UN Special Rapporteur on Adequate Housing

Response regarding

Questionnaire: The right to housing of persons with disabilities.

Response with regard to housing circumstances of people with Intellectual Disabilities in the Republic of Ireland. May 2017.

Submitted by Profound Ireland.

This document represents the views of people with Severe and Profound Intellectual Disabilities and shares data prepared jointly with SJOG PF&F Association.

Right to Housing.

Our research concludes that there is no right to housing of persons with disabilities guaranteed in domestic legislation or the Irish Constitution or supportive of any Human Rights legislation. Ireland continues to delay ratification of the UNCRPD.

Statistical Indicators.

Statistical review of the Irish <u>Health Research Board</u> (HRB) National Intellectual Disability Database (NIDD) annual statistics between <u>2005</u> and <u>2015</u> demonstrate a concerning trend in modern Irish Housing and Disability policy.

During the 11 year period there was a net increase of 3,191 people registered on the NIDD database.

- The overall State Party provision of housing for PwID increased by just 38 in 11 years (0.43%).
- The number of people with intellectual disability (PwID) housed in accommodation requiring funded Supported Living (b,c and d below) **reduced** by 349 places (-4.3%).
- The number of PwID being supported by family, in the family home, increased by 3,300 (21%).
- The number of persons with disabilities housed in Residential Centres (Institutional settings) reduced by 1,094 while corresponding provision of additional supported living Community Group Homes (b) increased by just 755, accounting for some transfers under de-congregation.
- At present the vast majority of PwID (19,157) live in their parent's or sibling's home. This represents 68.2% of the total compared with 63.5% in 2005. This reliance on residence in the family home is most unsatisfactory since more than half (9,846) are in the "moderate, severe or profound" categories requiring regular and often constant care from elderly or ill parents.
- While those in the "independent" category, requiring no support staff, have fared relatively well, the numbers in staff-funded accommodation has reduced.
- Overall, less than 4 bed spaces per annum for people with intellectual disabilities have been provided during the last 11 year period. This is the equivalent of only one home per annum.

Conclusion: The Irish State have undertaken measures considered retrogressive under points 40-46 of Draft General Comment No.5 of the Committee on RPD and failed to meet the existing and emerging housing need of PwID and have actually reduced provision for People with Intellectual Disabilities if they require support services to live in the community, with increased dependence on informal support from family.

		% of		% of		%
	2005	total	2015	total	Change	Change
At home (Parents or Sibling)	15,827	63.5%	19,157	68.2%	3,330	21.0%
Independent Living (Minimal or no staffing) (a)	810	3.3%	1,197	4.3%	387	47.8%
Community Group Home (b)	3,502	14.1%	4,257	15.1%	755	21.6%
Residential Centre (c)	3,334	13.4%	2,240	8.0%	-1,094	-32.8%
Other full-time res. (d)	1,237	5.0%	1,227	4.4%	-10	-0.8%
Of which psychiatric hospital)	-396	-1.6%	-154	-0.5%	242	-61.1%
No fixed abode	9	0.0%	9	0.0%	0	0.0%
Insufficient Information	<u>198</u>	0.8%	<u>21</u>	0.1%	-177	-89.4%
<u>Total</u>	24,917	<u>100</u>	<u>28,108</u>	<u>100</u>	3,191	12.8%

Source: Annual Reports of the National Intellectual Disability Database Committee, 2005 and 2015, Health Research Board, Dublin

Is there evidence of discrimination against PwID? The above mentioned 4 bed spaces represents a mere 0.2% of the minimum number of full-time residential places (2,167) currently required (See National Intellectual Disability Database, 2015).

In the case of the general population, a total of <u>91,600 households</u> were assessed as being in "housing need' in 2016 (Housing Agency, 2017). During that year a total of <u>18,300 homes</u> (either constructed or subsidised via the private rented sector) were provided by the government for those households. This represented 20% of total need (Government of Ireland, 2017). It is clear therefore that people with intellectual disabilities are experiencing serious discrimination in relation to housing provision in comparison with the general population in housing allocations.

The housing provision mechanisms preferred by the state (Housing Assistance Payment toward Private Rental Market) are totally unsuited to the PwID housing crisis.

<u>Congregated Settings and De-Institutionalisation</u> <u>Strategies.</u>

As shown in Progress Report on the Implementation of the Time to Move on from Congregated Settings plan a total of 2,717 PwID still lived in residential centres in 2015. This also shows that only 1,300 PwID moved from residential centres, or passed away, since 2005. The key Policy document Time to Move On from Congregated Settings: A Strategy for Community Inclusion, (2011) proposed that:

- All those living in congregated settings would move to community settings by 2017
- No new congregated settings would be developed and no admissions would take place to congregated settings
- The move to community homes would be completed within seven years and minimum annual targets would be set for each year in order to reach that goal.

No new congregated settings have been developed but <u>new admissions have continued</u> to take place out of necessity due to the discriminatory policy towards planning for PwID residing in their family homes. However, the proposal to move all those living in congregated settings within 7 years (i.e. by 2017) has been a significant failure.

Legislation, Policies and Programmes.

"Ireland is Policy Rich but Outcomes and Implementation Poor."

As outlined in above, no legislation, policy or programme exists in Ireland with the intention of providing a right to housing for persons with a disability. A number of official documents do make proposals for change. Time to Move On from Congregated Settings (2011) was mentioned above. In addition to this, the National Housing Strategy for People with a Disability, 2011-2016 stated that the "strategy vision" is:

To facilitate access, for people with disabilities, to the appropriate range of housing and related support services, delivered in an integrated and sustainable manner, which promotes equality of opportunity, individual choice and independent living.

The time frame for the above Housing Strategy has lapsed and has now been extended from 2016 to 2020 and an "Implementation Monitoring Group", chaired by the Housing Agency, has been established to assess progress. See <u>Rebuilding Ireland</u>: Action Plan for Housing and Homelessness Second Quarterly Progress Report (Feb. 2017).

The conclusion must be that people with disabilities have no right to housing and despite calls from academics and a range of organisations that such a right is essential, the various policy proposals make no reference to and do not envisage such a right.

Irish Legislation, Policies and Programmes							
related to Housing of People with Disabilities.							
Title:	Date	Period	Comment				
National Housing Strategy for People with a <u>Disability</u>	2011	2011 - 2016	Government Plan				
Time to Move On from Congregated Settings	2011						
National Housing Strategy for People with a Disability 2011 - 2016: National Implementation Framework.	2012		Government Document				
Advancing Years, Different Challenges: Wave 2 IDS- TILDA	2014		Trinity College: IDS TILDA				
First Progress Report on the National Implementation Framework for the National Housing Strategy for People with a Disability 2011-2016	2014		Government Document				
National Guidelines For Assessment and Allocation Process for Housing Provision for People With A Disability	2014		Government Document				
Progress Report On the Implementation of Time to Move On From Congregated Settings: Annual Report 2015.	2015		Government Document				
National Statement of Housing Supply and Demand 2016	2016	2017 - 2018	Government Plan				
NHSPWD Implementation Monitoring Group Minutes of 8th Meeting on April 19th 2016	2016		Government Document				

Rebuilding Ireland - Action Plan For Housing and Homelessness.	2016		Government Plan	
Understanding Family Strategies that enable Long Term and Sustainable Home Environments for Older People with Intellectual Disabilities.	2016		National Disability Authority / IDS-TILDA	
National Housing Strategy for People with a Disability - Second Report on Implementation Jan 2014 - Dec 2015	2017		Government Document	
National Guidelines For Assessment and Allocation Process for Housing Provision for People With A Disability	DRAFT 2017		Government Document	
Additional Documents are available at:				
https://www.housingagency.ie/our-publications/housing-for-people-with-a-disability.aspx				

As HRB statistics above demonstrate, actual implementation of policies has failed to deliver.

The "Time to Move On from Congregated Settings" plan of 2011 aimed to transition 4,000 People with Disabilities from institutionalised congregated settings into Ordinary Homes in Ordinary Communities by 2017. In 2015, a mere 150 People were transitioned to other arrangements with a further 121 People passing away. Of the 150 that transitioned, 23 (15.3%) were transitioned to Nursing Homes.

During the same period, 41 PwID were admitted into Congregated settings, 46.3% of which were identified as having a Severe or Profound Intellectual Disability.

In 2017, there are still 2,580 people with disabilities living in Institutions, with Government Plans being reduced to a <u>revised target of transitioning</u> only One Third (33%) by 2021.

Policy and Programmes have failed due to a Zero Sum (cost neutral) attitude towards state funding for disabilities.

Simultaneously, provision of appropriate independent living for Adults with Intellectual Disabilities which are currently cared for in their family homes has been <u>unavailable</u>, based almost exclusively on **Crisis / Emergency placement** upon the death or incapacitation of the family carer.

There are NO specific rights to a service or support for a person with a disability in Ireland. The Disability Act 2005 (part II) which provides for the right to an Assessment of need for PwID born before June 2002, has not been commenced.

The Department of Housing, and Local Authorities, are **prohibited** from allocating housing to people with disabilities if there is a requirement for Support Services, unless the Health Service Executive (HSE) will provide certification that necessary support services will be provided. The lack of transparency available regarding HSE figures prevents provision of statistically correct data, however the HRB statistics (above) and communicated lived experience within the ID community demonstrate that there has been close to Zero additional support services being approved other than for Crisis / Emergency provision. There is NO Support Service Funding Planning or Allocation to address the <u>National Housing Strategy for People With Disabilities</u> for people requiring residential and social care support.

Examples to support this perspective are these recent press articles 1, 2, 3.

Policies and Programmes are not sufficiently Outcomes Targeted.

De-Institutionalisation

Please refer to point 4 above.

The primary programme for De-Institutionalisation is the "Time to Move on From Congregated Settings" plan from 2011.

While the plan has been demonstrated to be a significant failure, there is also evidence of an increasing resistance to de-congregation from family advocates of people currently living in institutionalised settings.

Families are concerned that the lack of in-community facilities and activities will result in their Intellectually Disabled relatives being transferred into "mini-institutions" where levels of support and supervision and robustness of services will actually be less beneficial that their current quality of life within institutions. Again, the lack of transparency and empirical evidence and the inability to rely on HSE annual sectoral plans prevents qualitative critique of the actual adequacy of housing and support services in the community.

Responsibility for Overseeing Compliance.

"Ireland has continuously delayed Ratification of the UNCRPD."

Most, if not all, policy and programme initiatives have an appointed Implementation Monitoring Body. Each of these monitoring bodies is excessively dominated by personnel from state agencies and government departments with minority representation of advocacy groups and representatives.

Those organisations which are considered to be representative of people with disabilities and their families are primarily, if not exclusively, funded by the state agencies which are responsible for policy implementation.

Agencies / Institutions relevant to the Policy and Implementation monitoring	
National Disability Authority	NDA
Health Service Executive	HSE
Housing Agency	НА
Department of Housing, Planning, Community and Local	
Government	DHPCLG
<u>Irish Human Rights & Equality Commission</u>	IHR&EC
<u>Ombudsman</u>	

Right to Housing - Remedies

The Irish State does not recognise any legislative right to the provision of housing for People with Disabilities.

There are several policies and programmes which have not been implemented.

Most policies, including the Disability Act Legislation, include a caveat "subject to available resources", with such resources not being allocated to alleviate the increasing disability housing crisis.

Research has failed to identify any judicial or other appropriate remedy.

Initiatives and Role of Special Rapporteur

Accepting that the emphasis of this submission is specific to the Housing Needs of People with Intellectual Disabilities, there is a primary obstacle facing any and all initiatives.

Funding has not been made available for residential living support and social support services, with the Irish Government <u>increasing</u> reliance on the paternalistic provision of housing and primary support by families in significant contravention to the intent of the CRPD (not ratified) as detailed by Points 40 to 46 of the Committee on the Rights of Persons with Disabilities Draft Comment No.5 regarding Article 19 of the CRPD.

Independent research by IDS-TILDA has demonstrated that family support is not viable into the future, yet the Irish Government has failed to plan effectively and, to the contrary, has simultaneously reduced services such as respite which enable carer families to substitute in the absence of a Human Right to Independent Supported Living.

"The Irish State has manipulated the Intellectual Disability community into a position of complete powerlessness within a paternalistic system characterised by continued reliance on a Charity model within a Medical model of service provision."

It is our hope that the Special Rapporteur will shine a very strong spotlight on the situation in Ireland and initiate a comprehensive review and inquiry to highlight the discriminatory culture which is prevalent within the political and senior civil service tiers of our country, with international recognition as a Human Rights violator being the incentive which may be the agent for change.