as autonomy, liberty, choice and participation in community life. This may also be the case for de-facto congregated settings such as when young people are inappropriately placed in nursing homes. As shown throughout this policy paper, despite often well-intentioned staff and pockets of good practice, the overriding sentiment is that congregated settings are not consistent with a modern understanding of how people can be best supported to live a good life. Indeed, the continued existence of congregated settings represents a systemic test of the Public Sector Duty.

If public bodies were to fully meet their obligations under the Public Sector Duty, then one can argue that the pace of deinstitutionalisation should be faster and that there should be a redoubling of efforts to move people into community homes of their choosing.

1.6 Evidence from the International Literature

There is a substantial evidence-base internationally in support of the position that people experience an improved quality of life upon leaving congregated settings. A large 2019 study[9] that incorporated thirteen research papers sought to understand whether a move from institutional-style congregated setting to community-based living was associated with an improved quality of life for people with an intellectual disability. Some of the included studies used statistical measures of quality of life to understand the impact of moving out of congregated settings. Other studies reflected people's lived experience through case studies and interviews. Overall, the authors concluded that there was substantial agreement across all studies that moving out of congregated settings led to improvements in people's quality of life. Many of the included papers in this study referenced direct statements from people that had moved out of congregated settings, or from their relatives, Advocates

9 Mary McCarron et al., Effect of Deinstitutionalisation on Quality of Life for Adults with Intellectual Disabilities: A Systematic Review, 2019

or key workers. These statements are a powerful expression of the transformation experienced when moving out of a congregated setting into a more homely environment in the community. The following are two statements from that publication describing how people experienced this transformative change:

"My life is better; it's changed a lot because I have much more freedom…I can get away from others but at the hospital I couldn't get away… Here I can go out with the staff and I behave myself"[10]

"It is a hugely positive, yeah, he has totally changed in his character… his whole wellbeing has totally changed. He is totally content now"[11]



A study conducted in America and published in 2020 sought to gather the experiences of disabled people when they transferred from an institutional setting into community-based residences.[12] Over 150 adults with disabilities were interviewed in order to understand how a key piece of legislation (the Americans with Disabilities Act 1990) was enabling people to live in community settings. One theme identified by the researchers was 'Putting down roots', where people had to learn to live in a new community whilst also adjusting to the freedom and independence that this type of living brought about:

"Living in [a] nursing home was so structured, having to do things at a certain time. When you live in your own apartment, you still feel that way. "Wait a minute, I can eat when I want?!" You're free now." [13]

While participants reported positive experiences after moving to the community, many were careful to stress that ongoing supports were required in order to be truly integrated. Many people continued to experience everyday issues such as access to transport, education/ employment or other community activities:

"There are things I want to do but can't because my help only comes when they want to come, instead of when I need them to come. I've missed going to church many times because people wouldn't come early enough to help me get ready." [14]

10 Patricia O'Brien et al., Perceptions of Change, Advantage and Quality of Life for People with Intellectual Disability Who Left a Long Stay Institution to Live in the Community, 2001
11 Sarah Kilroy et al., Staff Perceptions of the Quality of Life of Individuals with an Intellectual Disability Who Transition from a Residential Campus to Community Living in Ireland: An Exploratory Study, 2015
12 A. M. Angell et al., "Starting to Live a Life": Understanding Full Participation for People with Disabilities after Institutionalization, 2020
13 Ibid.
14 Ibid.



A study carried out in Spain followed the lives of 90 people with intellectual and developmental disabilities while they transitioned from an institutional settings to community-based services.[15] Again, the study found that people's quality of life improved after the process of deinstitutionalisation. Importantly, the authors were keen to point out that improvements in quality of life were not achieved by simply moving from a large institutional setting to a community-based service. In fact, the **improvements depended on the "supports that the person receives to participate in daily activities and the degree to which the person makes decisions and choices about aspects of their daily life".**[16] This is a key point as it underlines the importance of genuine, person-centred care in addition to a less-institutional living environment.

Each of the studies and research papers described above support the view that moving from congregated settings to community-based living delivers positive outcomes for the people living in those services.



In Ireland, the National Disability Authority's *Moving in, Moving on* publication from 2021 also supports the view that quality of life outcomes for disabled people are poorer in congregated settings. All of the evidence presented above is relatively recent literature and underscores the consolidation of opinion that deinstitutionalisation leads to improved quality of life. Nevertheless, as noted in some of the studies, deinstitutionalisation alone is not enough. It should be followed by person-centred supports that ensure people can realise their basic human rights and lead full lives in the community.

1.7 How do other countries approach deinstitutionalisation?

The deinstitutionalisation of disabled people from large institutional settings and a higher degree of focus on human rights has been a defining feature of social policy reform across many high-income countries since the mid-twentieth century. While the drivers of deinstitutionalisation, human rights concerns, advocacy efforts, exposure to institutional abuse and rising costs, have been broadly shared, the policy models adopted, the pace of change, and the outcomes achieved vary significantly across jurisdictions. This section undertakes a comparative analysis of deinstitutionalisation frameworks in the United Kingdom, Scandinavian countries, Canada,

15 Patricia Navas et al., Empowering Lives: How Deinstitutionalization and Community Living Improve the Quality of Life of Individuals with Intellectual and Developmental Disabilities, 2025

16 Ibid.

Italy, Australia and New Zealand examining their ideological foundations, governance structures, implementation mechanisms, and ongoing challenges. The comparison highlights how differing welfare traditions and service models have shaped both successes and persistent gaps in achieving genuine community-based living.



1.7.1 United Kingdom

The United Kingdom represents one of the earliest large-scale adopters of deinstitutionalisation, particularly for people with intellectual disabilities and mental health conditions. The policy shift gained momentum from the 1960s onwards, driven by public scandals exposing institutional abuse, sociological critiques of 'total institutions', and growing political consensus that large hospitals were incompatible with dignity and individualised care. Key policy milestones included the 1957 Royal Commission on the Law Relating to Mental Illness and Mental Deficiency and, later, the development of care in the community as a core organising principle.[17]

The United Kingdom does not have a single approach to deinstitutionalisation. Instead, four distinct jurisdictions, England, Scotland, Wales and Northern Ireland, operate separate social care systems, legislative frameworks and funding models. As a result, progress towards community living has been uneven, with significant variation in policy ambition, investment, and outcomes.

1.7.2 England

England's trajectory has been shaped heavily by the exposure of institutional abuse, most notably the Winterbourne View scandal in 2011. The Government's subsequent Transforming Care programme sought to reduce reliance on Assessment and Treatment Units (ATUs) and move people with intellectual disabilities and autistic people into community settings. Despite clear commitments, progress has been inconsistent. Thousands of people remain in institutional or hospital-based environments, often far from home, with limited choice and prolonged stays. Independent reviews have repeatedly highlighted structural issues: insufficient community housing, fragmented commissioning and a lack of personalised support. England currently operates a quasi-market system with contracts commissioned by local authorities for adult social care across the charity and private sectors. Care providers are regulated under the Care Quality Commission. **England's experience demonstrates that closing institutions also needs extensive parallel investment in**

17 Alexandra Hamlin, and Peter Oakes, Reflections on Deinstitutionalization in the United Kingdom, 2008

housing, workforce capacity and personalised supports, otherwise this leads to stalled implementation and continued institutionalisation.

1.7.3 Scotland

Scotland has taken a more rights-based and personalised approach, underpinned by Self Directed Support (SDS) legislation and the continued operation of the Independent Living Fund (ILF). These frameworks emphasise autonomy, choice and control, enabling people to design support arrangements that fit their lives. While Scotland has closed most traditional institutions, challenges remain, including inconsistent implementation of SDS, variable local authority practice and shortages of accessible housing. Nonetheless, **Scotland's experience shows that strong legislative rights, personalised budgets and sustained investment in independent living infrastructure can accelerate community inclusion when implemented effectively.** The social care workforce is regulated under Scottish Social Services Council and care providers under the Care Inspectorate.

1.7.4 Wales

Wales's approach is shaped by the Social Services and Well-being (Wales) Act 2014, which embeds rights, voice and co-production within social care. The Act places duties on local authorities to promote wellbeing, prevent institutionalisation and support people to live independently. Wales has made progress in reducing large, congregated settings, but faces similar barriers to Ireland such as housing shortages, workforce pressures and uneven local implementation. The Welsh model highlights the importance of whole system reform and statutory duties that explicitly require community-based support.

1.7.5 Northern Ireland

Northern Ireland operates an integrated health and social care system, which provides opportunities for coordinated planning but also presents challenges. While traditional institutions have largely closed, some people continue to live in hospital-based or campus style environments due to limited community alternatives. The integrated model offers lessons on the benefits of unified commissioning but also illustrates that integration alone does not guarantee personalised, rights-based community living.

1.7.6 Comparative Reflections of United Kingdom countries

Across the United Kingdom countries, several themes emerge. First, deinstitutionalisation requires sustained political commitment, investment in housing and a skilled workforce capable of delivering personalised supports. Second, rights-based legislation (such as Scotland's SDS framework and Wales's wellbeing duties) can drive progress when implemented consistently. Third, England's experience demonstrates the risks of partial reform. Without adequate community infrastructure, institutional models persist even after policy commitments to end them.

Learning for Ireland: The UK experience demonstrates that deinstitutionalisation cannot be achieved through the closure of institutional settings alone. Ireland needs to align its deinstitutionalisation policy with sustained investment in suitable housing, workforce capacity and personalised community supports, while ensuring that new models do not reproduce institutional practices on a smaller scale.



1.7.7 Scandinavian countries

Scandinavian countries, particularly Sweden, Norway, and Denmark are widely regarded as global leaders in deinstitutionalisation for disabled people. Their approach was rooted in the concept of normalisation, developed in the 1950s and 1960s, which asserted that disabled people should have access to ordinary societal norms, including housing, work, and social participation.[18]

Unlike the UK's focus on closing institutions and moving people to different physical premises, **Scandinavian policies emphasised systemic transformation, combining gradual institutional dismantling with robust investment in community infrastructure.** Responsibility for service delivery was decentralised to municipalities, embedded within strong universal welfare states, and underpinned by legislation asserting people's rights rather than services being seen as discretionary. This enabled the development of small-scale housing, extensive home-based support, and innovative mechanisms such as citizen-controlled personal assistance.[19]

Research studies from these countries suggest that former institutional residents generally experienced improved autonomy, social participation, and life satisfaction following deinstitutionalisation, particularly where personalised supports were well resourced and stable. Importantly,

18 Jan Tøssebro, Scandinavian Disability Policy: From Deinstitutionalisation to Non-Discrimination and Beyond, 2016

19 Nordic welfare centre, Personalised Support and Services for Persons with Disabilities – Mapping of Nordic Models, 2021

the Scandinavian model recognised early that housing alone was insufficient; meaningful deinstitutionalisation requires sustained personal support, inclusive public services, and protection against segregation and discrimination.[20]

Nonetheless, recent research cautions against viewing Scandinavian deinstitutionalisation as having reached a successful conclusion. Economic pressures, workforce shortages, and the marketisation of some support services have increasingly challenged the original ethos of normalisation. While large institutions have mostly been phased out, concerns persist regarding social isolation within community settings and the erosion of self-determination through bureaucratic service controls.[21]

Learning for Ireland: The Scandinavian experience suggests that successful deinstitutionalisation requires a broader shift from providing places in services to enabling disabled people to exercise choice and control over where and how they live. For Ireland, this points to the importance of combining housing with personalised supports, inclusive mainstream services and safeguards against isolation or the emergence of new forms of segregation.



1.7.8 Canada

Being a country covering a vast geographic area, Canada represents a more fragmented deinstitutionalisation landscape. Responsibility for disability services rests primarily with provinces and territories, leading to significant variation in policy progress and outcomes. While many large institutions closed between the 1970s and 1990s, residential institutions for people with intellectual and developmental disabilities remain operational in several provinces.[22]

Canadian deinstitutionalisation efforts have often lacked the clear national policy direction evident in Scandinavian countries and the UK. Advocacy by disability organisations, coupled with Canada's ratification of the UNCRPD, has strengthened rights-based arguments for community living. However, implementation has been inconsistent. Community supports are frequently constrained by long waiting lists, housing supply constraints, and underfunded service systems.

20 Jan Tøssebro, and Anders Gustavsson, Deinstitutionalisation and Later Developments in the Lives of Persons with Intellectual Disabilities: Lessons from the Nordic Countries, 2025

21 Ibid.

22 Daniel Dickson, and Megan Linton, A Haunting Legacy: Systemic Ableism in Canadian Housing Policy for People Labelled with Intellectual and Developmental Disabilities, 2025

Research highlights the persistence of reinstitutionalisation through alternative settings that limit autonomy and choice for those who live there. Scholars have characterised this as the product of a 'policy legacy of systemic ableism', where institutional thinking continues to shape housing and support options despite formal commitments to deinstitutionalisation.[23]

Notwithstanding the above, Canada has generated important practice based learning on 'deinstitutionalisation done right', emphasising the leadership of disabled people themselves, family inclusion, and phased, person-centred transitions. These insights demonstrate that where adequate investment and values-based leadership are present, deinstitutionalisation can result in meaningful social inclusion.[24]

Learning for Ireland: Canada illustrates the risk that, in the absence of consistent implementation and adequate community capacity, institutional models can re-emerge in different forms despite formal commitments to deinstitutionalisation. For Ireland, this reinforces the importance of person-centred transition planning, meaningful involvement of disabled people and their families, and scrutiny of the lived experience and outcomes of community living rather than relying solely on the size or designation of a residential setting.

1.7.9 Italy

Italy occupies a distinctive position due to Law 180 (1978), the "Basaglia Law", which mandated the closure of psychiatric hospitals and replaced them with community-based services. Italy is the only country to have completely abolished asylums in a legal sense, completing closures by the late 1990s.[25]

The Italian reform was explicitly rights-based and anti-institutional, reframing care as a matter of citizenship rather than control. The Trieste model, in particular, has been internationally recognised as demonstrating how intensive community services can replace institutional care.[26]

However, subsequent evaluations of service delivery indicate uneven implementation, differences among regions, and under resourcing in some areas, raising concerns about gaps in support for people with complex needs. While Italy's experience challenges assumptions that institutions are necessary, it also highlights the importance of sustained political and financial commitment after legislative change.

23 Ibid.
24 Inclusion Canada, Deinstitutionalization – Done Right, 2021
25 R. Mezzina, Forty Years of the Law 180: The Aspirations of a Great Reform, Its Successes and Continuing Need, 2018
26 Ibid.

Learning for Ireland: Italy demonstrates the value of clear legislative and policy direction in establishing community-based support as the alternative to institutional care but also shows that legislative reform alone is insufficient. For Ireland, deinstitutionalisation therefore requires sustained resourcing and community infrastructure capable of supporting people with complex needs after they leave congregated settings.



1.7.10 Australia

Australia began closing large disability institutions in the 1960s, influenced by international civil rights movements and professional critique of outmoded models of care. By the late twentieth century, most large facilities had closed, and community living became the norm for residential disability services.

However, recent evidence, particularly from the Disability Royal Commission, demonstrates that many modern group home arrangements operate in ways that mirror institutional practices, limiting choice, privacy and safety for people. Scholars and policy analysts increasingly argue that **reducing building size without transforming governance and power relations is insufficient.**

The introduction of the National Disability Insurance Scheme (NDIS) (an individualised funding scheme coupled with a regulatory model for the provision of disability services in Australia) has increased resources allocated to disability care. However, the NDIS has been criticised by advocacy groups who argue that it has drifted away from its original promise of choice and control, with participants facing complex eligibility processes, inadequate funding, plan reductions, lengthy appeals, and unclear decision-making about supports.

Learning for Ireland: Australia provides a particularly important warning that reducing the size of residential settings does not necessarily amount to genuine deinstitutionalisation if institutional routines, restrictions and power structures remain. For Ireland, the quality of deinstitutionalisation should therefore be assessed not only by where and with how many people a person lives, but by whether people experience meaningful choice, privacy, autonomy, safety and control over their daily lives. Learning from Australia's individualised funding experience will be important for Ireland to examine if any move towards personal budgets is progressed.

1.7.11 New Zealand

The experience of reform in New Zealand offers an emerging model that integrates deinstitutionalisation within broader system transformation, rather than treating it as a standalone housing reform. The Enabling Good Lives (EGL) approach, developed by disabled people and families in 2011, calls for self-determination, ordinary life outcomes, and community participation.[27]

EGL shifts authority from service systems to individuals, emphasising flexible funding, community connectors, and mainstream inclusion. Early evaluations from pilot regions demonstrated improved autonomy, social participation, and engagement among disabled people, including Māori and Pacific communities.

While EGL is not solely a deinstitutionalisation policy, it provides a preventive framework against recongregation by embedding choice and control for disabled people at the system level. New Zealand's approach underscores the value of meaningful co-production and culturally grounded models in sustaining decongregated living models.

Learning for Ireland: The experience in New Zealand suggests that deinstitutionalisation may be more sustainable when embedded within wider disability-service reform based on self-determination, flexible supports and co-production. For Ireland, this supports moving beyond a model focused primarily on relocating people and towards one in which disabled people have greater influence over their housing, supports and participation in their communities.

1.7.12 Comparative Reflections and Policy Implications

Comparing the policy development and implementation outcomes described above highlights several critical dimensions of effective deinstitutionalisation that results in a better quality of life for people living in residential disability services. First, ideological framing matters. Scandinavian countries, New Zealand and Italy embedded deinstitutionalisation within broader commitments to equality and genuine inclusion, whereas the UK, Australia and Canada often treated it as a service reform rather than a societal transformation. Second, good governance and funding stability are crucial. **Decentralisation can support local innovation, but only where those local structures and authorities are adequately resourced and held to rights-based standards.**

27 Ministry of Social Development, Enabling Good Lives, 2011

Third, the evidence demonstrates that closure of institutions is necessary but not the end of the story. **Without sustained investment in personalised support, workforce development, inclusive communities and cultural change, deinstitutionalisation risks reproducing institutional practices in another form.**

Finally, all examples underscore the importance of ongoing vigilance: deinstitutionalisation is not a one-off policy achievement but a continuous process requiring monitoring, accountability, and the active leadership of disabled people. Ultimately, all citizens should be empowered to live a life of their choosing.

These comparative lessons are particularly relevant for jurisdictions currently reassessing congregated settings or still in the process of deinstitutionalisation.

They suggest that successful implementation depends less on structural reconfiguration alone and more on the alignment of policy, practice, and values with a clear commitment to human rights and improving the lived experience of disabled people.

1.8 Irish Disability Policy Advocacy: Voices for Structural Change

There is a wide range of organisations that have consistently drawn attention to the need for deinstitutionalisation in Ireland. These include disabled people's organisations, advocacy groups, non-governmental organisations, service provider groups, and State bodies. The following is a brief summary of some of the key organisations and reports that have contributed to the debate on congregated settings in the recent past. (*not intended to be an exhaustive list)

1.8.1 National Advocacy Service (NAS)

NAS is Ireland's independent advocacy service for adults with disabilities. Established in 2011 under the legislative framework of the Comhairle Act 2000 and the Citizens Information Act 2007, NAS is funded and supported by the Citizens Information Board and operates completely independently from disability service providers and funders. Its remit is to provide free, confidential and independent representative advocacy, particularly for disabled people in vulnerable situations who are isolated, living in residential or congregated settings, using day services, who communicate differently, or who lack natural supports. Enquiries may be made by individuals, family members, service providers or other

professionals or agencies, although advocacy is always directed solely by the will and preferences of the person concerned. Operating through four regional teams and a national office, NAS supports people across Ireland and, through its advocacy casework, has developed a substantial evidence base on the experiences, rights, choices and quality of life of disabled people. Several NAS publications have drawn on this casework and advocacy experience to examine the lives of people living in congregated settings and the barriers they face in exercising autonomy, choice and community participation.

While NAS Annual Reports (e.g. 2023, 2024) do not function as policy position papers, they are a key source of system level evidence on deinstitutionalisation drawn from advocacy casework. Across recent reports, NAS repeatedly identifies:

people living in congregated residential services, nursing homes, or inappropriate placements for reasons of disability rather than age or choice;

barriers to moving into the community due to housing shortages, lack of interagency coordination, and insufficient supports;

advocacy work supporting people to express their will and preferences regarding where and how they live.

The 2024 Annual Report explicitly highlights housing and inappropriate accommodation as a recurring issue that arises through their advocacy work and links this to human rights principles of autonomy, citizenship, and participation, implicitly aligning with Article 19 UNCRPD even where the Article is not always named directly.[28]

NAS has made the case for deinstitutionalisation on several occasions at the Disability Matters Oireachtas Committee. The Joint Committee on Disability Matters published its report on *'Planning for Inclusive Communities for persons with disabilities'* on 10th October 2024. The Committee made a series of important recommendations, including that the planning and shaping of inclusive communities requires more action by the State to mobilise an All-of-Government collaboration to establish mechanisms to ensure equal access and truly embed the rights of people with disabilities. The report also included a recommendation which stated, ***'Access to independent advocacy must be increased***

28 National Advocacy Service, *Annual Report 2024*, 2025

so that individuals in inappropriate settings have access to advocacy. National Advocacy Service (NAS) must be adequately funded to access all settings.' At the most recent appearance in April 2026 discussing the 'living arrangement for persons with disabilities', NAS representatives drew attention to the slow progress in the deinstitutionalisation effort and the impact that has on Ireland's duties under the UNCRPD. In addition, the prevalence of those aged under 65 and living in nursing homes was also raised as an example of another form of congregated setting.

The NAS Casebook series is particularly valuable for deinstitutionalisation analysis because it provides anonymised case studies illustrating real-world examples of how institutionalisation and housing exclusion occur in people's lives. While the Casebooks are not framed as deinstitutionalisation policy documents, they demonstrate patterns of institutionalisation and transinstitutionalisation that are highly relevant to Ireland's UNCRPD obligations.[29]

1.8.2 Independent Living Movement Ireland (ILMI)

The ILMI adopts the strongest anti-institutional stance in the Irish disability landscape, rejecting congregated settings as a form of segregation, exclusion and control. As a Disabled Persons' Organisation, its perspective is directed by disabled people themselves and emphasises choice, personal assistance, and control over living arrangements as non-negotiable rights.

ILMI argues that replacing congregated settings with smaller community group homes is insufficient if control remains with service providers and funders rather than individuals in the form of personal budgets. Its advocacy draws directly on UNCRPD principles, criticising Ireland for structural non-compliance and over-reliance on residential service models.

1.8.3 Inclusion Ireland

Inclusion Ireland takes a clear rights-based position that congregated settings should be fully closed, arguing they are incompatible with dignity, autonomy, and Article 19 of the UNCRPD. It consistently frames congregated settings as a human rights violation, rather than a neutral service model, highlighting poor outcomes, lack of choice, and segregation from ordinary community life.

29 National Advocacy Service, *Casebook 2023*, 2024

Key publications and advocacy include sustained campaigning around *Time to Move on from Congregated Settings (2011)* and subsequent critiques of slow implementation, alongside references to the *Wasted Lives*[30] report and its own document on housing: *Housing for people with intellectual disabilities – The lack of support for independent living.*[31] Inclusion Ireland is a leading voice within the Oireachtas Disability Group, regularly highlighting that thousands of people remain in inappropriate congregated and institutional placements.

1.8.4 Disability Federation of Ireland (DFI)

DFI supports the policy objective of ending congregated settings, while placing strong emphasis on system readiness, resourcing, and governance. Representing service provider organisations as well as advocacy bodies, DFI's position is that deinstitutionalisation must occur, but must be planned, adequately funded, and paced in a timely manner to avoid crisis-driven or unsafe transitions.

Through the **Oireachtas Disability Group**[32], DFI has highlighted persistent underinvestment, missed targets, and over-reliance on emergency placements. It consistently calls for implementation of *Time to Move on*, arguing that failure to close congregated settings represents a broken care system rather than resistance to reform.

1.8.5 National Disability Authority (NDA)

The NDA is a statutory advisory body rather than an independent advocacy organisation. Nevertheless, it has provided strong evidence-based support for deinstitutionalisation. **It frames congregated settings as associated with poorer social, personal, and quality-of-life outcomes, while also recognising the complexity of transition and the bottlenecks caused by national housing shortages.** The NDA has published several key documents outlining the evidence base in support of deinstitutionalisation, in the context of both quality-of-life improvements for people and cost.

NDA publications support the deinstitutionalisation effort and document positive post-transition outcomes for people, focusing on good practice, cost implications, and change management. The NDA's stance is that

30 Office of the Ombudsman, *Wasted Lives: Time for a Better Future for Younger People in Nursing Homes,* 2024

31 Inclusion Ireland, *Housing for People with Intellectual Disabilities – the Lack of Support for Independent Living,* 2019

32 The Oireachtas Disability Group is a coalition of national disability organisations that was formed in 2017 to advocate collectively on disability policy and funding priorities with members of the Oireachtas.

congregated settings should end as a matter of public policy, subject to careful planning and strong safeguarding.

One NDA publication worthy of specific mention in the context of deinstitutionalisation is the *Outcomes for Disability Services framework*.[33] The framework reflects a shift from measuring service inputs and activities towards assessing the real-life outcomes experienced by disabled people. It identifies nine key outcome domains that are considered essential to a good quality of life: living in one's own home in the community; exercising choice and control in everyday life; participating in social and civic life; having meaningful personal relationships; accessing opportunities for personal development and fulfilment of aspirations; having a job or other valued social role; enjoying a good quality of life and wellbeing; achieving the best possible health; and being safe, secure and free from abuse.

NDA Publication: Outcomes for Disability Services framework
The framework aligns with Ireland's broader policy objective of delivering person-centred, rights-based supports and provides a useful lens through which the impact of disability services can be assessed.

1.8.6 Irish Human Rights and Equality Commission (IHREC)

IHREC has played a significant role in framing deinstitutionalisation as a human rights obligation rather than solely a service-reform objective. Since Ireland's ratification of the UNCRPD, IHREC has been the State's designated independent monitoring mechanism for implementation of the Convention and has consistently highlighted concerns regarding the continued use of institutional and congregated models of residential care for disabled people.

In its submissions to international monitoring bodies and its work on UNCRPD implementation, IHREC has repeatedly drawn attention to Article 19 of the Convention, which recognises the right of persons with disabilities to live independently and be included in the community. IHREC has argued that the continued existence of congregated settings, alongside barriers to accessing housing and personalised supports, limits the realisation of these rights in Ireland. Its reporting emphasises the need for a rights-based approach to disability policy, including access to community living options, individualised supports, participation in decision-making, and safeguards against institutionalisation and transinstitutionalisation.

33 Authority National Disability, Outcomes for Disability Services, National Disability Authority, 2016

1.8.7 Office of the Ombudsman

The Office of the Ombudsman is an independent statutory body that investigates complaints about public services and public bodies in Ireland. Through investigations and systemic reports, the Office has highlighted issues relating to disability services, healthcare, housing and access to community supports. In 2021, the Ombudsman published the landmark report *Wasted Lives: Time for a Better Future for Younger People in Nursing Homes*.[34] The report examined the experiences of people under 65 who were living in nursing homes for older people because appropriate community supports were unavailable. It found many individuals were effectively institutionalised despite wishing to live independently in the community and concluded that Ireland needed to move further from a medical model of disability towards a rights-based, person-centred approach consistent with the UN Convention on the Rights of Persons with Disabilities (UNCRPD).

The report has become a significant reference point in discussions about deinstitutionalisation, independent living and disability policy in Ireland. It highlighted how **gaps in housing, personal assistance and community supports can limit people's choice and autonomy, resulting in lives being constrained by systems rather than shaped by individual preferences and aspirations.**

1.8.8 Health Information and Quality Authority (HIQA)

HIQA is the independent regulatory agency for health and social care services in Ireland. It commenced regulation of residential disability services in 2013. HIQA does not have an explicit advocacy role but has drawn attention to congregated settings as representing an outdated model of care for disabled people.[35]

HIQA inspection reports have repeatedly identified systemic risks in congregated settings, including institutional practices, restrictive routines, and limited personal autonomy. While neutral in tone, its findings have indirectly reinforced the case for deinstitutionalisation by evidencing persistent structural deficits in these services.

1.8.9 Genio

Genio has played an important role in advancing deinstitutionalisation and community inclusion in Ireland. It has worked with the HSE and

34 Office of the Ombudsman, Wasted Lives: Time for a Better Future for Younger People in Nursing Homes, 2024

35 Health Information and Quality Authority, 10 Years of Regulating Designated Centres for People with Disabilities, 2024

disability organisations to support the transition of people from congregated settings into community-based living. Genio has promoted person-centred and self-directed supports, emphasising choice, autonomy and participation in community life, across a small number of funded projects. Through research, funding and service innovation, it has provided evidence of how community living can be implemented in practice. Its role is therefore significant in linking disability policy with practical service reform and demonstrating alternatives to institutional care.

1.8.10 The ÁT Network (Áiseanna Tachaíochta)

The ÁT Network has contributed to disability policy advocacy in Ireland by promoting independent living, personal assistance and self-directed supports for disabled people. Its work challenges traditional institutional and service-led models by emphasising that disabled people should have choice and control over where and how they live. The ÁT Network therefore supports the wider deinstitutionalisation agenda by advocating for community-based living, autonomy and meaningful participation in society. The ÁT Network is the first and main organisation to facilitate direct payments to disabled people in Ireland.

1.9 Summary

As shown in this chapter, congregated settings have long been a feature of Ireland's disability services system, particularly for adults with intellectual disability and complex support needs. Historically reinforced by block funded services and a medicalised model of care, these settings have resulted in many people spending much of their adult lives in institutional settings, with limited choice and autonomy. Although subject to inspection by HIQA, **reports have repeatedly identified systemic issues such as restricted choice, institutional practices, safeguarding risks, and weak governance, underscoring the limitations of congregated settings as an appropriate residential model of care and their inability to consistently support people to exercise control over their daily lives, relationships, routines, and future aspirations.**

Irish policy has increasingly recognised that congregated settings are incompatible with contemporary understandings of quality of life and rights, most notably through the 2011 *Time to Move on from Congregated Settings* strategy, which committed the State to supporting people to move into dispersed housing with individualised supports. However, **the strategy was never placed on a statutory footing, successive targets have been missed, and progress has been uneven**

across regions and providers. Despite disability strategies endorsing community living in principle, deinstitutionalisation has remained one priority among many, lacking binding targets or enforcement mechanisms. As a result, a substantial proportion of people in residential care continue to live in congregated settings. This is despite the fact that there is broad agreement they should be phased out. **Importantly, the objective of deinstitutionalisation is not simply relocation from one building to another, but the creation of the conditions that allow disabled people to live meaningful and self-directed lives, with the same opportunities for belonging, participation, relationships, and personal development as other citizens.**

Ireland's ratification of the UNCRPD in 2018 fundamentally reframes deinstitutionalisation as a legally binding human rights obligation rather than some kind of aspirational service reform. Article 19 establishes a clear duty on the State to end institutionalisation, ensure real choice about where and with whom people live, and provide the supports necessary for community inclusion. In the Irish context, housing has emerged as a central structural barrier to deinstitutionalisation, with shortages of accessible and affordable homes and limited supports meaning that institutional and transinstitutional living arrangements persist. While reforms such as the Assisted Decision Making (Capacity) Act 2015 strengthen individuals' rights to participate in decisions about their lives, they cannot compensate for the absence of viable housing options in the community. **Equally, rights cannot be fully realised where people lack access to the personalised supports needed to pursue their own goals, maintain relationships, participate in community life, and make everyday choices about how they wish to live.**

Comparative international experience demonstrates that successful deinstitutionalisation is possible. This is contingent not only on closing institutions but on sustained investment in housing, personalised supports, governance, and cultural change; without this, institutional practices are often reproduced in smaller settings. **International evidence also suggests that positive outcomes are most likely when supports are organised around the preferences, strengths, and ambitions of the individual, rather than around service convenience or organisational structures.** In Ireland, a broad coalition of advocacy organisations, statutory bodies, and regulators have consistently highlighted the moral, practical, and legal imperative to end congregated living for disabled people. Together, their analyses show that the challenge facing Ireland is no longer one of policy intent or conceptual clarity, but of translating established rights-based commitments into action that enables disabled people to live ordinary lives, in ordinary homes, included as full members of their communities **and supported to pursue lives of their own choosing, on an equal basis with others.**

Case Study:

Lived experience example
Stephen

Context

Stephen lived in an institution for people with intellectual disabilities since he was a young man, in a house on a campus setting with six others. Now, of pension age, Stephen spent much of his time alone and went for his meals to the large dining hall, near his home. Stephen was told by some staff that a deinstitutionalisation process would commence, and he would have to leave his home and move elsewhere. Other staff indicated to Stephen that he could remain in the institution. Stephen stated from the outset that he did not want to leave his home and he appeared withdrawn and worried in his early engagement with the NAS Advocate. Stephen, for a long period, appeared unable to articulate his worries and concerns about moving to the community and chose not to engage with staff or supporters in their efforts to implement transition planning recommendations.

Actions by Advocate

Over a long period of time working with Stephen, NAS Advocates supported him to seek clarity and honesty from the service provider in their engagement with him. Advocates challenged the poor practice of the service and raised concerns in relation to the inadequate response to Stephen's complex needs.

Outcome

Stephen went on to grow in confidence and began to state clearly and unequivocally his needs, wishes and queries about the move to a new home. Stephen began to self-advocate and initiate conversations about his worries with questions that were responded to by staff with person-centred understanding and empathy for the person in their situation. Advocates regularly supported Stephen to seek updates and pose questions to senior decision makers in writing, with responses received.

After a number of years, Stephen moved to his new home with two other people. His home is modern, warm and comfortable, and he now engages in home and community life at his own pace and by his own choosing. Stephen has told the Advocate how much better this has made his life.



2. Lived Experience, Will and Preference, and the Role of Independent Advocacy

This chapter tells the experiences of people living in congregated settings, as relayed through NAS Advocates and other key stakeholders. It examines how congregated living affects people's autonomy, privacy, dignity, safety, communication, daily routines and access to community life. It also sets out examples of the changes people experience when they move from congregated settings into smaller homes in the community with appropriate supports.

Lived experience is an essential form of evidence in rights-based policy analysis. It provides insight into how rights are experienced and realised in practice, rather than solely how they are articulated in policy, legislation or service standards. The perspectives of people directly affected by policies and services can reveal barriers, inequalities and unintended consequences that may not be apparent from administrative, quantitative or institutional evidence alone. Incorporating lived experience therefore strengthens the evidence base by helping to identify the gap between formal rights and people's everyday experiences, while also reflecting the rights-based principles of participation, inclusion and giving people a meaningful voice in decisions that affect their lives. Most importantly, it places the voice of the person front and centre, which is a key driver for NAS producing this paper on congregated settings.

2.1 The Lived Experience of Congregated Settings

Through both its policy work and individual advocacy work, NAS has engaged with and supported many disabled people who needed support while living in congregated settings. Advocates have visited these centres, spent time with people, observed the care provided, spoken to family and close friends and spoken with staff and management. NAS has also supported several large-scale closures and transitions from congregated settings over the past number of years, to ensure that people had access to independent advocacy.

The previously detailed volume of NAS advocacy work on issues relating to housing and living arrangements, residential settings and, more specifically, deinstitutionalisation provides an indication of the breadth of knowledge of NAS and its Advocates.

As such, in this chapter you will read descriptions and observations from people that have worked with people living in congregated settings and other key national stakeholders. The excerpts and examples throughout were gathered in 2026 for the purposes of this paper.

2.1.1 The physical environment

One of the most common observations from Advocates and other contributors to this paper is the institutional nature of the premises and the general physical environment of congregated settings. Many are located in places that are somewhat removed or separate from the local community. The buildings are often dated, sterile and not homely. For some people, they have lived there most of their lives and that can be a sobering thought:

"Geraldine is a middle-aged woman who has an intellectual disability. She had lived, since the age of 4, in a large campus-based institution that was highly institutional in nature. The building itself was multistorey, old, imposing, and stark, with long corridors, high windows and large dormitory style sleeping areas and communal spaces. There was also a centralised kitchen, so despite it being Geraldine's home, it bore little resemblance to what most of us would recognise as a home. There was a marked absence of the usual characteristics that create a home and very few items of a personal nature. It lacked any sense of cosiness, warmth, familiarity, or individuality typically associated with living in a home in the community."

Excerpt from lived experience example - Geraldine

The atmosphere in these settings is often clinical in nature and the odours are more what you would expect to find in a hospital as opposed to someone's home. The design of the congregated settings also means that people's autonomy, choice and dignity is compromised, as described in the following:

"I remember being really taken aback that people lived in bungalows on the campus. There are probably 20 bungalows. Some of them would have 10 people living in them still to this day. The food was made centrally in a big, old-fashioned building, a big kitchen. And even though each house had their own kitchen, it was never used and it was often locked because it was seen as a risk maybe if someone went in, they could be at risk of burning themselves or something. So, the kitchen was for decorative purposes. And then you would have the chicken on the Monday, the ham and the cabbage on the Tuesday,"

NAS Advocate

"Some of the settings are different to others and better than others and some are stark…When I describe the environment that people are living in, it's mostly their bedrooms, I suppose, tend to be personalised. But outside of that…it's all very system-centred and institutional in feel. So, for example one bungalow in that particular setting, there's nothing soft, there are no cushions, there are no blankets, in the main living room there's just a fireplace and there's a TV that has a bracketed protector around it and nothing else except a sofa and a chair and the linoleum floors. So that is very stark. People don't have access to it as an ordinary home. For example, they don't use the kitchen or other rooms and some rooms are locked. It would be very medicalised. Some of these places are very clean but they're very clinical and not homely at all."

Marge Lysaght – Social Health Education Project, Cork

The examples above clearly show that congregated settings were designed according to a medical rather than a social model of care. Disabled people were seen as ill and needing to be "looked after" or "cared for", rather than empowered to live their lives in a way of their own choosing. The description of a centralised kitchen that serves food according to a routine menu is what one might expect to encounter in a hospital setting. It also means that people living in these centres have no opportunity to use their own kitchen to prepare their own meals or snacks, something which most would take for granted as part of everyday normal life.

Case Study:

Lived experience example
Tom

Context

A NAS Advocate became involved in supporting Tom, who lived most of his life in a congregated setting, where care planning was predominantly focused on clinical needs rather than the person's quality of life, personal goals, or community participation. Annual reviews were led by staff and centred on clinical opinions; the person was often excluded from meetings or not consulted about decisions affecting him. Information was not shared with Tom, his Advocate or family in advance of meetings, limiting meaningful participation. The service demonstrated resistance to advocacy, frequently involving the Advocate only when situations had reached crisis point and expecting the Advocate to provide solutions rather than working collaboratively.

Actions by Advocate

The Advocate consistently raised concerns about Tom's rights, quality of life, and participation in decision-making. They challenged the service's medically-focused approach and highlighted the importance of understanding his wishes, particularly where fear or anxiety was influencing decisions, rather than interpreting this as non-compliance. The Advocate sought access to relevant information before review meetings, promoted person-centred planning, and questioned whether the goals identified by professionals reflected Tom's own aspirations. They also challenged attitudes that undermined supported decision-making and reminded the service of its responsibility to respect his will and preferences.



Outcome

Advocacy prompted greater recognition of the need for person-centred practice and rights-based decision-making. Although resistance from the service remained, advocacy ensured Tom's views were represented, highlighted systemic barriers to participation, and encouraged professionals to recognise that organisational goals should not replace Tom's own wishes and preferences.

The number and skill mix of staff in congregated settings also presents challenges for providing a good quality of life. NAS Advocates regularly engage with staff working in congregated settings. Indeed, many of the enquiries to provide advocacy to someone in a congregated setting come from the staff working in the service. Clearly, there are many conscientious staff working in these settings that strive to provide the best care possible. However, they are often limited in doing so due to the institutional nature of the care practices and settings:

"There are staff that see the practices as not being the best and yet they're, kind of, stuck and that's their job. They're working there, but they have to manage it, I suppose, and do their best by the people who are there, you know? And there's some people, maybe, see this as like, "oh yeah, people with disabilities need to be minded and this is my job."

NAS Advocate

"It's about the capacity for staff to give individual attention. People don't get enough individual attention often, and that's the whole nub of it. And it's about having somebody dedicated who can be with them, identify their needs, identify their communication style and make sure that nothing is missed. It's having dedicated one-to-one personal staff who actually have the time and are trained in knowing what the background of the person is and translating that to the person-centred plan."

NAS Advocate

"There's one person who does not communicate with words and their key worker…when you witness how she works with that particular person, he's very engaged, seems very relaxed. And she explained to us, well, 'yeah, we don't have any pictures'. But told us that she pulls out her phone to explain things and gets pictures herself. So, it's very dependent on individual staff who decide they're going to make that effort, rather than an organised system of supporting communication."

Marge Lysaght – Social Health Education Project, Cork

As shown in the examples above, some staff strive to do their best with whatever limited time and resources they have available to them. However, there are still centres where the culture is very paternalistic and where staff see their role primarily as caregivers under a medical model:

"The work of staff was observed to be more task-centred and not person-centred. So, staff genuinely seem to see their role as making sure people are washed, cleaned, fed, and that's it. So, there's a very limited amount of engagement outside of this observed. What we actually see when we observe is that staff are often separate. They're often in the kitchen while people are in common living areas…staff are generally not observed engaging in activities with people they support. They don't seem to think it's their role because the staff makeup and the skill set…it's nursing staff, it's healthcare assistants for people with intellectual disabilities. These are completely different jobs to social care work and they're not hiring social care workers where a key part of their role would be making sure people have meaningful occupation and their quality of life from the social side is more supported."

Marge Lysaght – Social Health Education Project, Cork

Clearly, an attitude persists in some services where the old model of institutional care is still viewed as the most appropriate way to care for disabled people. This is despite policy and regulatory prescriptions and the voices of those who have decongregated themselves advocating for a more person-centred approach to care.

The physical environment can also impact on how neurodivergent people experience care settings:

"The physical environment is actively harmful in ways which are not understood or recognised. I'm particularly thinking about neurodivergent people with different sensory processing needs which are highly misunderstood. I'm talking mostly about autistic, ADHD, dyslexic, dyspraxic, dysgraphic people…there's a lack of understanding that sensory bombardment or other things can cause physical pain."

Nem Kearns – Disabled Women Ireland



Public Sector Duty and Person-Centred Practice

The Public Sector Duty requires services to consider whether organisational systems, staffing models and service cultures promote equality and human rights. Care that is primarily task-focused rather than person-centred risks limiting people's autonomy, participation and opportunity for self-determination.

2.1.2 Protection from abuse

Another common issue found in congregated settings relates to abuse. There are often concerns for people who feel afraid in their homes due to the behaviours exhibited by others that impact them. This is often the case in congregated settings due to the large numbers of people and the interpersonal difficulties that can arise through living with people where compatibility gets little consideration or input from those directly affected.

"One person started vocalising and physically lashing out and cleared the entire room… staff report that the people in this centre are living in fear of that person and are walking on eggshells around the person. Some people are even being physically lashed out at. And that is a form - even though it's not recognised under legislation - of domestic abuse: threats or living in fear of violence and intimidation. We do come across situations where there is abuse or what the service staff might call "safeguarding" between people living together. It's a constant theme in these settings".

Marge Lysaght – Social Health Education Project, Cork

The response in these scenarios is often to remove people from the scene until the risk has reduced. However, the net effect of this is that people do not feel safe in their homes or are curtailed in having full access to their own homes. Consequently, some people are reluctant to spend time in communal areas and prefer to stay in their bedrooms.

"There was an older gentleman who was living with a house-mate. The emotional abuse he'd been experiencing from his house-mate had been going on several years. And as the person got older, the staff had accepted a situation of ongoing conflict for years. This gentleman got older, became more fragile, physically, emotionally, in all kinds of ways. And whenever he'd come down the hall, another person would scream at him in the morning: "f* off". He would just take himself back to his room. And as far as the staff were concerned, "he likes to go to his room whenever she does that". That was the actual plan to manage the situation."**

NAS Advocate

This older man had a routine of going to his bedroom whenever he felt threatened by another person. In effect, this is a form of reverse seclusion where the person has no option but to remove themselves from a situation and wait until they feel safe enough to come out.

It is extremely important to remember that the people exhibiting behaviours (such as shouting, hitting or bullying) are often not to blame for their actions. In the majority of cases, people are not aware of their actions and do not understand the impact of their behaviour on others and have not had any say in with whom they would wish to live. Moreover, they are often trying to communicate an unmet need. Indeed, an underlying cause of these behaviours is often the living conditions in congregated settings:

Lorcan lives in a congregated setting that can be challenging at times due to the diverse needs of the people who live there. In recent years, he has experienced an increase in behaviours that may suggest a need to communicate underlying emotional or mental health difficulties. Initially, it was thought that these changes may have been associated with the arrival of another person who had moved to the unit on an emergency basis. Although that person later moved on, Lorcan continued to experience difficulties. Those who know him well and support him on a daily basis feel that the cumulative impact of spending many years in the same congregated environment may have affected his wellbeing and quality of life.

Excerpt from lived experience example – Lorcan

Evidently, in such circumstances, while the victims of abusive behaviour need support and protection, the exhibitors of these behaviours are themselves often subject to conditions that also make them victims in their own right.

Ireland is not alone with respect to violence against disabled people. A 2025 report[36] by European Union Agency for Fundamental Rights found "widespread" and "staggering" examples of violence in institutions where disabled people live.

2.1.3 Activities and occupation

People living in congregated settings, and their Advocates, often speak about the lack of meaningful and stimulating activities. When large numbers of people live together it is simply not possible to support every person to live in the unique ways that they would prefer to. Moreover, the low levels of staffing relative to the number of people means the opportunity to be part of their community is limited:

36 Rights European Union Agency for Fundamental, Places of Care = Places of Safety?: Violence against Persons with Disabilities in Institutions, Publications Office of the European Union, 2025

"In one location people are always sitting around all day. And when you look at their activities record… it's literally sitting on the couch - recorded as "spend time chilling out on the couch with their peers'. We know that sometimes they get in a van, they drive a couple of miles down the road, go around a roundabout and they come back into the house. That's considered 'getting out and about'. They don't even leave the vehicle. Staff working here also said, 'we try to get out every second or third day, but that doesn't always happen because there are staff shortages.'

In a different location, what we've observed in over four months. We were there for over 40 hours and if I look at the stats from our observations, there were only a few occasions observed where people were gone out and about. So observed outings were very, very limited."

Marge Lysaght – Social Health Education Project, Cork

"There was a group of older ladies living in a campus setting and the provider had a reducing staff roster. So, during the day, it had a full staff complement. And as the day went on, the rosters, the number of staff in the centre reduced and then out of hours and weekends and public holidays and Sundays, there was a skeleton staff, which meant that people never got out. None of them had a bus pass, for example, to use public transport."

Regional Manager – Health Information and Quality Authority

As shown in the examples above, the number and type of activities available in congregated settings is often limited. People do not have the freedom to spend time as they wish or to take part in meaningful activities in their communities. This can have a knock-on effect on the physical and mental health of the people living in these centres. A further problem is found in the lack of hobbies or pastimes that people can choose for themselves. For example, it may be the case that there is only one mode of transport available and only enough staff to support people leaving the centre in a group rather than individually. Inevitably, there are situations where people are going on activities that are likely not of their choosing:

"If you live in a congregated setting, there may be seven or eight people living there, even four people living there, you might have one staff who works overnight, a couple of staff working during the day. Some people go to day services. That's the normal kind of typical pattern, you know? But if you as an individual in the evening want to do something, you don't drive, you've limited access to transport and you need support to access the community.
And there's only one staff available at night. And there's four, five, six, and seven people living there. You can be damn sure everybody's doing the same thing. Everybody's going to the cinema together. Everybody's going to go bowling together because it suits the system. That is the only way that we can support you is to support you in a group. So, your individual desires, needs, ambitions, dreams, how can they ever be realised if you don't have that personalized support to help you to do the things and explore the things that you want to explore?"

Derval McDonagh – Inclusion Ireland

While many people in congregated settings attend a day service outside of their home, this is not the case for all. While there are no published statistics available on the number of people living in a congregated setting that attend day services, contributors to this social policy paper estimate that approximately half remain at home and do not attend a day service. This is especially the case for people who are older and perhaps do not wish to participate in the activities that are made available in day services.

"So, what are the other people living in congregated settings who are not going to a day service doing? Now, some of them might be retired…they've gotten older, they don't want to go anymore, and that's fine, that's their choice. But I wonder: are there people who are in congregated settings without a day service who could benefit from one, but maybe there's none available or they're not a priority or something? And particularly when it's not that easy to get into a day service unless you get in through the school leaving process. There's limited funding there for other people to get in."

Dr. Rosalyn Tamming – National Disability Authority

It is important to note that not all people wish to participate in day services. They may prefer to be outdoors or to spend time alone. As such, while day services can be an important part of someone's day, they do not suit all needs all of the time.

2.1.4 Communication

People living in congregated settings often communicate in multiple different ways. While some can communicate their needs verbally, other people communicate through different means such as signing, gestures, noises and facial expressions. Therefore, it is vital that staff in congregated settings are familiar with people's communication needs. Unfortunately, this is not always the case:

"In one location, there are more than 25 people living there, I'd say 5 or 6 communicate with words, but their communication with words may be limited. They have no speech and language therapy support… And when you ask about this and communication supports, the attitude seems to be 'why would they need that?' How can you have choice or expression of will and preferences when people can't communicate it or nobody's allowing that to happen? And there are people there that could benefit from all that support."

Marge Lysaght – Social Health Education Project, Cork

While some staff efforts to communicate with people are well intentioned, they sometimes fail to meet the needs of those very people, as shown in the example below:

"You would see the daily activity written up on the board. On one occasion, it was all coloured in, with bubble writing and beautiful. It was 'yoga in the morning at 10am', or whatever. And I asked staff the question 'well, I know that people don't communicate with words here. And I don't think they read? …would you put up a picture of somebody doing yoga instead? And they looked at me and said, 'we never thought of that'. There's a complete lack of support there for aiding communication… the staff aren't receiving support or training either, to be fair to them."

Marge Lysaght – Social Health Education Project, Cork

The different methods of communication used by people in congregated settings can also lead to differences in the choices available to them. Sometimes, when individuals can communicate verbally, their views are prioritised over others. This was the case in the example below where people who could verbally communicate their will and preferences were effectively being prioritised over those that could not:

"People with better verbal communication, and those with families to advocate for their decongregation [deinstitutionalisation], they would have been the first groups to move with the *Time to Move On* strategy. They would have been prioritised, I suppose, to move out first".

NAS Advocate

Whether intentional or not, those who communicate differently were lower down the priority list for deinstitutionalisation, simply because they could not self-advocate and make their own case to move out into smaller homes in the community. In a further example of the sometimes-paternalistic nature of the care provided in congregated settings, people are not being communicated with in terms of vital information about their families:

"A staff member had been talking to me about a person, their father had died a couple of months previous. And I said, 'well, how was this person responding to that?' And they just said, 'oh, well, he doesn't know…he'll find out next time he goes home.' It was shocking to me, especially because they told me that this person understands everything you say. He doesn't communicate verbally, but he fully understands everything that's told to him. And he does engage in other ways. He'll give you eye contact and he'll touch you and he'll pull you along and guide you to places. So, it was just really sad that this staff member thought that was just okay."

NAS Advocate

2.1.5 Privacy and dignity

Living with large numbers in congregated settings means that a person's privacy and dignity can be compromised:

"The people who we have met…There is a communal bathroom where a person has to be wheeled down a hallway where they will have to be naked to be wheeled down to the shower or to the bathroom."

NAS Advocate

"The walls would be quite bare. There would be a lot of documents and things on the walls relating to fire, compliance, all of that kind of thing. And very little like lamps, rugs, anything that makes a home feel like a home would be missing in those environments."

NAS Advocate

There are some people that exhibit presentations that can compromise both their own, and other peoples' privacy and dignity:

"A person might be stripping off their clothes and they're walking around the house undressed…and other people living there are seeing this, you know? This would be another thing that's quite common in another campus I'm on."

NAS Advocate

There are also occasions where people's dignity is compromised due to the practices or culture within congregated settings. This is especially the case where staff adopt a medical model of care or where there are staff shortages that result in poor practice:

"We've heard numerous times that people who would be incontinent at night, depending on where they go, they're told they need to put on pads because it's easier for the staff. So that takes away their dignity and their respect."

Shelly Gaynor – Independent Living Movement Ireland

"That gentleman I'm talking about…I was asking about, he wears a 'nappy' for want of a better word, which is kind of shocking because this is a young man that would make his own bed. He likes to help with the cooking, and he will help with the cleaning. But I was asking, 'what's going on? Why is he wearing an incontinence pad?' And the staff just said, 'oh, well, he always has.'"

NAS Advocate

When living in congregated settings, people are often seen as a homogeneous group as opposed to individuals that have their own personalities, preferences, interests and pastimes. This means that activities are planned to meet the needs of the group rather than each individual. This compromised people's dignity as they are not afforded the opportunity to express and exercise their individual will and preferences.

Privacy, Dignity and Equality

Respect for privacy and dignity is a core human rights obligation. Public bodies and publicly funded services should continually assess whether practices, environments and routines uphold a person's dignity and promote their right to be treated as an equal citizen. Moreover, decisions made in this respect should be based on the evidence of lived experience in line with current guidance on the implementation of the Public Sector Equality and Human Rights Duty.

2.1.6 De-facto congregated settings in Ireland and their impact on people

As noted earlier, the *Time to Move On* policy defines congregated settings for disabled people as "living arrangements where ten or more people share a single living unit or where the living arrangements are campus-based". Nursing homes are generally excluded from this definition because they primarily provide care to older people and to people who need full-time care due to frailty or cognitive conditions such as dementia. However, Ireland now has a significant population of younger disabled people living in nursing homes rather than in community-based or age-appropriate supports.

The most recent available data (July 2025) shows there were over 1,200 people under the age of 65 living in nursing homes.

The Office of the Ombudsman drew attention to this cohort of the population in the 2021 publication entitled *'Wasted Lives'*.[37] The report described how people under 65 were experiencing a de-facto congregated setting due to being inappropriately placed in nursing homes that typically care for older people. One of the reasons underpinning these placements is the funding model, which favours full-time residential care over other models such as home care or assisted living. This means that for young people that experience a traumatic event such as a brain injury or stroke, the configuration of state funding sometimes leads them to live in a nursing home, even though this may be contrary to their will and preferences. Further, the Ombudsman's report found that quality of life for young people in nursing homes was poor because the service is set up to meet the needs of an older population. For example, social activities in nursing homes are focused on meeting the needs of older people and are often, therefore, not age appropriate for those under 65:

37 Office of the Ombudsman, Wasted Lives: Time for a Better Future for Younger People in Nursing Homes, 2024

Adam is a 51-year-old man who acquired a brain injury after a fall at home 6 years ago. He was admitted to a nursing home from hospital, and he spent almost 5 years there before returning home. Whilst in the nursing home Adam had 6 hours of rehabilitative assistance (RA) support per week, and his RA brought him out of the nursing home. However, he said that apart from this, he did not leave the nursing home. He said that there were not many activities in the nursing home as many of the people living there had dementia and were not able to engage in them.[38]

In 2025, NAS supported 108 people who were under 65 and living in a nursing home, while 104 such people were supported in 2024. NAS Advocates working with younger people living in nursing homes have observed practices and quality-of-life issues that are broadly reflective of congregated settings. David's case, described on the following page, is typical of the difficulties faced by younger people who are inappropriately placed in nursing homes:

38 Ibid.

Case Study:

Lived experience example
David

David is in his mid-fifties and currently lives in a nursing home. David previously lived at home with his elderly parent. He uses a wheelchair and has an autoimmune disease. On engaging with a NAS Advocate, David expressed his will and preference to leave the nursing home, as his quality of life was decreasing, and his mental health was rapidly deteriorating. David referred to the profile of people he was living with being significantly older than him, the noise made outside of his room regularly and expressed his frustrations regarding staff members coming into his room unexpectedly.

David expressed how he is a social person who enjoys attending events and shows, and this is no longer a simple process as arrangements regarding transport must be made in advance with staff in the nursing home. David also mentioned that he feels his physical health was negatively impacted by his lack of day-to-day movement. David also revealed that some relationships he had developed with other people in the nursing home who have subsequently passed away has left him feeling isolated. He described that the stress and sadness this is placing on him is leading to a sense of hopelessness. David's experience illustrates the impact of being inappropriately placed in a setting that is not suitable for his age has had on him. His physical health deteriorated due to the lack of stimulation and movement. His mental health was also affected by the environment of the nursing home, which was often noisy and where he could not access transport easily. David also felt his privacy was compromised due to nursing home staff entering his room unannounced. This led to David experiencing a low quality of life in the nursing home and expressing a strong desire to live somewhere else.

While David's story is distressing, he was capable of verbal communication with the NAS Advocate and could explain what he wanted to change about his life. This is an added barrier for people who communicate differently. This was the case for Jason who lived in a nursing home and communicated using hand gestures and verbal expressions:



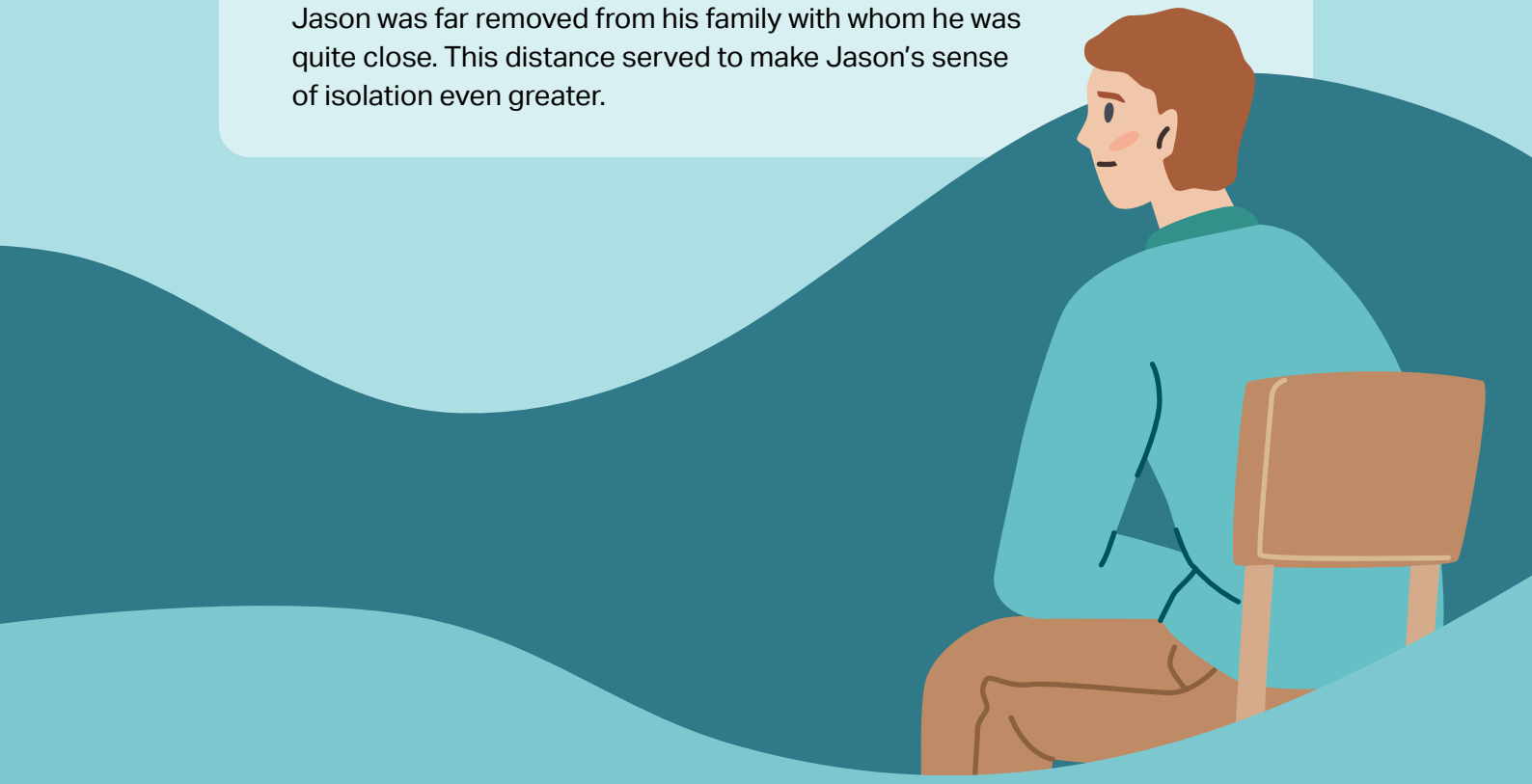
Case Study:

Lived experience example
Jason

Jason is 35. He had an acquired brain injury and was moved into a nursing home in 2015. The nursing home was approximately 125 km from his family home. Jason was quite close to his mother, but she found it difficult to visit him on a regular basis. Jason also had a 14-year-old daughter. Jason's mother supported him to contact NAS, reporting that Jason wanted to leave the nursing home. Jason could speak but struggles to do so and mostly chooses to communicate using a thumbs up to indicate he agrees with something. Jason also communicates through a lot of verbal expressions such as looking happy (smiling) or looking unhappy (more serious face).

Jason was given very limited choices in the nursing home of what he would like to do from day to day, when he would eat, when he would like to get up, where he would go. Jason chose mostly to disengage from any planned activities in the nursing home.

Jason's experience above demonstrates how a large setting such as a nursing home, that provides a specific model of care for older people, is not an appropriate setting for a young person. His means of communication was not supported and there was not much choice available to Jason in terms of how he spent his day. In addition, Jason was far removed from his family with whom he was quite close. This distance served to make Jason's sense of isolation even greater.



A further point of interest highlighted by some contributors to this social policy paper was another setting that represents a more subtle form of congregated setting: **day services**. **Many disabled people that live in congregated settings also attend a day service.** This is typically a service provided in daytime hours where people can undertake specific activities, often arranged or operated by the same service provider that runs the congregated setting. Day services are intended to provide an outlet for people to leave their accommodation and engage in activities that are meaningful, such as education, training, therapies, employment and socialising. Undoubtedly, there are many day services that provide a good service and where people engage in activities that are stimulating and tailored to their needs. Nevertheless, **some Advocates noted that day services are often an extension of a congregated setting and are not always engaging spaces for disabled people:**

"So, this particular individual was shuttling between a nursing home where they shouldn't have been and the day service…the only thing they really enjoyed doing was art and they probably had a lot of skill in that direction. The approach was: 'let's get a group of people together who like art'. When I went in and saw what they were doing, I came out and was really upset by it because you wouldn't have put any of it in front of a two-year-old…poor materials…you wouldn't give it to an intelligent preschool child. And this was acceptable. And this had been art for years. There was one staff member there doing their absolute best with seven or eight people…institutional approaches, I think, in day service are equally huge, equally."

NAS Advocate

As shown in the examples above, **while congregated settings are most commonly thought of as campus-based settings that provide care to large numbers of people, the institutional practices sometimes found there can be reproduced in other settings.** Nursing homes are geared towards caring for the specific needs of older people. When a younger person lives there, it can feel like a congregated setting because there are large numbers of people living together and time with staff can be limited. The same applies to some day services where people attend regularly yet experience only minimal interaction and stimulation, therefore simply transferring the institutional atmosphere to a different location.



Public Sector Duty and Appropriate Living Arrangements

Public bodies should examine whether disabled people have the same opportunities as others to choose where and how they live. Where people are placed in settings because suitable alternatives do not exist, there should be active efforts to address those inequalities.

2.2 Community Living: Evidence of Transformative Outcomes

As shown in the previous section, many of the people who contributed to this social policy paper were able to retell countless occasions of where people had experienced support that was not person-centred and did not enable them to live a good quality of life. However, it is equally important to say that there are examples of good stories and positive outcomes for those who had transitioned out of congregated settings and into homes in the community. The following section will offer some examples of these stories and also summarise the international literature that provides an evidence base in support of improved outcomes for those that leave congregated settings. For additional information and evidence on the positive impacts of deinstitutionalisation, see the National Disability Authority's 2021 research publication *Moving In, Moving On - An evaluation of the outcomes and costs of congregated and community models of service in the disability sector.*[39]

Before proceeding, it is worth drawing attention to an important point that is often overlooked: **disabled people who need support should not automatically be expected to live in group-style accommodation.** There are few other examples in society where people are involuntarily housed with people who are not close family or friends. For example, a person waiting for social housing would not ordinarily be told to share a home with another person or family they do not know. For most people, such a suggestion would seem unreasonable. Yet there remains an assumption that, for disabled people, sharing housing with people they do not know is acceptable.

"Imagine being told tomorrow morning, you're going to live with these five people and a committee has decided that you're fairly compatible, and you seem to have similar enough interests and…you know what I mean? So, we think: great, these five people would be fantastic living together and off you go now. And that's it for the rest of your life. Like, can you imagine any of us being told that? And yet this is what happens to people with intellectual disabilities all the time. There's a committee who's deciding your most fundamental freedoms, the most fundamental parts of your life that make you who you are, make you the human that you are, your home, who you choose to spend your time with, and how you choose to live your life. These are all decided by other people, and with the best will in the world and the best compatibility assessments and risk assessments and safeguarding assessments… it's an impossible thing to get that right".

Derval McDonagh – Inclusion Ireland

39 National Disability Authority, Moving in, Moving On: An Evaluation of the Outcomes and Costs of Congregated and Community Models of Service in the Disability Sector, National Disability Authority, 2021

2.2.1 The impact of transitioning out of congregated settings in Ireland

The *Time to Move On* policy provided an impetus for service providers to accelerate efforts to progress deinstitutionalisation. In addition, the introduction of regulation for residential disability services by HIQA in 2013 further underscored the need to improve people's quality of life and make services more person-centred. As shown elsewhere in this paper, progress towards these goals has been slow. Nevertheless, there are countless examples of positive outcomes for people who have experienced successful deinstitutionalisation. The following are some stories retold by contributors to this social policy paper.

"One example that comes to mind is a non-speaking autistic person with high support needs that I spoke to at a conference and who was there with their support person. They had been living in a congregated situation from quite young, about 14-ish. And they were saying that they felt pride in themselves, the feeling that they had woken up from a coma. That they were a person now, living a life now, which they didn't feel previously."

Nem Kearns – Disabled Women Ireland

"I picked the support person; it was my choice to live on my own. At first, I couldn't leave the house for about 6 or 8 weeks because I was nervous on my own. And then after that, I said to the support person that I would like to do activities out in the community. And he also showed me how to do cooking and how to keep the place clean. So, I go out now every week, I go to do table tennis and bowling, and I do park runs. And then I sometimes go to the pub for the traditional Irish music on Monday nights as well. And then I'm able to travel on my own now. I think it is really important part of that story is how your support person links you in with different clubs and...he would come with you at the start, but then eventually you were confident enough to go on your own."

Paul Alford – Inclusion Ireland

"A gentleman in his forties spent most of his time in his bedroom in the bungalow on the campus. And he had a one-to-one agency staff that they recruited that would come in every day and just stay with him in his room and follow him everywhere because he was an extraordinary high risk of falls, even though he was a physically able person. But he was so weak from lack of…basically, getting out of bed, he was completely depressed and he had muscle wastage, he had autism…he only ate certain types of food.

He was having recurrent chest infections and had had numerous days in hospital, all because of lack of moving, lack of getting out of bed, lack of actually, you know, he wouldn't even walk outside the campus. He was that depressed and demotivated.

He then moved to a beautiful house out in the countryside. And within six weeks of that, he had gone to the pub for the first time. He had gone for walks in the local area. He was eating. They had a pantry…He would come into the pantry and pick out different vegetables and stuff like that. And they were now making him vegetable pasta, bolognese and stir fries. And when I met him…I actually couldn't believe it. He walked in. I couldn't believe the change in him. He had put on weight. He had more energy, stamina. It was like day and night and that's what that man needed. He needed something to be able to get up for. He needed to have agency in his life. He needed to have opportunities, something different. He started actually using words as well. The staff didn't know he actually could communicate, so he started verbalising. Some staff had worked with him for years, they didn't know he actually had some of the language he had. It can be transformational, absolutely transformational."

Regional Manager – Health Information and Quality Authority

The example directly above shows that this person's fundamental needs were not being met in the congregated setting where he previously lived. The move to the community setting brought about tangible changes that vastly improved this man's quality of life. It is important to note that it was not only the change of housing that brought about these improvements. It was also simple things like the access to view and choose what food to eat that contributed to the positive change.

Paul Alford is someone who formerly lived in a congregated setting. He was interviewed for this paper and spoke about his time living in an institution, his struggle to be heard when he said he wanted to leave, and the transformation in his life when he got a home of his own. His story (below) is reproduced with his consent.

Case Study:

Lived experience example

Paul Alford's Journey from Institutional Care to Independent Living

Paul spent much of his life living in a large institutional setting after being moved from his family home as a child because he had an intellectual disability. He grew up separated from his parents and siblings and had little control over his daily life. He shared a dormitory with nine other people, followed strict routines set by the institution, and was expected to do what he was told. Decisions about where he lived, what he ate, when he went to bed, and how he spent his time were made by others. He also worked in institutional workshops and later in a local business for minimal pay, while the institution controlled his money.

Over time, Paul began to question why he could not make decisions about his own life. After receiving money that had been owed to him, he decided he wanted to buy his own home. Achieving this goal was not straightforward. Paul had to advocate strongly for himself and challenge the belief that he should remain in institutional care. Despite resistance from both staff and family members, he continued to express his wish to live independently. With support from advocacy groups and others who believed in his right to choose where he lived, Paul spent three years campaigning for the move. After living in an institution for more than 32 years, he was finally able to move into a home of his own in the community.

The move transformed Paul's life. For the first time, he was able to choose who supported him and how he wanted to live. Through a personal budget, he selected his own support worker and gained greater control over the supports he received. He now makes decisions about his daily routine, manages his own home, pays his bills, cooks, cleans, goes on holidays, and participates in activities that matter to him. He has developed friendships and connections within his local community through social activities, sport, and everyday interactions with neighbours and local businesses. These relationships provide practical support and a sense of belonging that was absent during his years in institutional care.



Paul's story illustrates the profound difference that choice, autonomy, community inclusion, and personalised support can make in a person's life. It demonstrates both the barriers that people living in congregated settings may face when seeking to exercise their rights and the positive outcomes that can be achieved when people are supported to live independently in the community. Paul's story is indicative of how quality of life can improve once a person attains their independence. While Paul was a fierce advocate for his preference to live by himself, he also acknowledges the key role played by his support worker during and after his move out of the congregated setting.

Clearly, it is not enough to simply relocate from a congregated setting to a small residence in the community. The provision of additional supports is essential if people are to attain a higher quality of life. Those supports may be additional staff that have the skills and time needed to get to know people's will and preference and to work to achieve those. It may also be improved access to the community, through transport or supports to engage in education or employment.

"Their home suddenly becomes far more homely. So, it's all personal. They have their own space. Their home has become their own. They really felt pride. You could see the pride in having more independence, I suppose. They could leave their home, go over to the day service, come back, but it was very much their home and their living room. They're showing me their Easter eggs in their kitchen cupboards. I'd say a sense of pride in their home is what I see a lot. They can't wait to come in and show you the furniture they've bought and things like that. And then, for those people, they tend to have their own support staff or their own car or they have their own system of getting out and about in the community as well. So, you do see that, they're getting out a lot more."

NAS Advocate

"People were proud of their homes. I remember the team who were doing the interviews saying that they'd go in and people would be showing them around and really proud of where they lived and 'would you like to see my bedroom' and this type of thing. So, it was positive even for the people who had higher levels of care needs, there just seemed to be reports from staff that people…they'd come out of themselves a little bit. There was a little bit more time for people to engage with them and spend time with them and to get to know them a little bit better because there was an increased ratio of staff to people."

Dr Rosalyn Tamming – National Disability Authority

Evidently, people who move out of congregated settings develop a sense of 'home' that they did not experience while living in a congregated setting. The new environment appears to open up new possibilities for how they choose to live their lives and what activities they participate in. There is also a sense that they become part of the communities they live in through ongoing and dedicated efforts to ensure genuine integration and inclusion:

"I know a few people who are part of their own local community. They're doing their tidy towns and they're not just involved in things through their day services or anything. They're actually participating in community life in their neighbourhoods. They're good neighbours to people.

I know of people that I would have met in the early days of transition who moved into an estate, into a lovely house, and became great neighbours to everyone around them. So, they're minding cats in one house if they're gone on holidays, they're watering plants and vice versa. Neighbours are popping in and doing all of that. They've become very integrated, but a lot of that is down to the efforts that staff would have made to support them. So, transition didn't just stop with the transition from the congregated setting. It continued in some good examples where people were invited in and the demystification of meeting people who communicate a little differently was done in very gentle ways."

NAS Advocate

The experiences listed above offer illuminating and often heartwarming stories of the positive impact for people who move out of congregated settings. Clearly, many people are being empowered to live more independently and with greater choice and autonomy. The next section of the policy paper will describe the evidence in support of deinstitutionalisation in the literature.



Evidence of Positive Change

The Public Sector Duty encourages public bodies to use evidence to improve outcomes. The positive experiences described by people who have moved into community living demonstrate the importance of investing in models that promote choice, inclusion and independence.

The positive examples of community living show what is possible when housing, support and person-centred planning align around the individual.

However, they also make clear that successful deinstitutionalisation depends on conditions that are not yet consistently available across Ireland. The following section therefore turns from the evidence of what works to the structural barriers that continue to prevent people from moving into ordinary homes in their communities.

2.3 Structural barriers to Deinstitutionalisation

While the *Time to Move On* policy has been in place for 15 years, the pace of deinstitutionalisation has not kept up with original targets. The contributors to this social policy paper have identified a range of barriers to deinstitutionalisation. These barriers can be grouped loosely as structural, cultural and systemic in nature. The following section will outline the principal barriers that are frustrating efforts to move people into more person-centred homes in the community.

2.3.1 Shortage of housing

Almost all contributors flagged the housing crisis in Ireland as a significant barrier to deinstitutionalisation. Suitable housing is scarce, and the high cost of housing is also a problem.

"A lot of those campuses in Dublin are in prime locations. If you were looking for property there, you're talking €600,000 or €700,000. That's a barrier because: do you want to move people out and then move them into County Meath, County Kildare, County Wicklow? No. So that's a significant barrier."

Regional Manager – Health Information and Quality Authority

"The provider's decision to plan for moving just X number of people per year means that at this pace of transitions, it will take over 15 years. And this is assuming everyone will decide that they want to live together. But some people may want to live on their own, so they'll need more houses to accommodate that".

Marge Lysaght – Social Health Education Project, Cork

There appears to be no easy solution to the nationwide problem of housing shortages. However, it is unfortunate that people that may have been waiting years and, in some cases, decades, to move out of congregated settings are experiencing further delays due to circumstances beyond their control and the control of the service providers that are responsible for their care.

2.3.2 Staffing

When people move to the community there may be a requirement to provide additional staffing hours and expertise, over and above that which was available in the congregated setting. This is a logistical and recruitment challenge for service providers:

"The last time I was at one of the meetings, there was somebody from the agency saying that they haven't got enough neuro nurses to allow people to move into the community. So, for people who had spinal injury or indeed acquired brain injury, they felt that the local community nurse wouldn't be able to meet their needs".

Shelly Gaynor – Independent Living Movement Ireland

There are, unfortunately, other instances where staff do not wish to change established work practices or their place of work in order to accommodate deinstitutionalisation.

"And then you have staff not wanting to move because of personal circumstances. They've never worked in the community before, they're afraid to do it, union issues, working issues. In congregated settings, staff probably tend to work set hours. In some community settings, they want to do a responsive roster, which is a roster to respond to the particular need of the person. So that would be a barrier."

Regional Manager – Health Information and Quality Authority

2.3.3 Prioritisation

Several contributors raised concerns that deinstitutionalisation is no longer being treated with sufficient urgency, either by individual service providers or by the State more broadly. They described a growing perception that other pressures, including support for younger people in nursing homes and adults living with ageing parents, are competing with and sometimes displacing the deinstitutionalisation agenda. While each of these groups has serious and legitimate needs, the effect can be that people already living in congregated settings are treated as less urgent because they are deemed to have "somewhere" to live. This risks normalising segregated living arrangements and leaving people behind despite clear policy and human-rights commitments.

"The under 65s in nursing homes and those elderly parents with adult children with disabilities at home…what seems to be happening is their need for services are being prioritised over the decongregation [deinstitutionalisation] effort. I suppose the feeling is the ones in congregated settings, 'At least they have somewhere. They're safe.' It may not be brilliant, but it's better than the under 65s in nursing homes, inappropriately placed. Or the people living at home where the parents are unable to provide care any longer…And when the money is scarce and houses are scarce, I definitely think the people in congregated settings are being left behind."

Dr Rosalyn Tamming – National Disability Authority

"A huge aspect of this is resourcing, right? And to me it's less of a scarcity of resources, but less of a prioritisation of the allocation of those resources, right? Because in the last budget we saw a massive investment into disability services. There is a commitment to spend more, but very little is actually about moving people out of congregated settings. So, there's a huge aspect of the resourcing and how we choose to spend resources. I think there is a lack of recognition of the fact that, potentially, we could save a lot of money in the long term by people living better lives in non-congregated settings, there is a certain amount of evidence that supports that. But a huge part of it comes down to political will, I think is another massive element."

Amy Hassett – Disabled Women Ireland

There were also some contributors that questioned the urgency with which some service providers were working on deinstitutionalisation:

"There is a property that the service provider purchased that needs to be renovated. And this has been ongoing since 2023. And so, there is a property that is there and construction works went out to tender. The tender may run out before work commences. We know that there's another property that has been purchased that there's planning in again. There's a query over the plans for that house. And do those plans meet the needs of the individuals from that institution that we're talking about? It seems to be a lack of will by the decision makers".

NAS Advocate

2.3.4 Staff or family resistance to a person leaving a congregated setting

It is often the case that family or relatives advocate on behalf of a person where they may not be in a position to self-advocate. In the absence of a formal decision-supporting arrangement under the Assisted Decision-Making (Capacity) Act, family members do not have a legal decision-making role in relation to where an adult lives, and even with a legal decision-making role explicitly cannot detain or restrain a person. However, service providers can sometimes be more responsive to family wishes than to the individual's own will and preferences. Consequently, there are occasions where family members are reluctant to discuss or consider a move from a congregated setting.

"The service provider did have an opportunity for those people to move out – this was before we were involved as an advocacy service. They had two community houses where they were going to move people- they were talking about moving the young people into the houses- and the families stopped it and the service allowed the families to stop that".

Marge Lysaght – Social Health Education Project, Cork

Participants emphasised, however, that such concerns often arise from genuine care and a desire to ensure the wellbeing and safety of a family member rather than from opposition to community living itself. For many families, particularly those whose relatives have spent much of their lives in institutional or congregated settings, the existing arrangement may be perceived as safe, familiar and dependable. Where families have had limited exposure to examples of disabled people successfully living ordinary lives in their communities with appropriate supports, it can be difficult to imagine alternative possibilities or outcomes. Moreover, families may have concerns about poor or inadequate planning around transitions. This underlines the importance of good planning in order to avoid the need for emergency placements in crisis situations.

"Some family members, and maybe older family members, feel that their son or daughter is safe where they are and being looked after well. So, why would you change that? Why would you move them out?"

NAS Advocate

Concerns about moving from congregated settings may therefore reflect understandable anxieties about change, uncertainty about the availability and quality of community supports, and a wish to protect

a loved one from potential harm. However, such concerns can also inadvertently limit expectations about what a person might achieve or experience when supported to live in a community setting, particularly where opportunities to see positive examples of deinstitutionalisation have been limited.

There were also instances of staff voicing resistance to people leaving congregated settings.

"Staff were maybe thinking, 'oh, that person, moving out isn't right for them. They've lived here for X amount of years.' So maybe they can't envision that someone can have a different life and a higher quality of life as well."

NAS Advocate

This may reflect the influence of institutional thinking among some staff, whereby long-term living in a congregated setting becomes viewed as a reason to remain there rather than an indication that alternative opportunities and supports could be explored. Such attitudes can limit recognition of a person's potential for greater autonomy, community participation and improved quality of life.

2.3.5 People's needs

The needs and age profile of some people living in congregated settings means that careful attention and planning is required to identify suitable accommodation in order for that person to move out. In some cases, people are so institutionalised in their current home that a move elsewhere might cause significant anxiety or upset.

"The fact is that people have lived for so long in these settings. There are many people like this but for example, one gentleman has been in care since he was nine. He's now in his fifties. He's had absolutely no experience of living in a community. So how does he even understand what these opportunities are or what the choices are before he moves out or even to say, 'yes, I want to do that' or to express will and preferences because they've had no exposure."

Marge Lysaght – Social Health Education Project, Cork

3. Discussion: From Service Reform to Rights Realisation

This policy paper set out to examine the slow pace of closure of congregated settings for disabled people in Ireland, drawing on policy analysis, international comparison, and crucially the lived experiences of those NAS supports as relayed through Advocates and other key stakeholders.

Taken together, the findings presented throughout this paper point to a clear and consistent conclusion: congregated settings are not compatible with a modern, rights-based understanding of disability, and their continued existence reflects a persistent gap between policy intent and lived reality.

A central theme emerging from this analysis is the tension between Ireland's stated commitments to deinstitutionalisation and the slow pace at which meaningful change is occurring. Irish policy has, for 15 years, recognised that congregated settings are inconsistent with quality of life, autonomy, and community inclusion for disabled people. The *Time to Move on* strategy explicitly framed deinstitutionalisation as a matter of community inclusion rather than service modernisation, while more recent policy frameworks have aligned these commitments with Ireland's obligations under the UNCRPD. However, despite this conceptual clarity, implementation has been fragmented and uneven. **The fact that over 2,200 people were still living in congregated settings in 2023 underscores the extent to which progress has lagged behind ambition.**

The evidence presented in this paper suggests that this implementation gap cannot be attributed to a lack of policy direction, but rather to structural and systemic barriers. Chief among these is the absence of accessible, affordable housing in the community. As outlined in the discussion of Article 19 UNCRPD, housing is not simply one component of deinstitutionalisation; it is an essential structural precondition. Without a sufficient supply of dispersed housing, alongside flexible and individualised supports, transitions out of congregated settings are either delayed or result in transinstitutionalisation. The example of an individual waiting over a year to move into a home already allocated to them due to staffing constraints highlights how even positive developments can stall within an under-resourced system.

At the same time, the persistence of congregated settings reflects deeper cultural and organisational legacies. **The descriptions provided by NAS Advocates and others of physical environments that are "stark", "clinical", and "restrictive" illustrate how these settings continue to**

embody a medical model of care. In such environments, people are often treated as a group rather than as individuals, with routines, meals, and activities organised around institutional efficiency rather than personal preference. This is further reinforced by block funding models, which incentivise provider-led service configurations and limit flexibility in responding to individual needs.

The experiences of people within these settings provide some of the most compelling evidence of their wide-ranging limitations. Across multiple domains: privacy, dignity, safeguarding, communication, and access to meaningful activity, there is a consistent pattern of restricted autonomy and reduced quality of life. People are often unable to exercise basic choices about how they spend their day, who they spend time with, or even what they eat. In some cases, individuals live in fear of others due to incompatibility and inadequate responses to abuse, leading to situations where people withdraw to their bedrooms as a form of self-protection.

Such examples highlight how congregated living arrangements can undermine not only individual autonomy but also fundamental rights to safety and dignity and the ability to enjoy one's own home.

Importantly, this paper does not suggest that these outcomes are solely the result of individual staff failings. On the contrary, as recounted in this paper, many staff members are committed to providing high-quality care but are constrained by systemic conditions. Limited staffing ratios, task-oriented roles, and insufficient training in person-centred approaches all contribute to a situation where even well-intentioned staff struggle to support people in a meaningful way. This reinforces the point that deinstitutionalisation is not simply a question of relocating people, but of transforming how people are supported to live good and meaningful lives.

The contrast between life in congregated settings and life in the community is particularly striking.

People's stories presented in this paper demonstrate that when people move to smaller, more personalised living arrangements with appropriate supports, the impact can be transformational.

Individuals who were previously isolated, disengaged, or experiencing poor physical and mental health often show rapid and sustained improvements. Increased autonomy, access to community life, meaningful relationships, and opportunities for choice all contribute to enhanced wellbeing.

These outcomes are consistent with the international evidence base, which, as shown in this paper, overwhelmingly supports the view that deinstitutionalisation leads to improved quality of life.

However, the findings also highlight that deinstitutionalisation alone is not sufficient. The quality of outcomes depends heavily on the nature of the supports provided post-transition. Without adequate staffing, training, and resources, there is a risk that institutional practices will be replicated in smaller settings. This phenomenon, observed in countries such as the UK and Australia, serves as an important cautionary lesson for Ireland. **It underscores the need to move beyond a narrow focus on housing and to adopt a holistic approach that encompasses support provision, community integration, and the empowerment of individuals.**

It should also be borne in mind that, as per the official definition, congregated settings are those where 10 or more people live. While the stated ideal is four or less, there remains a significant cohort living in services of 5-9 people. This cohort are not a focus of deinstitutionalisation, yet likely have similar needs to those in congregated settings. As such, this group of people are somewhat overlooked in the context of the deinstitutionalisation effort.

Another critical issue identified in this paper is the existence of de facto congregated settings, particularly in the form of nursing homes providing care to younger disabled people. These settings replicate many of the characteristics of traditional congregated settings, including large numbers of people, limited choice, and a lack of age-appropriate activities. The experiences of individuals such as David and Jason illustrate how such placements can lead to deteriorating physical and mental health, social isolation, and a loss of autonomy. **These cases highlight the broader point that institutionalisation is not defined solely by the size or type of a setting, but by the extent to which it restricts choice, control, and participation.**

It should also be acknowledged that 'recongregation' is taking place. While data on this is limited, there is anecdotal evidence that people are still being admitted to congregated settings. This may be because service options in certain areas are limited, or there may be temporary or respite admissions. It may also be because people's needs change as they get older and they may not be able to age in place in the community. Often, the outcome for such people is to move to a congregated setting.

There is also a wider point to be made about the availability of data on deinstitutionalisation. There was a period prior to 2020 when progress reports were regularly produced by the HSE. These reports provided data

on people that left congregated settings and moved to the community, as well as those who died or moved to a nursing home or other setting.

These progress reports have not been produced for some time and NAS is calling on the Government and the HSE to address this gap.

From a policy perspective, the findings of this paper point to a need for improved coordination and a greater sense of urgency. There is certainly a sense that the political will to pursue full deinstitutionalisation has waned over the past number of years. **The fragmentation of Ireland's policy landscape, with multiple strategies addressing different aspects of disability and housing, has contributed to a lack of clear ownership and measurable progress on deinstitutionalisation.** The Public Sector Equality and Human Rights Duty provides a potentially powerful mechanism for driving change, but its impact depends on how rigorously it is implemented and monitored. If public bodies were to fully meet their obligations under this Duty, it is reasonable to expect a more concerted and accelerated effort to transition people out of congregated settings.

Finally, the role of independent advocacy emerges as a critical enabler of change. NAS plays a vital role in amplifying the voices of those who may otherwise go unheard. The experiences captured in this paper illustrate not only the challenges people face but also their aspirations for a different kind of life, one characterised by choice, independence and inclusion. These voices should be central to any future policy development or service reform. Notwithstanding this, NAS and other advocacy services continue to be under-resourced. This poses a challenge in terms of meeting the needs of disabled people across the country.

Nobody should have to be placed on a waiting list to access advocacy services and NAS is calling on the Government to improve funding for these vital services. In light of the above, NAS's principal recommendation arising out of this paper is to call on the Government and the HSE to produce a new national deinstitutionalisation delivery plan.

The plan should have a clear implementation roadmap that includes annual targets, accountability frameworks, resourcing commitments and transparent progress reports. Ireland's ratification of the UNCRPD, and forthcoming review of the country's progress towards these goals, underscore the need for a renewed focus on deinstitutionalisation. A Government commitment to a new deinstitutionalisation plan would be a

positive signal of a renewed political will to improve the quality of life for people living in congregated settings in Ireland.

In conclusion, this discussion reinforces the central argument of the policy paper: **congregated settings are fundamentally incompatible with a rights-based approach to disability because they restrict choice, privacy, safety, communication, community participation and control over ordinary life.** Ireland has made significant progress in articulating a vision for community-based living, but implementation must now accelerate if the State is to meet its national policy commitments and international human-rights obligations.

The evidence presented in this paper is clear: when people are supported to live in ordinary homes, with appropriate individualised supports, they experience better outcomes across many aspects of their lives. The challenge now is to translate this evidence into action so that all disabled people in Ireland have the opportunity to live as full and equal members of their communities.



4. Policy Recommendations

The recommendations below should be implemented according to a clear set of principles: a rights-based and person-centred approach; meaningful participation of disabled people; defined responsibilities and timeframes; adequate resourcing; and transparent monitoring and accountability. Implementation should focus not simply on completing moves from congregated settings, but on ensuring that people have genuine choice, control and the supports necessary to live meaningful lives in their communities. Based on the contents of this social policy paper, NAS proposes the following recommendations:

1

Establish a National Deinstitutionalisation Delivery Plan

Target: Government / Department of Health / HSE / Local Authorities

Ireland should publish a revised national deinstitutionalisation plan with clear targets, timelines, funding commitments and public reporting requirements. This plan must explicitly embed the Public Sector Equality and Human Rights Duty (Public Sector Duty) into its core governance, impact assessments, and reporting structures. To eliminate discrimination and protect human rights, the plan must require public bodies to proactively assess, address, and monitor equality and human rights outcomes at every stage. Fifteen years after *Time to Move On*, implementation must move from aspiration to accountability.

2

Recognise Deinstitutionalisation as a Human Rights Priority

Target: Government

The transition from congregated settings should be explicitly recognised as a key mechanism for delivering Ireland's obligations under Article 19 of the UNCRPD. People should not be required to remain in institutional or segregated living arrangements because of delays in policy implementation.

3

Put the Will and Preferences of the Person First

Target: Service Providers / HSE / Decision Support Service

Public bodies and all relevant service providers must fully operationalisetheir statutory obligations under the Public Sector Duty by ensuring that all decisions relating to housing and living arrangements are strictly guided by the person's will and preferences. To fulfil the Duty's mandate to protect human rights and encourage equal opportunities, individuals who communicate differently must receive the necessary accommodations and supports to participate meaningfully in decisions about where and with whom they live. Lived experiences must directly inform and shape policy through an inclusive, accessible consultation process.

4

Accelerate Access to Community Housing

Target: Department of Housing / Local Authorities

A dedicated housing pathway should be established and ringfenced for people leaving congregated settings. Housing supply constraints cannot continue to be a barrier to the realisation of fundamental human rights.

5

Target Investment that Supports People to Achieve a High Quality of Life

Target: HSE / Service Providers

Deinstitutionalisation must be accompanied by adequate, person-centred supports in the community that are appropriately funded. Success should be measured not by where a person lives, but by the extent to which they can exercise choice, participate in community life and achieve the outcomes that matter to them.

6

End the Creation of New Congregated and De-facto Congregated Settings, and Set a Target Date to Cease New Admissions

Target: Government / HSE

Public investment should prioritise individualised, community-based living arrangements and avoid models that risk recreating institutional practices in smaller settings. This principle should also apply to placements of younger disabled people in nursing homes. A commitment should also be made to identify a target date after which new admissions to congregated settings will cease. There should also be a commitment to the production of data and reporting on the deinstitutionalisation effort to robustly monitor implementation.

7

Strengthen Independent Advocacy

Target: Government / HSE

Every person living in a congregated setting should have access to independent advocacy if they wish to use it. NAS is also calling on the Government to develop a strategy on advocacy that acknowledges its key role and funds it accordingly.

8

Embed Human Rights and Community Inclusion in Regulation

Target: HIQA

The quality of a residential service should be judged not only by safety and compliance, but also by the extent to which people experience autonomy, privacy, meaningful relationships and participation in their communities. Inspection and regulatory frameworks should continue to strengthen their focus on these outcomes, including whether people's will and preferences are properly documented when a move from a congregated setting is being considered. The public sector duty should be built into all applicable inspection and regulatory frameworks to ensure rigorous monitoring of such preferences are documented and respected when a move from a congregated setting is being considered, ensuring that regulation actively drives positive outcomes for individuals.

9

Support Disabled Persons' Organisations to Lead Change

Target: Government / Funders

Disabled Persons' Organisations should be adequately resourced to contribute to policy development, monitoring and implementation of deinstitutionalisation initiatives. People with lived experience of disability must be central participants in shaping the systems that affect their lives. Public bodies must ensure that people with lived experience of disability are central, active participants in shaping, auditing, and reforming the systems that affect their fundamental rights.

10

Build the Evidence Base on Life After Deinstitutionalisation

Target: Research Bodies / Academic Institutions / National Disability Authority

Further research should examine the long-term experiences of people who have moved from congregated settings into community living. Particular attention should be paid to quality of life, relationships, community participation, health outcomes and the extent to which people feel they have genuine choice and control over their lives. An additional avenue for research could be explored in the context of human rights and equality. For example, who waits longest for accommodation moves, who may be left behind during the deinstitutionalisation process, and how outcomes might differ in accordance with a range of factors such as support need, communication, age, gender, ethnicity, Traveller/Roma identity, migration status, geography and access to family or independent advocacy.

Glossary of Key Words and Ideas

The glossary focuses on concepts that are central to the paper's discussion of congregated settings, deinstitutionalisation/decongregation, independent advocacy, housing, disability rights and community living.

Term	Meaning in the context of this paper
Article 28 (UNCRPD)	The UNCRPD provision on an adequate standard of living and social protection. The paper links it with Article 19, particularly in relation to access to adequate, accessible and affordable housing.
Autonomy	A person's ability and right to make decisions about their own life and exercise meaningful control over everyday choices, relationships, routines and living arrangements.
Block funding / block-funded model	Funding provided to a service or provider as an overall allocation rather than being directly tied to the individual needs and choices of a particular person. The paper argues that this can reinforce provider-led service arrangements and reduce flexibility.
Choice and control	The ability of a person to influence and decide what happens in their own life, including where and with whom they live, their daily routine, relationships, activities and supports.
Community-based living	Living in an ordinary home within the wider community, with appropriate supports, rather than living in an institutional or segregated setting.
Community inclusion	Being an active and equal member of the wider community, with opportunities to develop relationships, use ordinary services, take part in activities and exercise the same rights and choices as other people.

Term	Meaning in the context of this paper
Congregated setting	A residential arrangement where groups of people with disabilities live together in shared accommodation, often on a campus or in a purpose-built or repurposed facility. The paper notes the national policy definition of settings where ten or more people live together, or campus-based arrangements.
Decongregation	The process of supporting people to move from congregated or institutional settings into ordinary homes in the community. The paper stresses that this is not simply relocation: it requires choice, personalised supports, community participation and a meaningful improvement in quality of life.
De facto congregated setting	A setting that may not formally meet the standard definition of a congregated setting but reproduces many of its features, such as large-group living, restricted choice, institutional routines or segregation. The paper particularly discusses younger disabled people living in nursing homes in this context.
Deinstitutionalisation	The broader shift away from institutional models of care towards community-based, person-centred and rights-based supports. It includes changing not only buildings but also service cultures, funding, decision-making and the balance of power.
Designated centre	A residential service that is registered and regulated under the Health Act 2007 and associated regulations. In the paper, HIQA's oversight of designated centres is discussed as part of the regulatory framework for disability residential services.
Direct Payments	Funding made available in a way that gives a person greater direct control over arranging and purchasing their own supports. The paper refers to Direct Payments in the context of the ÁT Network and self-directed support.
Disabled Persons' Organisation (DPO)	An organisation led and directed by disabled people themselves. The paper treats DPO involvement as important to ensuring that disability policy and reform are shaped by the people directly affected.

Term	Meaning in the context of this paper
Dispersed housing	Ordinary houses or apartments located within the general community rather than grouped together on a disability-service campus. The paper draws on Time to Move On in presenting dispersed housing as part of the intended alternative to congregated settings.
Human rights-based approach	An approach that treats disabled people as rights-holders rather than simply recipients of care. It focuses on dignity, equality, autonomy, participation, inclusion, accountability and the State's obligations to respect, protect and fulfil rights.
Independent advocacy	Support that is independent of service providers and is directed by the person's own will and preferences. In the paper, advocacy helps people express their views, understand and exercise their rights, participate in decisions and challenge arrangements that do not reflect their wishes.
Independent living	Having choice and control over one's own life and the supports needed to participate in the community. It does not mean living without support; it means that support should enable the person to direct their life rather than having their life directed by a service.
Individualised supports	Supports designed around the particular person's needs, wishes, circumstances and goals rather than a standard service model applied to a group.
Institutionalisation	A situation in which people are separated from ordinary community life and are subject to institutional structures, routines or control that limit personal choice and autonomy. The paper emphasises that institutionalisation can exist even outside very large institutions.
Institutional practices	Routines, rules or ways of organising services around the needs of the institution rather than the individual, for example rigid schedules, group-based decisions, restricted choice or limited privacy.

Term	Meaning in the context of this paper
Lived experience	The direct experience of people affected by the issue. The paper places particular emphasis on the experiences, views, wishes and aspirations of people who live, or have lived, in congregated settings.
Mainstream services	Ordinary public and community services available to the general population. Article 19 is used in the paper to support the principle that these services should also be accessible and responsive to disabled people.
Medical model of disability	An approach that focuses primarily on a person's impairment, diagnosis, care or treatment needs. The paper contrasts this with approaches that focus on rights, social barriers, autonomy, inclusion and the person's own choices.
Natural supports	Informal support available through family, friends, relationships or other people in a person's life, rather than through paid or formal services. NAS places particular importance on advocacy for people who have few or no natural supports.
Ordinary life / ordinary community life	A recurring idea in the paper describing the opportunity to have an ordinary home, relationships, routines, activities, roles and community connections of one's own choosing, rather than having life organised around a disability service.
Personal assistance	Individual support that enables a disabled person to carry out everyday activities and participate in community life in a way that supports their own choices and direction.
Person-centred approach	Planning and providing support around the individual person: their wishes, communication, relationships, goals, strengths and needs. The paper contrasts person-centred practice with task-centred or service-led approaches.

Term	Meaning in the context of this paper
Public Sector Equality and Human Rights Duty	The duty under section 42 of the Irish Human Rights and Equality Commission Act 2014 requiring public bodies to have regard to the need to eliminate discrimination, promote equality and protect human rights. The paper applies this duty to decisions about funding, housing, commissioning and service models.
Quality of life	The overall experience of a person's life, including wellbeing, safety, health, relationships, choice, meaningful activity, personal development, belonging and participation in the community.
Restrictive practices	Practices that limit a person's freedom, liberty, movement, choice or control. The paper discusses the need to reduce or eliminate restrictions that interfere with dignity, privacy, bodily integrity and ordinary community life.
Rights realisation	Moving beyond statements of rights or policy commitments so that rights are experienced in practice. The paper uses this idea to emphasise outcomes: whether people actually have homes, choices, supports, relationships and community participation.
Safeguarding	Measures to protect people from abuse, neglect, exploitation, intimidation and other forms of harm while respecting their rights, autonomy and wishes.
Self-directed supports	Supports in which the person has greater authority over how assistance is designed, organised and delivered, rather than being fitted into a fixed provider-led service.
Social model of disability	An approach that focuses on the barriers created by society, environments, systems and attitudes rather than locating disability solely within the individual. The paper links this approach with equality, inclusion and human rights.

Term	Meaning in the context of this paper
Structural barriers	System-level obstacles that prevent change even where policy commitments exist. In this paper these include shortages of suitable housing, staffing pressures, funding arrangements, prioritisation, fragmented responsibility and limited community alternatives.
Supported decision-making	Providing the assistance a person may need to understand, consider and communicate decisions while maintaining the person's own legal agency, will and preferences. The paper links this principle to the Assisted Decision-Making (Capacity) Act 2015.
Supported living	Community living in which a person has the individualised assistance required to live in an ordinary home and participate in community life. The paper distinguishes this from simply moving people into smaller service-controlled settings.
Transinstitutionalisation	Moving a person from one institutional or segregated arrangement into another rather than achieving genuine community living. The paper warns that smaller settings can reproduce institutional control if choice, autonomy and individualised supports do not change.
Will and preferences	What the person wants, values and chooses. This is a central concept in the paper and in supported decision-making: decisions and advocacy should be guided by the person's own wishes rather than by what others consider best for them.
Whole-of-government responsibility	The principle that decongregation/deinstitutionalisation cannot be delivered by disability services alone. The paper emphasises coordinated responsibility across housing, health, local government, disability services and other public bodies.

References

Angell, A. M., L. Goodman, H. R. Walker, K. E. McDonald, L. E. Kraus, E. H. J. Elms, L. Frieden, A. J. Sheth, and J. Hammel. ""Starting to Live a Life": Understanding Full Participation for People with Disabilities after Institutionalization." Am J Occup Ther 74, no. 4 (Jul/Aug 2020): 7404205030p1-30p11. https://dx.doi.org/10.5014/ajot.2020.038489.

Authority, National Disability. Moving in, Moving On: An Evaluation of the Outcomes and Costs of Congregated and Community Models of Service in the Disability Sector. National Disability Authority, 2021.

Dickson, Daniel, and Megan Linton. "A Haunting Legacy: Systemic Ableism in Canadian Housing Policy for People Labelled with Intellectual and Developmental Disabilities." Canadian Journal of Political Science 58, no. 3 (2025): 565-90. https://dx.doi.org/10.1017/S0008423925000253.

European Union Agency for Fundamental, Rights. Places of Care = Places of Safety?: Violence against Persons with Disabilities in Institutions. Luxembourg: Publications Office of the European Union, 2025.

Hamlin, Alexandra, and Peter Oakes. "Reflections on Deinstitutionalization in the United Kingdom." Journal of Policy and Practice in Intellectual Disabilities 5, no. 1 (2008): 47-55. https://dx.doi.org/https://doi.org/10.1111/j.1741-1130.2007.00139.x.

Health Information and Quality Authority. 10 Years of Regulating Designated Centres for People with Disabilities. Dublin, 2024.

Health Information and Quality Authority. Annual Report 2023. Dublin, 2024.

Health Service Executive. Time to Move on from Congregated Settings. 2011.

Inclusion Canada. Deinstitutionalization – Done Right. 2021.

Inclusion Ireland. Housing for People with Intellectual Disabilities – the Lack of Support for Independent Living. 2019.

Kilroy, Sarah, Jonathan Egan, Marie Walsh, Sharon McManus, and Kiran M. Sarma. "Staff Perceptions of the Quality of Life of Individuals with an Intellectual Disability Who Transition from a Residential Campus to Community Living in Ireland: An Exploratory Study." Journal of Intellectual & Developmental Disability 40, no. 1 (2015/01/02 2015): 68-77. https://dx.doi.org/10.3109/13668250.2014.984666.

McCarron, Mary, Richard Lombard-Vance, Esther Murphy, Peter May, Naoise Webb, Greg Sheaf, Philip McCallion, Roger Stancliffe, Charles Normand, Valerie Smith, and Mary-Ann O'Donovan. "Effect of Deinstitutionalisation on Quality of Life for Adults with Intellectual Disabilities: A Systematic Review." BMJ Open 9, no. 4 (2019): e025735. https://dx.doi.org/10.1136/bmjopen-2018-025735.

Mezzina, R. "Forty Years of the Law 180: The Aspirations of a Great Reform, Its Successes and Continuing Need." Epidemiol Psychiatr Sci 27, no. 4 (Aug 2018): 336-45. https://dx.doi.org/10.1017/s2045796018000070.

Ministry of Social Development. Enabling Good Lives. 2011.

National Advocacy Service. Annual Report 2024. 2025.

National Advocacy Service. Casebook 2023. 2024.

National Disability, Authority. Outcomes for Disability Services. Dublin: National Disability Authority, 2016.

National Disability Authority. Overview of Uncrpd Article 19 in Ireland - Living Independently and Being Included in the Community. 2022.

Navas, Patricia, Víctor B. Arias, Eva Vicente, Laura Esteban, Verónica M. Guillén, Natalia Alvarado, Inés Heras, Paula Rumoroso, Laura García-Domínguez, and Miguel Ángel Verdugo. "Empowering Lives: How Deinstitutionalization and Community Living Improve the Quality of Life of Individuals with Intellectual and Developmental Disabilities." Research in Developmental Disabilities 157 (2025/02/01/ 2025): 104909. https://dx.doi.org/https://doi.org/10.1016/j.ridd.2024.104909.

Nordic welfare centre. Personalised Support and Services for Persons with Disabilities – Mapping of Nordic Models. 2021.

O'Brien, Patricia, Avril Thesing, Bryan Tuck, and Angus Capie. "Perceptions of Change, Advantage and Quality of Life for People with Intellectual Disability Who Left a Long Stay Institution to Live in the Community." Journal of Intellectual & Developmental Disability 26, no. 1 (2001/01/01 2001): 67-82. https://dx.doi.org/10.1080/13668250020032778.

Office of the Onbudsman. Wasted Lives: Time for a Better Future for Younger People in Nursing Homes. 2024.

Tøssebro, Jan. "Scandinavian Disability Policy: From Deinstitutionalisation to Non-Discrimination and Beyond." Alter 10, no. 2 (2016/04/01/ 2016): 111-23. https://dx.doi.org/https://doi.org/10.1016/j.alter.2016.03.003.

Tøssebro, Jan, and Anders Gustavsson. Deinstitutionalisation and Later Developments in the Lives of Persons with Intellectual Disabilities: Lessons from the Nordic Countries. 2025.

Wolfensberger, Wolf. The Principle of Normalization in Human Services, 1972.

National Advocacy Service
For people with disabilities

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