A Home Not an Institution; Rights Not Charity

Disability Matters Oireachtas Committee 1st July 2021

Short Biography

Ann Marie Flanagan from North Clare: MA Public Administration; a Mental Health Professional, working for Shine for 20 years; Previous to that a Direct Payments Advisor in the UK; currently completing an LLM in Disability & Human Rights Law and Policy NUIG, researching Social & Economic Rights of Disabled People to have a home and IL supports; Article 19 CRPD; co-founder of Disabled Peoples Org in Clare, Director of Independent Living Movement Ireland; 2020 Candidate for Seanad Administrative Panel.

I live in our recently built home with my partner Derek and year 9 son Robert. I use a motorised wheelchair and a Personal Assistant Service to enable me to live my chosen life.

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Cathaoirleach and members of the Committee thank you for the invitation to contribute today. I would like to dedicate this contribution to Jennifer Hynes. Jennifer, as some of you know, is also from Clare, living in nursing home since April 2019, not of her choosing, with no end in sight. She is a resilient and powerful woman, self-advocating to be seen and heard as an equal, wanting to live in the community. And to the warriors of the Clare Leader Forum a pan disability DPO, who believe in the right to live a life with dignity, privacy, equality, respect and autonomy, driven by the mottos; *Rights Not Charity* and *Nothing About Us Without Us.*

Article 19 CRPD coupled with the commitment of the Oireachtas are central to realising our human rights. Like so many others in society a place to call home, is one of the most pertinent issues of our times, impacting a disproportionate number of disabled women, men and children of all ages and impairments.

It's a welcome opportunity to contribute to a narrative of human rights of disabled people with regards to a home, Independent Living supports and community participation.

We need a paradigm shift in realising disabled people as rights holders. Prevailing attitudes and practices interfere with disabled people being recognised as needing our own homes, live, participate and work in our communities, as per our will and preference[1], equal to others.

Disability injustice[2] and ableism are among the key drivers for continued investment in practises that sustain the deprivation of liberty, inequity in accessing justice and lack of supports for independent living. Homelessness is hidden by policies of institutionalisation in residential centres, in nursing homes, in relatives' homes without choice, without a PAS. My contribution to the discourse on the right to Independent Living is to hopefully evoke an urgency to act swiftly, intentionally and empathically, to redress these inequalities and to meaningfully included us in the solutions.

PAS and a home are fundamental human rights. The exclusion of a significant portion of the population from statistics and policy responses to homelessness, housing needs, unemployment etc further normalises the othering and segregation of disabled people. Clumping in PAS hours with home help and home care and without a right to the minimum hours needed, has similar consequences.

Disabled people include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers hinder full and effective participation in society on an equal basis with others [3]. Disabled men, women and children have the same needs for a home equal to nondisabled people. Disabled people are not vulnerable by virtue of impairment but as a consequence of harmful systems. Policies and services that segregate, maintain inequality and fuel ableism as a normative response to disabled people's housing

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[1] Fox, N. (2013) What's Fair? Realising the right to Independent Living for people with intellectual disabilities: what Ireland needs to do. Thesis submitted for the Degree of PhD Centre for Disability Law and Policy, Faculty of Law, National University of Law, Galway

[2] Disability Justice, https://disabilityjustice.org/justice-denied/dehumanization-discrimination-and-segregation/

[3] UN, Article 1, https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-1-purpose.html

and independent living needs. It limits the meaning of a home; community participation; private and family life.

The majority of society understands disability through a non-disabled lens, which reduces the rights of disabled people. Consequently, disabled people are disproportionately impacted by deprivation including homelessness. Systemic ableism assigns value to appearance, ability to reproduce, earn, and ascribed behaviours; evaluating a prescribed inability to conform to a constructed idea of normality, intelligence and productivity[4].

The terms homelessness or a home when describing disabled peoples living situations are not generally ascribed. It is assumed we either remain in the family home with aging parents or live in institutions in the form of residential care, nursing homes or hostels. It is normalised to such a degree many family members believe that institutions are where disabled relatives need to live for their own safety.

Wasted Lives report made for difficult reading; I want to thank Mr. Tyndell for giving a voice to the 1300 young people in nursing homes for older people through no fault of their own, other than having an impairment that requires independent living supports, and a lack of recognition of their right to autonomy, privacy and dignity in their own home. For too many, the lack of informed consent and belief that it would only be for a short while, tuning into years, is harrowing. To learn that 4 people have died since the publication, 20 more young people are in nursing homes with a meer18 people being supported to leave this year is devastating. [5]

Still there remains 3000 people living in congregation settings, living in spaces with 10 or more other people, with no tenancies, no control over the decisions regarding what happens every day or times of activities, who supports them, segregated from communities and families, at greater risk of having a poor quality of life compared to people who live in the community. They continue to live in unsuitable, outdated accommodation. Important aspects of everyday life are unavailable such as the privacy of their own room, access to their own kitchen or laundry facilities.[6]

We have no statistics with regards to the number of people who are forced to live with elderly parents or relatives do to the lack of vital supports such as PAS. Its assumed adults with disabilities living in family homes choose it. Many do not. It keeps people in poverty traps, forcing disabled people to resort to relatives becoming “carers”, becoming passive dependents, oppressed, depressed, exclude from the homeless, unemployment and other vital statistics and data informing public policy.

We have to examine the €2 billion spend on specialised services through the lens of disabled people. We need question the assumptions that residential care, years in day services with little progression, going into residential services to give respite to family members, segregated from community life are what disabled people want and need. We need to move

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[4] Jamelia Morgan, Reflections on Representing Incarcerated People with Disabilities: Ableism in Prison Reform Litigation, School of Law, University of Connecticut, 2019

[5] Wasted Lives, Ombudsman, 2021

[6] HIQA, https://www.hiqa.ie/hiqa-news-updates/people-disabilities-living-congregated-settings-have-poor-quality-life-hiqa

beyond service led models that perpetuate paternalism, and certain disabled people cannot live independently, or need and want a home and family life[7].

The consequences of systemic and cultural ableism, discriminates and normalises segregating disabled people. For example the images on our screens, news reports on radio, political debate and conversations about housing and homeless individuals does not conjure up images of homeless Disabled parents, homeless Disabled children, Disabled rough sleepers. When in fact one in four people who on the Social housing waiting lists and are homeless are disabled people.[8]

The need for a home and independent living comes in many forms:

A mother with MS, one leg too heavy to lift any more, she can’t use crutches as her hands are too weak. She has her 4 children, ages 12, 9, 8, 3. She in living in emergency accommodation. Her children go to school 3 miles from the hotel. Their lives are unbearable. Her pain and fatigue makes it more difficult. Stress is exacerbating it. Her need for a home is urgent. Her keyworker is hoping to have a place in a Homeless Hub. Not a home!

The parents with their 3 children, one of whom has a physical disability, looking for emergency accommodation. The Landlord sold their home. Father has had to reduce his hours to help. Mother lost her job. Their child’s access needs make it difficult to find a house.

The disabled mother in a domestic violence situation scared for her children and herself. She cannot leave with her children because she does not have PA hours and the shelters cannot accommodate her, and her hoist. There is no end in sight.

The university graduate in her early 20’s forced to refuse a permanent job in the city, because she lost her PA hours funded by Department of Education while in university, the HSE put her on a waiting list, so she cannot stay in her shared house, has to move down the country to live with her sister and her family, sharing a bedroom with her young niece, forced to remain on Disability Allowance, sinking into depression with no career options where she is, eventually she ends us in a Day Centre.

The 39-year-old woman who left her home to go to hospital and was moved to a nursing home, forced to relinquish her LA house, where weeks turn into 3 years, still waiting for supports, locked in her bedroom for most of a year during Covid, when she can go to the Day Room patiently spends hours repeating the same few sentences to the same older people in their late years with advanced dementia, her life ebbing away.

The 27-year-old woman, who arrives at the homeless clinic mid pandemic in a rural town with her bags and asks for emergency accommodation, refused support, they insist she returns home to her father’s council house, she explains she can’t in a distressed state, she moves between friends sofas, she’s refused HAP, her mental health deteriorates until she is

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[7] Fiona Keogh, Expert Reference Group on Disability Policy, REPORT OF DISABILITY POLICY REVIEW, http://www.fedvol.ie/_fileupload/Next%20Steps/ERG_Disability_Policy_Review_Final.pdfaccessed January 2021

[8] IHREC and ESRI, Discrimination and Inequality in Housing in Ireland” IHREC and ESRI report https://www.ihrec.ie/discrimination-and-inequality-in-housing-in-ireland-set-out-in-new-research/), 2018

involuntary admitted by the gardai, devastated and hopeless, eventually given temporary accommodation, remaining fearful.

The 30 year old woman with an intellectual disability who moved from her family home, to a shared a house with two others, whom she did not choose to live with; described as community living. There is only one support staff daily so she regularly has to do what others want, they go in a small groups, as she is not allowed to do things on her own or the staff member is too busy. She is upset and getting depressed. Because of her label of ID, she is not heard.

Disabled people need to be recognised as having social and economic rights: to a home with the necessary infrastructure and supports. Disabled people need to be heard. People who are categorised as having "complex needs", those with intellectual disabilities, people with significant mental health issues and people with high physical support needs deserve to be supported to live their chosen lives, equal to others.

Article 19 of the UN Convention states that disabled people have a right to live with who we want and where we choose with the supports needed on an equal basis to others[9]. This article does not select people depending on impairment or perceived capacity. It means every person.

It has long been accepted in Ireland and internationally that PASs offer Disabled people independent living yet after 30 years since its inception it remains less than 5% of the total budget for disability specific services, and only people with physical and visual impairments can access it. People needing support in making decisions continue to be victims of Wardship under the 1871 Lunacy Act. It must be repealed urgently and the Assisted Decision Making Act 2015 fully commenced on time. These outdated laws and policies feed an ideology that people with significant impairments are subhuman[10], a drain on the finite resources. These policies and practises maintain structural and systemic institutionalisation of disabled people.

It is not all about resources. To make sustainable, meaningful change, the state needs to support the involvement of those directly impacted. There are many ways to do this. Seek out disabled people who are critical thinkers and solution focused. Capacity build disabled people when necessary. Include people with different impairments and cultural backgrounds. View disabled people with the same value as consultants. We are the experts. We have the solutions. We can support you as you support us.

I hope you continue with fundamental human rights as the drivers for your work, with sustained dialogue with and inclusion of disabled people at all levels regarding policy, law, finance, systems change.

Míle buíochas....

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[9] European Network on Independent Living, The Right of People to Live in their Communities, http://enil.eu/wp-content/uploads/2012/03/CommDH-IssuePaper20123_E.pdf

[10] Disability Justice, https://disabilityjustice.org/justice-denied/dehumanization-discrimination-and-segregation/