

INCLUSION IRELAND

National Association for People with an Intellectual Disability

Deinstitutionalisation in Ireland; a failure to act

February 2018

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Ireland plain English guidelines.**



Easy to Read Summary



Over recent years, Ireland has done what other countries have done and started to stop the use of institutions for disabled people.



In 2011, a report was published on institutions called 'Time to Move on from Congregated Settings'.

Time to Move on from Congregated Settings
A Strategy for Community Inclusion

The report looked at a type of institution called a 'congregated setting' – where 10 or more people live.

Report of the Working Group on
Congregated Settings
Health Service Executive
June 2011



The report said that all congregated settings should be closed by 2018, but this didn't happen.



Many people who lived in an institution in 2011 still live there.

Some people moved to a different type of institution, other people have died.



This report looks at how the policy has failed.



This report looks at research done around the world.

The report says that:

- The State policy has failed.
- Institutions are abusive.
- Institutions are a breach of rights.
- Living in the community is better for people with disabilities.
- Many people don't think that people with disabilities can live in the community.
- There hasn't been enough money put in place to make the moves happen for people.
- There have been other barriers to people moving such as not enough houses.
- Politicians, public bodies and human rights organisations have not led the way.



Inclusion Ireland is asking for some things to happen:



- An organisation called the Irish Human Rights & Equality Commission (IHREC) should look into why the move from institutions has taken so long.
- IHREC should see if people with disabilities have had their rights abused in institutions.
- The government should set up a group to look at the money that has already been spent on closing institutions.
- The group should also put in place a plan to close institutions and support people to move to the community.

About Inclusion Ireland

Established in 1961, Inclusion Ireland is a national, rights-based advocacy organisation that works to promote the rights of people with an intellectual disability.

Inclusion Ireland uses a human rights-based approach to its work. This recognises persons with an intellectual disability as rights holders with entitlements, and corresponding duty bearers and their obligations. Inclusion Ireland seeks to strengthen the capacities of persons with an intellectual disability to make their claims and of duty bearers to meet their obligations.

The vision of Inclusion Ireland is that of people with an intellectual disability living and participating in the community with equal rights as citizens, to live the life of their choice to their fullest potential. Inclusion Ireland's work is underpinned by the values of dignity, inclusion, social justice, democracy and autonomy.

1. Introduction

The need to shift away from institutionalised living for people with disabilities has been a feature of Irish policy for decades. Multiple reports have made recommendations on the need to move from institutionalised settings to community living arrangements with access to community-based services¹.

The Committee on the United Nations Convention on the Rights of Persons with Disabilities have clearly stated that while institutions may differ in size, they share common characteristics, namely:

“Isolation and segregation from community life, lack of control over day-to-day decisions, lack of choice over whom to live with, rigidity of routine irrespective of personal will and preferences, identical activities in the same place for a group of persons under a certain authority, a paternalistic approach in service provision, supervision of living arrangements and usually also a disproportion in the number of persons with disabilities living in the same environment”.

¹ For example, the Report of the Review Group on Mental Handicap Services (1990); Towards an Independent Future, the Report of the Review Group on Health and Personal Social Services for People with Physical and Sensory Disabilities (1996); report of the Commission on the Status of People with Disabilities (1996)

A person can experience institutional life in a group home or even in their own home where the state has failed to provide the supports required to make mainstream services available and accessible².

Inclusion Ireland's understanding of deinstitutionalisation and community living is informed by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) which acknowledges that deinstitutionalisation involves more than just the closure of large, residential settings. It is about removing institutional cultures and practices and ensuring that accessible, inclusive housing, services and supports are available to persons with disabilities in community settings.

The Health Service Executive (HSE) provides residential services to approximately 8,400³ people with disabilities. Many of these services could be characterised as institutional in nature. In addition, over 1,200 people with disabilities, under the age of 65 live in nursing homes⁴. Many thousands more are living with ageing parents with no realistic alternative housing due to the lack of personalised supports.

1.1 Limited scope of Time to Move on: A Strategy for Community Inclusion

In June 2011, the HSE published a strategy designed to implement deinstitutionalisation in Ireland. 'Time to Move on from Congregated Settings – A Strategy for Community Inclusion' focused specifically on 4,000 people in 72 centres which it called 'congregated settings'. This was defined as ten or more people sharing a single living unit or where the living arrangements are campus-based.

Publication of the strategy was considered a milestone and established a national policy for a new approach to community living for persons with disabilities.

Despite the limited ambition of this strategy in focusing on large 'congregated settings', it is now clear that the policy has failed. The strategy was clear in recommending that all congregated settings would be closed within 7 years (by 2018). In 2018 at least 2,580 people with disabilities are still living in large, segregated institutions in Ireland⁵. The total of 2,580 being used by the HSE is unreliable given that 'Time to

² ENIL (2016). *Submission for the day of general discussion on the right of persons with disabilities to live independently and be included in the community*, p4.

³ HSE (2017). National service plan 2018.

⁴ RTE. *More than 1,200 people under 65 living in nursing homes for the elderly*. 8 Aug 2017 <https://www.rte.ie/news/2017/0808/895907-disabilities-nursing-homes/>

⁵ As of February 2017 - PQ 5585/17, HSE, 2017.

move on from congregated settings' adopted a narrow definition of an institution. It excluded residential settings for people with autism as well as 'intentional communities'⁶ in its analysis.

Despite the "compelling case for action" described in the strategy, action has not been forthcoming and today persons with disabilities experience segregation, human rights abuses and deprivation of liberty by virtue of remaining in these congregated settings. Through its inaction, Ireland is in breach of several international rights covenants as well as domestic and Constitutional law (discussed in detail on page 8).

1.2 About this paper

This paper critiques the process of deinstitutionalisation to date in Ireland. Given that this has focused on the closure of so called 'congregated settings', our analysis focuses primarily on Ireland's progress on delivering the commitments in 'Time to move from congregated settings: A Strategy for Community Inclusion'.

This report outlines the serious violation of human rights that are caused by institutional living. It analyses the reasons behind the failure to advance deinstitutionalisation and looks at the political indifference and institutional complacency that has enabled institutionalisation to endure. Lastly, it makes recommendations on how to progress the closure of congregated settings and calls for concerted effort and leadership to end the practice of deinstitutionalisation in Ireland.

2. Background to deinstitutionalisation

There is an international movement towards deinstitutionalisation and independent, supported living in the community and it is as part of that international movement that Ireland is working to close its institutions.

In Ireland, our use of institutions (e.g. Magdalene Laundries, Industrial Schools) has been persistently criticised internationally and by national authorities. It is broadly accepted that our use of such institutions should be a relic of the past and a reflection of an Ireland that has now gone. To consider these institutions as part of the past is to forget the large numbers who continue to reside in institutions and to ignore that institutionalisation is the model of choice for supporting disabled people.

⁶ Definition given in TTMO: 'An intentional community' is a planned residential community designed to promote a much higher degree of social interaction than other communities...Intentional communities include co-housing, residential land trusts, communes, eco- villages and housing co-operatives". In the Irish context, intentional communities include Camphill Community and L'Arche Community.

In the 1980's, while groups across the country were campaigning for community homes for people with a disability the state was building additional institutional settings.

"As a paediatrician specialising in intellectual disability, I can well recall the outcry among the many that were committed to the community care model, following the announcement that the building of an institution for people with intellectual disability in Swinford was to go ahead. At the time, there was already an excellent, countywide, community based service for children with intellectual disability in Co Mayo, and people wanted similar services to be extended to adults.

Most of those professionally involved with the intellectual disability services in the west of Ireland signed a document petitioning the health authorities not to proceed with the plan for the institution, but instead to invest the money available in developing community services."

Dr. Sinead O'Nuallain, Irish Times 18th December 2014

Multiple reports in the 1990's made recommendations on the need to move from large institutions to domestic scale accommodation with access to community-based health services⁷. These reports and other developments culminated in the publication of the 'Time to Move on from Congregated Settings' report in 2011.

3. The case for closing institutions

3.1 Institutions are abusive environments

'Time to Move On from Congregated Settings' painted a grim picture of isolation, segregation, lack of basic privacy and lack of dignity. There was little opportunity for individuals to explore interests and choices and people were often confined to a set range of centre-based and group activities with few off-campus activities. The report was damning in its depiction of institutional life which resulted in "lives lived without dignity"⁸.

⁷ For example, the Report of the Review Group on Mental Handicap Services (1990); Towards an Independent Future, the Report of the Review Group on Health and Personal Social Services for People with Physical and Sensory Disabilities (1996); report of the Commission on the Status of People with Disabilities (1996)

⁸ HSE (2011). *Time to move on from congregated settings: a strategy for community inclusion*. p14

For decades, there was no oversight or inspection of disability services and so there was no way of ascertaining whether residential services were of a sufficient standard. The strategy was written when the Health Information & Quality Authority was at its interim phase (iHIQA). However, a report published at the time indicates a level of awareness that all was not right within residential services for people with disabilities, with one Project Manager of the view that:

“When HIQA start their inspections and see some of the situations I have observed they are likely to comment about people’s human rights and the need for people to be treated with dignity & respect⁹”

The initial focus of HIQA inspections has been more on health, safety and governance regulations with a commitment in the National Disability Inclusion Strategy to progress this and ensure that inspections focus on rights and “key quality of life outcomes”¹⁰. When we consider that HIQA have been inspecting against narrow, essential parameters then it becomes even more worrying that non-compliance is a common occurrence.

Inclusion Ireland’s report on the first 50 HIQA inspections, covering over 700 residents, demonstrated extensive non-compliance and living arrangements that were bordering on the abusive¹¹. Health and safety, independent advocacy, restrictive practices and correct checking of medicines were common themes of non-compliance.

RTE analysed 420 inspection reports for its programme ‘Inside Bungalow 3’ and found that less than 2% of services were fully compliant. A subsequent report on Áras Attracta found evidence of “widespread institutional conditioning and control of residents resulting in limitations in their rights, choices and freedom and a lack of a stimulating environment and fulfilling activities”¹².

A 2017 report stated that a “significant” number of people with disabilities are living in institutions that are “not fit for purpose” and pointed to institutionalised practices and a lack of safeguarding¹³. The same report highlighted that some residents told HIQA inspectors that they felt they were not listened to in relation to their desire to self-medicate and that

⁹ Ibid

¹⁰ Department of Justice and Equality (2017). *National Disability Inclusion Strategy*. Pg37

¹¹ Meagher, M. & Conroy, P. (2015). *The distant voice: A working paper on the first 50 Health Information and Quality Authority (Hiqa) inspections of residential services for people with disabilities*.

¹² Aras Attracta Swinford Review group (2016). *What matters most*.

¹³ HIQA (2017). *Overview of regulation 2016*.

there was a closed-circuit television (CCTV) within their home, which they believed was intrusive.

Midway through 2017, the Irish Human Rights and Equality Commission (IHREC) criticised the conditions in institutions in its submission to the United Nations Convention against Torture stating “HIQA ...has established that chemical restraint is practiced” as well as “evidence to suggest extensive use of environmental restraints such as locked doors and high fences surrounding centres”¹⁴.

It is clear that notwithstanding the fact that institutions are now regularly inspected, they are fertile grounds for abuse to occur.

3.2 Institutions are a breach of legal rights

Alongside the abuses that occur, institutions are in themselves a breach of legally-held rights. The State is bound to certain civil and political rights including prohibition of torture, right to liberty and security, right to respect for privacy and family life and the prohibition of discrimination¹⁵.

Additionally, our own Constitution gives rise to rights to personal liberty, privacy, fair procedure and bodily integrity.

The Irish Courts have held that even though Ireland has not ratified the UNCRPD the “broader range of constitutional ‘personal capacity rights’ now fall to be informed by the United Nations Convention on the Rights of Persons with Disabilities”¹⁶. This means that the rights of persons with disabilities to liberty, privacy and bodily integrity should be informed by the UNCRPD.

The UNCRPD is clear in its opposition to institutional living and on the right of persons with disabilities to a life in the community. Article 19 reaffirms the “equal right of all persons with disabilities to live in the community, with choices equal to others’ and to “full inclusion and participation in the community”.

It is therefore imperative that the Irish State stops the continued use of and new admissions to these institutions which are a clear breach of domestic and international rights.

¹⁴ IHREC (2017). *Submission to the United Nations Committee against Torture on Ireland’s second periodic report*.

¹⁵ European Convention of Human Rights has been incorporated into Irish Law since 2003.

¹⁶ M.X. v Health Service Executive (2012) IEHC 491

3.3. Living in the community results in better outcomes for people with disabilities

There is a vast bank of research contrasting the outcomes of community living with institutional living and the evidence is beyond debate – individualised and supported housing in the community is far superior to institutions.

Multiple evaluations and reviews of evidence have shown the benefits from moving from institutions. These include: improvements in adaptive behaviour, a decrease in challenging behaviour, increased competence and personal growth, community presence and participation, engagement in meaningful activity, contact from staff, increased satisfaction of persons with disabilities and family, contact with family/friends, social networks and friendships, self-determination and choice and quality of life¹⁷.

Recent research comparing large institutions, smaller group home type living and independent settings in Ireland indicates that outcomes are best for people with disabilities in personalised, community settings¹⁸.

Furthermore, the quality of life afforded by community-based services is better than institutions. As has been shown by the HIQA inspections to date, there can be an overly strong focus on practical issues such as cleanliness or record-keeping but according to the European Network of Independent Living¹⁹ “the fundamental evidence of quality in independent living...is based on whether the support provided enables the individual to live as they wish and to realise their full potential.”

4. Trading one institution for another: implementation of policy on deinstitutionalisation

In the 6 years since the ‘Time to Move On from Congregated Settings’ (TTMO) report was published, of the 1,500 reduction in people living in large institutions only around 10% have moved into their own home.

¹⁷ Multiple papers provide evidence for this. For a brief review of these, see Mansell, J. & Beadle-brown, J. (2010). *Deinstitutionalisation and community living: position statement of the Comparative Policy and Practice Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities*

¹⁸ Mc Conkey, R., Keogh, F., Bunting, B., Garcia Iriarte, E., & Flatman Watson, S. (2016). Relocating people with intellectual disability to new accommodation and support settings: Contrasts between personalised arrangements and group home placements. *Journal of Intellectual Disabilities, Vol 20(2)*, 109-120.

¹⁹ ENIL. (2014). Myth buster: Independent Living

There have been a significant number of people who have died and most have traded one institution for another with a move into nursing homes or other institutions (see fig 1 below). It is also worth noting that a national policy of no new admissions to institutions has not been put in place²⁰.

The number of people making the move to community living is shockingly low. For example, of the 150 people leaving an institution in 2015, less than 10% moved into their own home. Almost three quarters of those who moved actually moved to other institutions with almost 20% moving into a nursing home and 53% moving into an inappropriately occupied home of at least 5 people. A home of 5 or more is explicitly against the recommendations of TTMO. As stated earlier, the size of the institution is irrelevant but it is clear that the larger the number of individuals living together, the greater the chance of the 'qualities' of institutional living emerging.

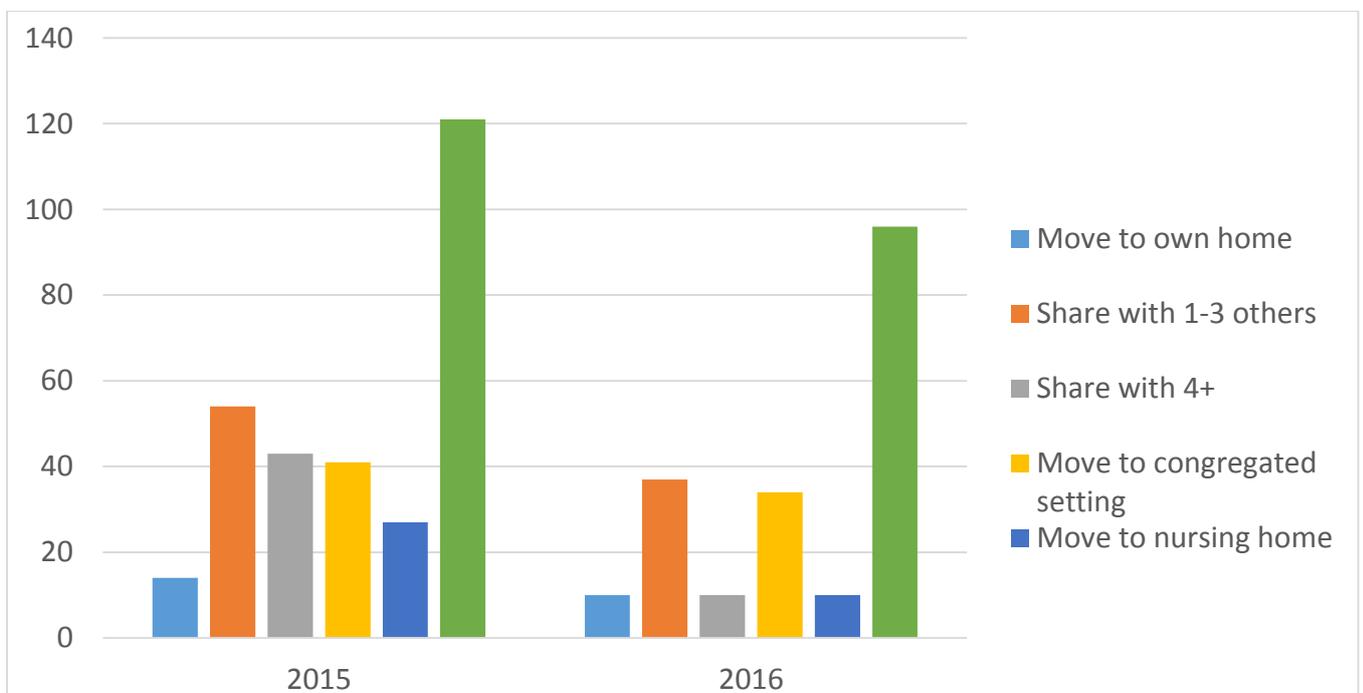


Figure 1. Moves from and into institutions

By 2016, despite significant funds being available for the process, progress slowed. Only 74 people moved out of an institution that year²¹. Sadly, with the deaths of 96 people in 2016, more people died than moved to the community.

²⁰ Correspondence between Marion Meany, Head of Reform, Disability Services, Social Care Division and Louise O'Reilly TD - 17th February 2017

²¹ HSE (2017). *Progress report on the implementation of Time to Move on from Congregated Settings – a strategy for community inclusion, Annual Report for 2016.*

The above figures clearly demonstrate the failure to implement deinstitutionalisation and to support people with disabilities to have the kind of life to which they have a right. However, other data available on the living situations of people with disabilities indicates a much broader problem with implementing policy on deinstitutionalisation and community living in Ireland.

Data available from the National Intellectual Disability Database (NIDD) indicates the high level of institutionalisation of people with intellectual disabilities in Ireland. Of the 28,275 people registered with the NIDD in 2016, only 4% were living in an independent setting. 27% were living in residential settings, many of which have institutional characteristics. Most people were living at home with family members or relatives (69%)²². While many of these are children, many are adults with disabilities who are living at home because no alternative home with the right supports is available.

As stated previously, a person can experience institutional life in a home setting where the state has failed to provide the supports required to ensure a person with a disability can live an independent life in the community²³. Indeed, Local Authority guidelines for housing people with disabilities clearly state that people with disabilities:

“Shall not be deemed adequately housed when their current address is a congregated setting, institution, hospital/nursing home, community-based group home, or when they, although an adult, remain in the family home due to their personal circumstances and/or support needs, including their need for adapted living conditions where the family home is unsuitable”²⁴

Despite commitments on deinstitutionalisation and community living in *Time to Move on from Congregated Settings*, the *Value for Money Review of Disability Services* and subsequent *Transforming Lives* programme, the *National Housing Strategy for People with Disabilities* and most recently in the new *National Disability Inclusion Strategy*, in practice, the state is continuing to operate a policy of institutionalisation of people with intellectual disabilities.

²² HRB (2017). *Report of the NIDD, 2016*.

²³ ENIL (2016). *Submission for the day of general discussion on the right of persons with disabilities to live independently and be included in the community*, p4.

²⁴ Department of Environment, Community and Local Government (2014). *National guidance for the assessment and allocation process for housing provision for people with disability*.

5. Why has 'Time to Move On' failed?

The HSE and Government have failed to deliver 'Time to Move on from Congregated Settings'. Furthermore, there is an attempt to weaken the commitment to deinstitutionalisation in Ireland. The 'Programme for Partnership Government' contains a much weaker commitment to reduce the number of people in large institutions "by at least one-third by 2021 and to ultimately eliminate all congregated settings".

Given the multitude of reports of human rights violations within them and the clear evidence that people live better lives in personalised settings in the community Inclusion Ireland believes that the continued use of institutionalised models of support amount to discriminatory practice against person with a disability. Inclusion Ireland has identified the following factors that contributed to the failure to implement deinstitutionalisation.

5.1 Lack of leadership

It is the view of Inclusion Ireland that one of the biggest barriers to the deinstitutionalisation process has been a lack of leadership from government and from state bodies concerned with health, social care, equality and human rights.

Time after time there have been inconsistent messages and a lack of commitment to the process of deinstitutionalisation. While at times, the Minister for Disabilities has expressed "deep commitment to the policy of decongregation", another comment that "not all people ... will be suitable for transitioning to community living"²⁵ represents a worrying step backwards from Government policy and contradicts all evidence.

While the governmental position has at times wavered, so too has that of opposition TDs. Some have called for the abolition of outdated institutional practices while others have argued to keep institutions open²⁶, particularly it seems, where the institution was in their particular constituency.

Leadership is crucial in asserting the benefits of deinstitutionalisation, to the individual but also to society and the consistent lack of leadership among politicians is a worrying indication that the status of persons with

²⁵ Dáil Debate Tuesday, 18 October 2016

²⁶ For example, see comments made during Joint Committee on Health debate on Regulation of Residential Services for Adults and Children with Disabilities, Wednesday, 3 May 2017.

disabilities is still seen in terms of their 'deficits' rather than their status as equal citizens.

Beyond the political establishment, other state-agencies have failed to show clear leadership on the issue including HIQA, the National Disability Authority and the Irish Human Rights & Equality Commission.

The Irish Human Rights & Equality Commission (IHREC) - failure to use its powers

The resistance of the Irish Human Rights and Equality Commission to use their statutory powers to conduct an inquiry into the continued use of institutions in Ireland represents a failure on behalf of these citizens and has contributed to the continuation of a system where human rights abuses are a daily occurrence for the people who live in institutions.

The Irish Human Rights and Equality Commission Act, 2014 which established the Irish Human Rights and Equality Commission (IHREC) sets out the body's role and provides it with a number of powers.

Its primary functions include:

- To protect and promote human rights and equality,
- To promote understanding and awareness of the importance of human rights and equality in the State,
- To encourage good practice in intercultural relations, to promote tolerance and acceptance of diversity in the State and respect for the freedom and dignity of each person, and
- To work towards the elimination of human rights abuses, discrimination and prohibited conduct.

IHREC' powers include:

- To keep under review, the adequacy and effectiveness of law and practice in the State relating to the protection of human rights and equality;
- To provide practical assistance, including legal assistance, to persons in vindicating their rights;
- To conduct inquiries in accordance with Section 35 of the Act where it considers that there is evidence of (i) a serious violation of human rights or equality of treatment obligations in respect of a person or class of persons, or (ii) a systemic failure to comply with human rights or equality of treatment obligations.

IHREC can conduct enquiries under Section 35 where there is, 1) evidence of a serious violation of human rights or equality, 2) the matter is of grave public concern, 3) and that it is in the circumstances necessary and appropriate so to do.

Inclusion Ireland wrote to IHREC February 2015, following the abuses in Áras Átracta exposed by Prime Time Investigates and the subsequent public outcry. We argued in our submission that the continued use of congregated settings to house persons with a disability; the failure of the HSE and state to close these settings; and the evidence of abuse, inequality and rights restrictions in these settings satisfied the grounds under which they could conduct an enquiry.

We argued that the rate of progress of the deinstitutionalisation process in Ireland would ensure that persons with a disability would remain institutionalised for a further two decades.

IHREC response

17 months after our submission we received a written reply.

The reply stated that the Irish Human Rights and Equality Commission had decided against using its power of inquiry.

IHREC informed Inclusion Ireland that information they had received 'in confidence' from the HSE and the Department of Health held significant weight in their decision not to conduct an inquiry.

The secretive nature of the information IHREC received means Inclusion Ireland is not in a position to comment on its veracity. We can be confident though that the reassurances that IHREC received in regard to the pace of deinstitutionalisation has not been borne out in the subsequent two years.

IHREC stated that the decision not to conduct an inquiry was based on the final part of the 3-part test "that an inquiry is not necessary or appropriate".

As the test is considered to be a cumulative test, Inclusion Ireland assumes from this that IHREC agreed there is serious Human Rights violations in institutional settings and that the matter is of grave public concern.

In reaching its decision, IHREC considered that any inquiry would be examining past events. Inclusion Ireland is at a loss to understand how the ongoing institutionalisation of thousands of persons with an intellectual disability and the continued admissions of people to large institutions constitutes 'past events'. In place of an inquiry IHREC committed to conducting research to conduct 'a human rights and equality analysis' of the implications of the transition of persons with disabilities from congregated settings to community living.

No such research has been conducted.

Inclusion Ireland's Position

The Inclusion Ireland position remains the same, we believe that institutions amount to a serious violation of the human rights or equal treatment of persons with a disability by virtue of physical and verbal abuse, lack of freedom to exercise choice and control in their daily lives, restrictive practices and restraint and a lack of independent advocacy.

We maintain that it is both necessary and appropriate for the Irish Human Rights and Equality Commission to conduct an inquiry as the institutionalisation of persons with a disability is current Government policy and practice.

The Health Information and Quality Authority (HIQA)

HIQA is responsible for the monitoring, inspection and registration of all residential services for both children and adults with a disability in Ireland, at an estimated cost of €5million per annum²⁷.

Since November 2013, all designated centres for people with disabilities, both children and adults, must be registered with HIQA. This involves the service being approved following a registration inspection against national standards.

HIQA has threatened on several occasions to close centres down but not delivered on those threats. An inspection of the Tús Nua centre in

²⁷ <https://www.irishtimes.com/news/social-affairs/residential-centres-for-disabled-to-face-inspections-1.1367765>

Wicklow in October 2017²⁸ found the centre to be majorly non-compliant in several areas including, support to pursue meaningful activities, responses to ongoing peer-to-peer assault risks, inadequate skill-mix among staff, poor knowledge about adult safeguarding and lack of effective fire evacuation procedures.

Media reports stated that despite a warning from HIQA the previous August, compliance remained poor²⁹ and HIQA delivered further warnings relating to registration. Despite residents living in a clearly abusive and risky environment the service was given almost 6 months without improvement without any emergency steps being taken.

In June 2015, a disability unit in Kilkenny, St Patrick's, was deregistered in the District Court in accordance with Section 64 of the Health Act 2007. This de-registration followed a first-ever inspection and was on foot of serious fire-safety and other concerns. The unit was not closed however; instead the HSE took over from the voluntary service provider which operated the centre. Almost a year later, HIQA discovered that the unit had failed to ensure adequate improvements³⁰.

The Health Act 2007 which authorises HIQA to act, designates the HSE as provider of last resort. This means that the HSE can be the funder, commissioner and also the failing service provider. HIQA have called for a robust commissioning model that would separate the functions of purchaser and provider in order to drive improvements in services for people with disabilities. In the absence of a commissioning model, five years on from the start of the registration process, HIQA are continuing to allow failed services to function.

The National Disability Authority (NDA)

The National Disability Authority too has failed to make any public statement in relation to the many abuse scandals or on the governance failings in the Central Remedial Clinic (CRC), Rehab, St John of Gods and Sunbeam House (to name but a few). During one of the most tumultuous periods in the history of disability services in Ireland, which has seen hundreds of HIQA inspection reports disclose ongoing and systemic

²⁸ HIQA report 5415; Published 08 Jan 2018

²⁹ <https://www.rte.ie/news/ireland/2018/0108/931775-higa-bray-residential/>

³⁰ <https://www.rte.ie/news/2016/0602/792920-higa-kilkenny/>

failings across the residential disability sector, the authority has remained publicly silent.

Other Stakeholders

More too is required from stakeholders, such as, unions, service providers and professional bodies to be engaged in the deinstitutionalisation process. Workers must be supported to adjust to new practices that promote the rights of persons with disabilities.

5.2 Local barriers and poor management

Inclusion Ireland, through its community engagement with persons living in institutions and family members, has gathered evidence from service providers, residents and families on barriers at a local level. People have reported:

- A shortage of houses.
- A slow-moving house purchase approval process from HSE estates.
- Lack of access to professional assessments (e.g. occupational therapists) regarding housing adaptations.
- The high cost of renovating houses.
- The pressure to future-proof houses leading to exaggerated renovation needs.
- Increased demand for funding for additional staff.
- Industrial relations issues
- Poor management of the process

There is also anecdotal evidence of failure to provide good quality, accessible and responsive services in local communities, as seen from Case Study 1.

Case Study 1:

Bridget* moved from a large institution recently but her family report that access to services is not what was promised:

“My sister moved to the community in May. In June she needed urgent medical care in the middle of the night. An ambulance was called and a staff member accompanied her to the hospital.”

We felt that her medical needs were well supported. However, now we are being told that the two waking night staff are going to be reduced to one. If this happens it means that our sister may be without support if another emergency situation arises at night. We were assured that in the move to the community, in our sister's contract of care, that the service would continue to provide adequate night coverage. It is extremely worrying that this may not be the case into the future".

Indeed, a recent study found that throughout the EU, the supports that people with disabilities receive to help them live independent lives in the community is not sufficient to meet their needs³¹.

Closure of institutions must go hand in hand with the development of accessible, local services. A failure to provide decent services in the community acts as a barrier to deinstitutionalisation and may result in people with disabilities and families feeling that accessing services was easier in institutional settings.

Anecdotal evidence of poor management has also been reported to Inclusion Ireland, including a failure to manage the transition process in a way that is respectful of the person moving.

Inclusion Ireland is aware of persons with disabilities that have gone through the discovery process to prepare them to move to the community but have been waiting long periods of time to be allocated housing. This kind of poor management undermines the process and results in additional stress and anxiety for both persons with disabilities and family members, as illustrated by Case Study 2.

³¹ EU FRA (2017). *From institutions to community living. Part 3: outcomes for persons with disabilities.*

Case Study 2:

It was agreed by Anne* and her siblings that she would move closer to her family. However, the family report that the work between the existing service provider and a new service provider has been largely left to the family:

“It has been a steep learning curve. The process of moving large numbers of people from the current service has delayed the move for our sister. As a result, she is one of only a few left in this service. The current situation is very challenging with decreased staff and staff that do not know how to support our sister. To move her into a different service has not been a priority. All that we hear is disagreement over funding and housing provision. Her care needs are currently not being met and we are very concerned for her wellbeing if this process is further delayed”.

The report on Áras Átracta "What Matters most" called for the HSE to "Place failing services into 'Special Measures'" including "the external appointment of an interim 'improvement team' which would oversee an 'improvement' action plan"³².

It is the view of Inclusion Ireland that management who have presided over the existence of these settings and the human rights abuses they have perpetuated cannot be relied on to close them effectively.

There is an urgent need for 'special measures' to be put in place to manage the final closure of these large institutions. This is essential to ensure that those leading the closure have the necessary skills to drive the timely transition of residents into the community in a supported, dignified and respectful way.

5.3 Funding of deinstitutionalisation

Concerns have been expressed about the potential cost of community living versus institutions. Even if this were true, high cost would not be sufficient to justify the denial of a basic human right.

³² Aras Attracta Swinford Review group (2016). *What matters most*. P.120

However, the evidence on deinstitutionalisation does not support the idea that there is additional expense and in fact, much like early-intervention, suggests that deinstitutionalisation reduces government spending over time^{33 34}. Despite this evidence, the myth around cost persists and could be seen as an “excuse for maintaining the status quo.”³⁵

The availability of funds does not appear to be the primary blockage to the implementation of ‘Time to Move on from Congregated Settings’. Indeed, it is a level of public investment which is capable of delivering successful supported community living arrangements in many other locations across the country (See Limerick Regeneration comparison, page 24).

Capital funding of €100m over a 5-year period has been made available by the Department of Health and the Health Service Executive to purchase houses in the community. The Department of Housing, Planning and Local Government allocated €10m to purchase houses for deinstitutionalisation in 2016 but only €2.3m was drawn down³⁶.

Apart from these sources of capital funding, a Service Reform Fund was established to assist with transitioning people out of institutions and into ordinary homes. An allocation of €18.7m was made to support transitions out of institutions³⁷.

Rather than just questioning whether sufficient funding has been allocated, it is useful to examine how existing funding is being spent. According to the EU Agency for Fundamental Rights, “deinstitutionalisation cannot happen without significant changes in the way services for persons with disabilities are budgeted for and financed”³⁸.

The UNCRPD Committee has pointed out that in many states, greater financial resources are dedicated to institutional services than community-based services³⁹. This is certainly the case in Ireland with almost two

³³ Mansell, J. & Beadle-brown, J. (2010). *Deinstitutionalisation and community living: position statement of the Comparative Policy and Practice Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities*

³⁴ Jolly, D. (2009). *Research Paper on Community Living and the Support of Independent Living: Costs and Benefits*. European Network of Independent Living.

³⁵ Council of Europe Commissioner for Human Rights (2012). *The right of persons with disabilities to live independently and be included in the community*, Issue paper, p.32.

³⁶ Irish Examiner, ‘Only €2.3 million of disability fund spent’, July 2017.

³⁷ PQ 21.11.17, 48738/17

³⁸ European Union Agency for Fundamental Rights (2017). *From institutions to community living, part 2: funding and budgeting*, p23

³⁹ CRPD Committee (2017). General comment No. 5 on Article 19. CRPD/C/18/1, 29th August 2017

thirds of the entire HSE disability spend of €1.68bn in 2017 allocated to residential services⁴⁰, many of which are institutional in nature.

The UNCRPD Committee has been clear in its direction “that public or private funds are not spent on maintaining, renovating, establishing, building existing and new institutions in any form of institutionalisation”⁴¹. Despite this, the ‘Capital Investment Plan 2016-2021’ includes an investment of €300m in replacing, upgrading and refurbishing long-term care facilities for older people and people with disabilities.

Redirecting funding from institutions to more personalised forms of support, including personal budgets, must happen in order for deinstitutionalisation to take place. The failure of the Department of Health and successive governments to tackle reform of disability services funding indicates the acceptance of institutionalisation of persons with a disability in policy and practice.

5.4 Lack of joined up working

Deinstitutionalisation is not just about the closure of institutions. It is about ensuring that a sufficient range of services exist in the community to prevent institutional care⁴². Likewise, community living is about more than just bricks and mortar.

There are many strands that need to be brought together to implement deinstitutionalisation and to make community living a reality. This requires joined up working across sectors such as housing and employment as well as health and social care to ensure that mainstream services are accessible to people with disabilities and allow for inclusion and choice.

There is an existing group dedicated to monitoring ‘Time to Move on from Congregated Settings’ but this group does not appear to have the power to bring together the various stakeholders in order to drive effective implementation of the policy. This is in spite of the ‘Time to Move On’ report stating that the framework required for this multiagency approach was already well established.

5.5 Negative societal attitudes towards people with disabilities

The myth persists that people with disabilities, and in particular people with complex support needs cannot live in the community. Research in

⁴⁰ HSE (2017). National Service plan

⁴¹ CRPD Committee (2017). General comment No. 5 on Article 19. CRPD/C/18/1, 29th August 2017. P11.

⁴² European Expert Group on the Transition from Institutions to Community Based Care (2012). *Common European guidelines on the transition from institutional to community based care.*

Ireland and internationally has shown that community living is possible for all people with the right supports.

Of those who participated in an Australian study on successful individualised, supported living, almost a quarter had high support needs⁴³. Recent Irish research confirms that people with complex needs can live outside of specialist disability accommodation and in fact, experience significantly higher improvements in wellbeing from a move to personalised settings^{44, 45}.

The supports required must be individualised and can range from informal supports from family, friends and mentors to structured, formal supports from mainstream services, supports from specialist disability services, right up to 24-hour medical support.

6. What can be learned from similar projects?

The implementation of other social housing projects in the past number of years provides a useful example of what works and what is less effective. The regeneration of areas of Limerick provides one such example and is described below^{46, 47}.

Limerick Regeneration Framework and Community Living Transition Plan: A comparison

Limerick Regeneration Framework Implementation Plan was published in 2007 to create safe communities where people enjoyed a good quality of life and a decent home. The plan was a response to the challenges facing communities in Limerick at the time, including crime, anti-social behaviour, high unemployment, high rate of lone-parent families, significant educational disadvantage, high levels of drug-use and, stemming from this, intense negative publicity.

⁴³ Cocks, E. (2016). *Individual Supported Living: enabling adults with intellectual disability to live in their own homes*. Presentation at Inclusion Ireland seminar, September 2016.

⁴⁴ Mc Conkey, R., Keogh, F. Bunting, B. Garcia Iriarte, E., Watson, S. (2016). Relocating people with intellectual disability to new accommodation and support settings: Contrast between personalised arrangements and group home placements. *Journal of Intellectual Disabilities*, 20 (2), 109-120.

⁴⁵ McConkey, R. Keogh, F. Bunting, B., Garcia Iriarte, E. (2016). Changes in the self-rated wellbeing of people who move from congregated settings to personalised arrangements and group home placements. *Journal of Intellectual Disabilities*, 1-12.

⁴⁶ Limerick Regeneration framework implementation plan. Baseline conditions and agendas. http://www.limerickregeneration.org/NewPlan/Baseline_Conditions_and_Analysis.pdf

⁴⁷ Fitzgerald, J., Limerick Regeneration – A Review 2007-2012. *Borderlands: The Journal of Spatial Planning in Ireland*

A former Dublin City Manager led implementation with key officials across government departments and state agencies as well as two independent regeneration agencies.

Housing development was carried out alongside social and community development, including 7 community projects, sports projects, music projects, 2 skills and training centres, community enterprises, community employment schemes, extracurricular school activities, further education grants and family support projects.

There were a large number of performance indicators to measure success of implementation, including youth dependency, employment rates, deprivation scores, progression rates to third level, health and wellbeing indicators and disability rates.

After the initial five-year term, the regeneration agencies were embedded in the local authority and in two community offices.

Although maybe not immediately apparent, there are many similarities between the 2 projects. The population in need of housing in both cases is between 3,000 and 4,000 people⁴⁸. The capital spend on housing is comparable (€102 million over 3 years in Limerick, €100 million over 5 years for the transition to community living). The proposed public sector investment in Limerick over 10 years was €1.64 billion. The cost of keeping people in congregated settings over the 3-year transition plan period alone was over €858 million⁴⁹.

Other similarities include social and educational disadvantage, an environment with exposure to criminality and anti-social behaviour in one case and neglect and abuse in the other, mistrust of the responsible agency, the need for re-housing through relocation and redevelopment and the need for a better quality of life and social inclusion.

⁴⁸ The overall population of the regeneration area in Limerick was 6000 but had approx. 60% dependent population (youth, elderly and people with disability) giving a figure of 3000 to 4000 which is comparable to the original population of congregated settings.

⁴⁹ Calculated using the average cost of congregated settings per person, per year (€106,000) as cited in Time to Move on from Congregated settings

Where the projects differ strikingly is in the level of public and political awareness of the need for both projects. The status and profile of the appointments to the regeneration project was also different. The regeneration project worked through a process of report, vision, consultation and plan with dedicated offices overseeing implementation and measurable key performance indicators.

The initial regeneration agencies were locally based and integrated but also independent in order to allay community mistrust in the local authority. Early recruitment of officers with extensive experience and also local community knowledge was a priority for the regeneration project. Local social, educational and community development work was a key part of the regeneration project.

Unlike the difficulties in Limerick which were in a single location and visible in the news, people with disabilities living in institutions are often invisible and dispersed. Perhaps because of this, the challenges of awareness raising, education, consulting, planning, preparation, recruitment of transition teams, of development of infrastructure and community supports for the move to community were underestimated?

6.1 Learning from Limerick regeneration

The Limerick regeneration project, though certainly not without its challenges and criticisms, illustrates the importance of leadership, political will, good management, cross-sectoral working, having a strong and visible focal point to coordinate work and of developing community-based supports alongside housing.

Both projects are similar in terms of population numbers, scale of housing need, issues of social exclusion and of budget but the priority and focus given to the Limerick project, at least in the set-up stages, was not matched in any way by the implementation of deinstitutionalisation.

By looking at an existing social housing project in Ireland with many areas of similarity, we can learn from what succeeded and what did not.

7. Conclusion: A systemic failure to act

There is no question that deinstitutionalisation and community living results in improved lives for people with intellectual disability. There is no question that the continued use of institutions is a violation of the rights of persons who reside there. And yet, these institutions remain with seemingly little impetus to finally close them.

The timescale identified for people to move to a community setting over a 7-year period will not be met. At the start of 2017, almost two thirds of the original 4,011 residents considered in the Strategy for Community Inclusion remained in an institution. The fact that more persons have died in an institution than moved to the community is a damning indictment of the Irish State's response to this process.

The failure to close these institutions given the multitude of reports of human rights violations within them is symptomatic of a political system that is indifferent to the rights of persons with disabilities.

The failure of government departments to tackle reform of disability services and to hold the HSE to account for delivery of the deinstitutionalisation process signals an acceptance of the institutionalisation of persons with a disability.

Where government fails to ensure the rights of its citizens are protected, those organisations tasked with protecting rights and upholding standards must hold the state to account. Here too, there has been a failure to act to vindicate the rights of persons with disabilities.

The CRPD Committee have called for governments to "establish mechanisms to monitor existing institutions and residential services, deinstitutionalisation strategies and the implementation of living independently in the community"⁵⁰.

With the continuing failure of the Irish State to ratify the UNCRPD, meaning no international monitoring, who exactly is vindicating the rights of the 2,500 people in Ireland's large disability institutions or the many others experiencing institutionalised life in smaller settings around Ireland?

Inclusion Ireland is calling for the IHREC to carry out a full, independent inquiry of the deinstitutionalisation process since 2011 to include their continued use and the admission of new residents, in violation of domestic and international law.

Inclusion Ireland is also calling for the Department of Health to establish an independent national oversight group to review the process to date, carry out an audit of funding allocated to deinstitutionalisation and to complete the move of the remaining persons living in institutions in a respectful manner.

⁵⁰ CRPD Committee (2017). *General comment no.5 on Article 19: Living independently and being included in the community*. CRPD/C/18/1, 29th August 2017

Recommendations:

- The Minister for Health should establish an independent National Oversight Group with involvement from a broad range of sectors that are crucial to ensuring an effective transition from institutional to community living, including representatives from Disabled Persons Organisations. The group should:
 - Drive the closure of institutions by publishing a multi-year, fully costed action plan to move the remaining residents out of institutions into homes in the community with the appropriate supports to lead good lives.
 - Implement special measures and put in place new management teams to drive the transition.
 - Carry out an audit of funding to establish how money has been spent and how much remains to move people to community settings.
 - Investigate the additional revenue that could be made available through the sale of institutional lands.
 - Examine the role that human resources issues are playing in the delay of closing institutions and engage with relevant stakeholders such as trade unions, regulatory and professional bodies.

- The IHREC should carry out an inquiry to:
 - Examine the continued use of institutions and the pace and process of deinstitutionalisation.
 - Determine whether the manner in which deinstitutionalisation has been implemented is in breach of the domestic and international legal rights of persons with disabilities.
 - Determine whether there is a legal basis for the use of community group homes in this deinstitutionalisation process to support people with disabilities.

What's next?

As stated throughout this paper, deinstitutionalisation is about more than the closure of large institutions. It is about a cultural shift in the approach to disability, from an institutionalised model of 'care' characterised by rigid routines, little opportunity to make decisions and paternalistic approaches, to one where people with disabilities are supported to live in the community and to exercise choice and control over their day to day lives.

Discussion on what constitutes deinstitutionalisation and community living in Ireland needs to become broader and take into account the many people with disabilities experiencing institutional life outside of so-called congregated settings.

For community living to be a reality, a number of elements need to be in place including the legal capacity to decide where and with whom and how to live, a realistic option of accessible housing, access to personalised and human rights-based disability and universal services and supports.

Inclusion Ireland will address these issues in a forthcoming position paper on deinstitutionalisation and community living.

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