

# De-institutionnalisation and the importance of Independent Living

26 June 2025
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### What is an institution?

- isolation and segregation from the community;
- no or limited influence over whom one has to accept assistance from;
- lack of control over day-to-day decisions, such as what time to get up, what to eat, who you spend your free time with, etc.;
- lack of choice over whom to live with;
- not being able to decide freely when to visit friends or family, or having this decision taken by someone else;
- facing restrictions over if and when one can have guests over;
- rigidity of routine irrespective of personal will and preferences;
- Imposing group activities under the authority of the service provider

# Recommendations for independent living and inclusion in the community

#### Preventative action

Invest in the prevention of institutionalisation happening in the first place through actions such as:

- Financial support for informal carers
- Guidance for families on managing certain medical conditions
- Guidance on understanding support systems and planning for the future
- In-home support for the person with disabilities and their family
- Mechanisms to retain personal links to one's family and local community
- Support in finding employment and managing finances
- Support in finding or retaining accommodation in the community

## Supporting people leaving institutions

Ensure adequate support for all people leaving institutions. This should take into account the following:

- 1. Providing accessible information and support to persons with disabilities who had been living in institutions to clarify what their options are for accommodation and support services outside of institutions.
- 2. Accompanying former residents of institutions in their transition towards living in the community and assisting in readjusting to a life based around their own choices and control.
- 3. Rebuilding links with families or friends, if this is what the person wishes.
- 4. Dealing with the psychological and physical trauma people have experienced in institutions, through access to rehabilitation, therapy, support groups, legal support etc.
- 5. Providing opportunities for employment, education, etc. of former residents

#### Personal assistance

Greatly increase the <u>budget given to personal assistance schemes</u>, in order to make it a viable option for people who want it.

In order to make personal assistance programmes work for persons with disabilities, it is essential to:

- Increase the amount of personal assistance that is covered by the State, in line with each individual's support needs;
- Reduce waiting times for people who have applied for State-funded personal assistance;
- Make sure personal budgets go to the person requiring personal assistance rather than going directly to the service provider.

# Accessible and affordable housing

- Adopt housing policies that increase the <u>availability</u> and <u>affordability of accessible housing</u>, including through social housing projects.
- Put in place housing support that enable persons with disabilities and their families to remain in their homes.



#### **Accessible communities**

- Invest urgently and ambitiously in improving the accessibility of communities for all people, particularly persons with disabilities. Making sure that public spaces and buildings are accessible, as well as all forms of public transport and public services.
- Big investment in making housing accessible. Ensuring that all new-builds are either readily accessible for persons with disabilities or can be easily and inexpensively rendered accessible. Retrofitting existing housing to be made accessible wherever possible.

## Support for persons with intellectual disabilities

- Independent living does not mean complete autonomy
- Means having choices
- Important to have support workers that understand these choices
- When non verbal, that can understand a person's expression of preference
- Particular care with presenting information in easy-to understand formats

### The role of technology

- Access to affordable assistive tech can improve independence
- Can in some cases reduce reliance on assistants (although should never replace human assistance)
- Can improve communication with personal assistants and clarify what a person needs
- Can help arrange when different service providers will be offering support
- Important to raise digital skills for persons with disabilities

### Training for support workers

- Familiarity with a person's rights under the CRPD
- Ethos of supporting a person with disabilities in how they want to live
- Taking cues from each person with disabilities no onesize-fits-all approach
- Increasing importance of learning how to use technology in supporting persons with disabilities

### Thank you for your attention

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