



Time to Move on Newsletter February 2021 Edition



Welcome, to this edition of the Time to Move on Newsletter, covering the February 2021 workshop on Taking a Rights Based Approach

Genio and the HSE have hosted a series of workshops in December 2020 and February 2021 to explore a range of key topics. This newsletter covers the February 3rd workshop on the topic of taking a Rights Based Approach in the delivery of disability services, with a particular focus on the decongregation process.

The workshop provided an opportunity for service providers to come together to view presentations and hear the evidence gathered by Genio Researchers in 2020 through their targeted interviews with service providers. At the workshop, the research team presented an overview of the key findings that had emerged under this theme. There was also valuable inputs from Mayo Community Living and Inclusion Ireland who presented on the day.

An overview of the February 3rd workshop is provided in this newsletter and if you would like email copies of the presentations from this or any other of our recent events please email us at timetomoveon@hse.ie



This event was attended by over 70 participants from 47 organisations and services.

We wish to thank all of those who took the time to present at the workshop:

***Maura Gavin, Mayo Community Living
Mark O'Connor, Inclusion Ireland
Dr Ciara Brennan, SRF Researcher***

We also thank our colleagues that facilitated the break-out rooms and everyone that contributed in those discussions on the day




Transforming Lives

Programme to implement the Recommendations of the "Value for Money and Policy Review of the Disability Services in Ireland" report

What the research tells us about

The gaps between human rights theory and what is happening in practice

This is a challenge for services and staff in terms of:

- Understanding the national drivers
- Implementing a top-down national policy on decongregation
- Enabling drivers for practice where there is a gap between theory and practice
- Navigating the regulatory and policy environment- HIQA, government policy, UNCRPD

The research gives us examples of what is happening from a staff perspective:

Where we see Rights Infringements	Where we see good Human Rights practice
Congregated settings have a significant impact on residents behaviour, lifestyle and wellbeing	Leadership that recognises challenges & supports the dismantling of inappropriate practice
Issues of staff being "oblivious" due to a level of institutionalisation, which means practice does not uphold human rights	Personal accountability of individual staff - moving away from group think - away from the way things were always done
There are some abysmal living conditions	Reduction in medication – looking at the causes of behaviour and managing those rather than the behaviour
	Nipping poor performance in the bud

UNCRPD Article 28
"The right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions"

Mayo Community Living: *Reflections on Building the Foundations for a Rights Based Approach*

- Management buy-in and support
- Identifying the mission, vision & values to promote and uphold a rights based service
- Teams hold a firm belief and commitment to the project
- Supporting staff development to adopt the new mission and vision
- Recognising it is a massive piece of work with staff
- Disability is not a defining feature. We are all people first
- Focus on language & pay a lot of attention to it
- Rights and entitlements as a citizen
- How our lives look different to the people we support
- Recognise the devaluation of people and what we can do about it

*What do we call people
 We call them people.*



What the research tells us about

The rights-based approaches being taken when supporting people to move from conareated settinas to the community

The research highlighted where services:

- Focus on staff strengths and taking a collaborative approach as a team
- Have a stand-alone transition team with requisite skills & training
- Matching the needs and preferences in new community homes- involving staff, families, and the person throughout the process
- Pursuing personalisation regardless of a person's ability to express their preferences verbal.
- Following a meaningful discovery process to capture what the person wants – “some people want to move with their pals, but sometimes it isn't what they want”

Mayo Community Living Reflections on getting started with a Rights Based Approach

Enabling the practical changes for People

- People registering with a GP
- Choosing their pharmacy
- Applying for social housing
- Taking up a tenancy with an AHB
- Getting Photo ID, & Public Services Card
- Getting a full Medical Card
- Having a keys to their own home and their rooms
- Having a safe in their rooms

Working with the People we support

- A lot of consultation with residents, asking people what they want.
- Building Profiles and capturing individual stories : Getting to know people in a different way
- Looking at peoples history- who are they, their family, their background
- Focussed on what practically in a person's life is non-negotiable
- Focussing of roles rather than “time filling”
- Independent advocacy for those that needed it
- People supported to have more of a say – weekly meetings
- Easy read documents, complaints and feedback forms

Supporting Staff & Culture change

- Intentionally looking at language
- Finding champions of change in the organisation
- Set about supporting staff - recognise the efforts before the process
- Don't label “everything old is bad, everything new is good”
- Human rights training for staff
- Human rights policy and committee
- Staff supervision and training
- Operational and transition work need to be kept separate to keep it all on track
- Closing of centralised services provided opportunities of “everyday services”- cooking in the home even in the houses on the campus



What the research tells us about

the role that staff play in developing a rights-based approach to service provision

The research **highlighted the views of** staff and managers on the role they play:

- It is fundamental that all people are recognised as rights holders
- Moving from being protective to stepping back to enable independence
- It is a balancing act to encourage choice and preference, promote rights but keep someone safe
- Addressing culture, “lifting shackles of institutional settings”
- Creating safe spaces for staff to reflect
- Support and sustain the process and make sure it is moving forward
- It is humbling to discover how little we knew about people

*We **knew** a lot about people- diagnosis, labels, medical history. But we did not **know** the person*

UNCRPD Article 12

*“Persons with disabilities have the right to recognition everywhere as persons before the law”... “safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, **will and preferences of the person**, are free of conflict of interest and undue influence, are proportional and tailored to the person’s circumstances”.*

Mayo Community Living

Reflections on the role of staff and embedding a Rights Based Approach

For the people we support, we must recognise:

- Lots of work can and should be done before people move- enhancing their QOL in interim
- Need to ask the right questions, but it is an ongoing process that never ends. There are always new questions and things to learn
- People change their minds! Nothing is stagnant and people make choices that are easy rather than what they really want, so we need to support ongoing moves.

*There are **33** bathrooms in the new homes and **no two** have the same tiles!*

Decongregation is a daunting but very rewarding journey.

No two journeys are the same.

Supporting the ongoing journey:

- Support people to show up as customers, consumers in the community
- Promote personal development and working on a culture to promote positive risk- having time alone, travelling independently.
- Celebrate successes and reflect
- Pay attention to how homes “stand out” in the community: bright lights on all the time, bins left out, lots of cars in the driveway
- Identify your “**Go To**” people: who to ask when you don’t have the answers
- Supporting people to live a good life as a member their community
- Avoid institutions of one



Inclusion Ireland:

19 Stories of Social Inclusion – Ireland: Stories of Belonging, Contributing and Connecting

There is a rich policy framework to work within moving to personalised services with a human rights basis– New Directions, Time To Move On, The National Disability Inclusion Strategy, the Personalised Budgets project.

General Comment 5 that links across many UNCRPD Articles provides a good focus “The right to be included in the communityin all spheres of life”

<https://inclusionireland.ie/19-stories-of-social-inclusion/>

Key points from the presentation and Jenny’s story that was shared on the day:

- During the interviews for the 19 Stories project there was little talk of “disability”
- Focussing on a person’s will & preference, their strengths & interests
- It is much more than moving from one setting to another
- Time needs to be spent “discovering” the person
- What can make a person happy is doing normal activities, the stuff we take for granted.



Feedback from the Breakout Rooms

What has been the experience of services taking a rights-based approach?

- Rights based training is crucial to keep away from institutions of one
- There has to be a strong culture and element of trust in staff to deliver person centred, rights based support on a daily basis
- Even for services that do not have “congregated settings” there are issues around congregated support and institutional practices
- Looking at our own lives compared with that of the people we support, our lives are very different in terms of relationships, lifestyle, choices etc., which brings into focus how much more needs to change
- Different funding streams and sections of service provision fragment people’s lives : day, residential, community, mental health
- There are challenges in society to accessing mainstream services on an equal footing
- Policies and procedures need to be amended to support human rights

What did you learn from the Workshop?

- The importance of language
- Leadership and ownership will take time and effort from all staffing level to support a rights-based approach.
- There is no end point, it’s an ongoing effort
- Services have moved from caring and minding people to focusing on peoples will and preference
- The challenge of people not being accepted into community
- How services have pushed back by leaving negative reviews on social media when attitudes & responses are poor.
- The pressure point of supporting “independent living”- when a person makes lifestyle choices that are potentially unsafe or detrimental to their wellbeing

What will be your focus after the Workshop?

- Look at the language we use
- Keep will & preference at the centre of what we do
- See each person as an individual
- Educate staff with Human Rights training
- Give staff time to digest new knowledge and embed a human rights approach
- Have a Rights Committees with an external Chair
- Review all policies and procedures
- Have a clear position in terms of litigation and our responsibility as service providers when people make bad choices
- Bring families on the journey with us and support people on an individual basis.

