



Living My Life Demonstration Housing Project



Living My Life : Demonstration Project Launch

03 November 2023

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Before I begin, on behalf of our young adults with **Intellectual Disability and the Proactive Carers**, we would like to thank you, **MacDara Hosty**, for taking on the role of voluntary independent chairperson of the Steering Committee and for your belief in our vision. Intellectual Disability will often be referred to as ID henceforth.

Minister, distinguished guests and friends

1. **A momentous day!** After years of struggling, today marks the day officially that a vision, a dream is to be realised. We, the ProActive Carers based here in Galway, have worked tirelessly as advocates for our young adults with an ID for many things over many years. But today marks the day we celebrate the feasibility of **our goal** in securing supported housing for our young adults through this pilot scheme of 32 places in the **Living My Life project**.
2. **As parents and guardians we all worry** about our young adults finding their way in the world, enrolling in college or an apprenticeship, securing a job and so on. But deep down we know that with a little



Living My Life Demonstration Housing Project



- help (namely financially) they will at some stage. However for our young adults with special needs it is not as simple as that, it is **not the rite of passage** that's taken for granted. But, I ask you, why isn't it?
- The thinking in recent years has thankfully changed.** Society now reflects a shift, I'd call it a seismic shift, from paternalism (the traditional institutional model) towards empowerment of people with disabilities. There are many reasons for this, most notably the adoption of the human rights treaty, the UNCRPD by the United Nations in 2006 to protect and reaffirm the human rights of disabled people. Our own government signed this in 2007 **BUT** it took 11 more years to be ratified and even then with some exceptions. **Article 19** of this treaty states that our young adults have the right to **'live in the community with choices equal to others'** and to **'have the opportunity to choose their place of residence and where and with whom they live'**. Fine words. Rights are one thing but enactment is quite another! Today we here in Galway are about to honour that.
 - The Assisted Decision-Making Act of 2015** or more commonly called the **Capacity Act** is **another important step** in progressing the rights of people with intellectual disability although it applies to everyone not just to people with ID. It is linked to our **Constitution**, to the **European Convention on human rights** and to the **United Nations Convention** on the rights of persons with disabilities. It is a **legal framework** which assists people with limited capacity to have more of a say in their own lives **and** to make personal choices. This ultimately leads to what I earlier referred to as **'empowerment'**. The person with disability is enabled to basically live their own lives on their terms. Sounds pretty simple!
 - However central to all of this is support.** None of the lofty Acts and Treaties mentioned would be possible without back up. As parents and carers we are fully cognizant of this. It is a **constant worry for** us about our young adults with ID and their ability to navigate this world independently. Sometimes our own desire to protect them from potential harm can override their wishes and create barriers to their own self-determination. We have had many discussions on this **but** we are all agreed this **Living My Life** project is the way forward. **As carers it is a giant leap forward for us too.** We know there will be challenges but we are willing to at least try.



Living My Life Demonstration Housing Project



6. **So how did all of this come about?** Our group, the Pro Active Carers has many members and we are in existence for 10 years. The original committee was working on behalf of 64 young adults with ID who through their families had expressed an interest in supported 'independent' living. Now this has grown to 126 in Galway city & county. That number is expected to increase. The following **core members** have contributed so much over many years. They are: Áine Hickey, Áine Ryan, Claire O Keane, David Davenport O Connor, Dorothy O Connell, Frank O Connell, Monica McAnena, Sandra Byrne and myself, Josephine Moran. Even with the UNCRPD, the Capacity Act and various policies regarding person-centred planning we identified a '**niche in the market**' so to speak. **In Ireland there are 66,600 people with ID and over 55% of adults with an intellectual disability are living at home with a parent or parents.** What happens if a parent, for various reasons, can no longer be in a position to care for the adult person with a disability? Emergency accommodation, **only if available**, would be provided by the Service Providers. What happens if the young adult with ID wishes to live independently? Or even semi-independently? The family have to organise it and apply to the waiting list of their Service Provider. **There is no automatic entitlement to housing.** Even on Council housing lists no category existed for intellectual disability. Our young adults were the **Hidden Homeless**. However, ProActive Carers have since pushed for and acquired intellectual disability to be categorised on Council housing lists.

Our group decided to visit different places in Ireland where Service Providers were de- congregating and setting up schemes to allow housing to happen. **But this was all within their own annual, allocated budgets which were already stretched to the maximum.** We invited groups to speak and collectively gained momentum in our quest. We met with various politicians, housing agencies and different groups and attended many meetings about our proposed plan. To some public bodies this was completely new, seemingly ambitious and quite honestly daunting! **But ... nobody said 'impossible'.** (Well at least not to our faces!) **We were a determined bunch!**

7. **We held Zoom meetings during Covid with Service Providers** namely Brothers of Charity and Ability West. They were fully



Living My Life Demonstration Housing Project



supportive but the old 'funding' issue kept raising its head! Our members knew monies would have to be **ring-fenced** if it were to succeed. As a group we suggested the idea of a Pilot Project to house people with Intellectual Disabilities. **Things progressed rapidly when the Service Providers submitted a proposal regarding our supported housing project for the 2022 Budget.** Minister, Ann Rabbitte came on board and met with Frank and Claire of the ProActive Carers. Minister Rabbitte's belief in and commitment to our young adults with ID has been inspirational to all parties and to her we are exceptionally grateful.

8. **The main objective of our group** is to ensure there is a system put in place for Carers of young people with ID in providing an opportunity to move into Supported Living **before** an emergency situation or the **death** of a carer might arise. In fact we envision that this will become a National Programme for the future and will act as a blueprint for the rest of the country. **We see this as an interdependent act between adults with ID, their families, the HSE, the Service Providers, the councils and housing agencies.** We acknowledge that our young adults need support at every step along the way and this is a vital part of the journey.
9. **The ProActive Carers wish to thank** the following people who shared our journey and vision: Firstly and in particular **Cathy McGrath** from Disability Federation of Ireland: Cathy helped us through many meetings, emails and phone calls to organise ourselves, to focus on what was important and generously helped us achieve our goal. She also helped liaise with other housing programmes around the country. **Audrey Pidgeon** of **Ability West** who was instrumental in getting the Minister on board and was fully supportive. **The Bros. of Charity** in particular **Sean Conneely and Marina Moore** for their continued support. **Sandra Byrne** from ProActive Carers who provided this venue for the launch and a room on many occasions for numerous meetings. **Claire O Keane and Frank O Connell** from ProActive Carers who formed part of the Steering Committee. A special mention must go to **Ann Boland** who was one of the founding members of ProActive Carers. Ann worked tirelessly until she sadly passed away two years ago. **All the original and current ProActive Carers and their families** including the Burkes, the Cunninghams, the Heneghans, the Hynes' and the Nolans. Please forgive any omission.



Living My Life Demonstration Housing Project

And our Minister, **Ann Rabbitte** who secured funding and supported us all the way. **Míle buíochas ó croí.** Our young adults are at the cusp of living **the shared vision** of the **ProActive Carers, Ability West, Bros. of Charity and the HSE.** At this point we would like to wish our newly appointed team of Olive, Kara, Síofra and Aoife well in bringing this project to fruition. To all our **young adults with ID** a special thanks. **YOU** are the reason we are here today. **YOU** deserve this and more. **YOU** light up our lives and the communities in which you live.

10. And finally in the words of **George Bernard Shaw** and quoted by **JFK** before the Irish Parliament in 1963: **Other people see things and say 'why'. But I dream things that never were and I say, why not?'** To our young adults with ID **we say: To live an ordinary life in an ordinary place.....WHY NOT?!**

NOW, HOW EXTRAORDINARY WOULD THAT BE? Míle buíochas.
Thank you.

Proactive Carers Galway, PCG

Proactive Carers Galway is a group of parents of adults with intellectual disabilities, representing up to 60 families living in Galway city and county. They are committed to securing **community based supported living for their adult children.**



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Example of ongoing support needs subject to housing provision:

- Sharing with 3 or 4 others with carer support
- Support requirements are not 24.7 but rather ad hoc throughout key points of contact in morning, evening and at night (7 days per week)
- Transition support and training required initially full time and gradually reduced according to capacity
- Overnight care / support Initially possibly daily support to ensure everything is going as it should and then gradual withdrawal until there is at least a weekly visit and a local support person to call on when required and for security
- Visiting support once a day
- Weekly support
- 1 night respite per month

CONTACT / FURTHER INFORMATION

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