

What does family and community-based living reform mean in practice?

Finnish experience

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Towards Inclusion

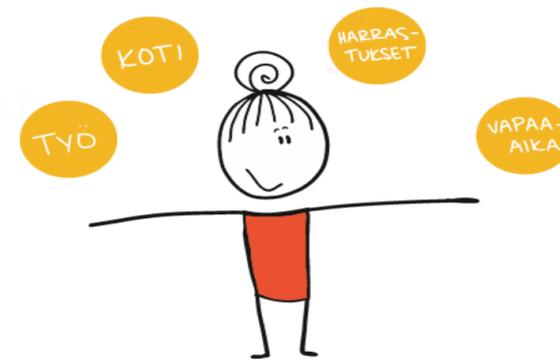
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Situation in Finland today

- In 2010 in Finland there was around 4216 person with intellectual disabilities living in institutions. In the end of 2018 the figure was 531.
- In Finland we have around 40 000 people with intellectual disability, 31 000 adults
- 12 000 of the adults are living in different kind of housing services, 9000 independently, 9000 with their families and 1000 in inadequate services.
- **Our system has been based on regional insitutions but this has changed**
- Legislation is based on inclusion and support needs, not diagnosis. This is also under development and transformation at the moment
- The most common living arrangement is a group home

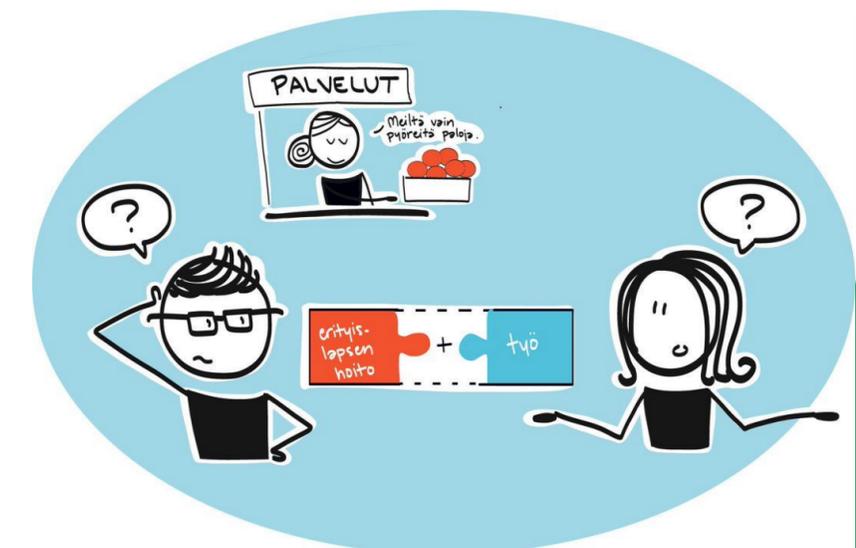


What has happened in Finland in terms of deinstitutionalisation?

- **Programme for organising housing and related services for persons with intellectual and developmental disabilities in 2010–2020**
- The aim of the housing programme has been to facilitate individual housing for persons with intellectual disabilities in ordinary living environments and thus to reinforce their social inclusion and equal treatment in communities and society.
- The development objectives for disability legislation in accordance with the Government Programme, the guidelines of the Finnish Disability Policy Programme and the UN Convention on the Rights of Persons with Disabilities define good housing as an important basis for independent living and social inclusion. Services are following the principles of UN Convention –support for the different areas of life
- The aim **is full citizenship and equal rights**. Legislation is giving a solid background for this, but at practical level there is lot of work done
- Services are good quality (still), but there is a lack of control and self determination. **Participation** has been the key work for last years, but we are still looking for different tools and methods to involve people with disability and their families fully

What has happened in Finland in terms of deinstitutionalisation?

- The aim of the housing programme for persons with intellectual disabilities has been to enable individual housing for both persons moving from institutions and childhood homes in accessible and functional flats in ordinary living environments. National Plan and resolution were published in March 2012. Main principles and areas of action were:
- Individual service design in all the phases of the process; taking into account individual needs and hopes when planning and providing services
- Respecting the rights of service users and involving them to the decision making process
- Developing new models for organising support at the same time when closing institutions
- Enough well-trained staff who is committed to work according common values
- Living in normal residential areas, not in the areas of institutions
- Different options for housing
- Not complexes for the different groups of people needing special support
- No big housing units
- Support for the transition process
- Not emphasising deinstitutionalisation but development of new solutions
- Tailor-made services which meet the needs of people



What has happened in Finland in terms of deinstitutionalisation?

Mid term evaluation on 2017 captured the main areas which need action:

- Self determination and freedom of choice of people with disabilities must be strengthen
- Evaluation of the needs of individuals and individual service design based on this.
- Ensuring the rights of disabled children for common childhood and supporting families in their everyday lives
- Many kind of living arrangements should be available
- Development of skills of staff, practices and working conditions
- Collaboration of different stakeholders



Success factors



- Strong international legal framework (UN Convention), as well as strong national legislation
- Political commitment on national level has been very important for the whole process.
- There is much more understanding for the fact what does living in institution mean for individual and that everyone has a right to have a home in community
- Good practices on local level have been developed
- Staff is well educated

Barriers

- Aggressive public procurement strategy has changed many things
 - Small providers have difficulties to survive
 - Strong position of big for profit companies
 - Service structure has become very standardized, the main solution always is the 24/7 group home
 - New institutionalisation process
- Choices of people are very limited in many areas. Also, lot of inequality between areas in terms of range of services and staff
- Self determination of people and families is still not in line with UNCRPD. In many cases people don't have so much to say about their services. They can't direct their own support and participation is in many times limited



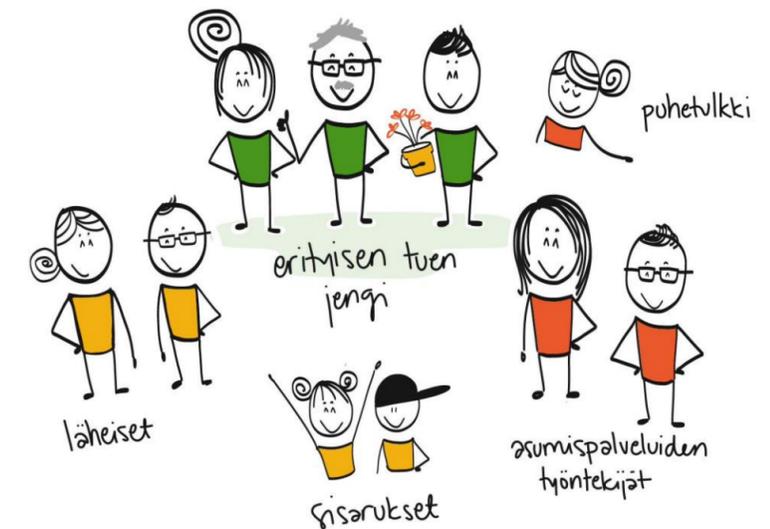
What we have learnt



- Key factor is collaboration. Building up trust and companionship with families, working with them for the best interest of their children → families should have the leadership in this process
- Support for transition is fundamental
- Co-production, developing new ways to support people together with people themselves, their families and communities.
- We must find our ways, in different levels, to support self determination of people and support them to make choices. There should be legislation, practice and people to support this.
- Scaling up innovations is not easy but we should try to do that –at national and international level
- Organisations should be committed to take human rights as the guiding principle and understand the responsibility they carry in making human rights real in the lives of people with especially profound disability

Developing community based individualised services

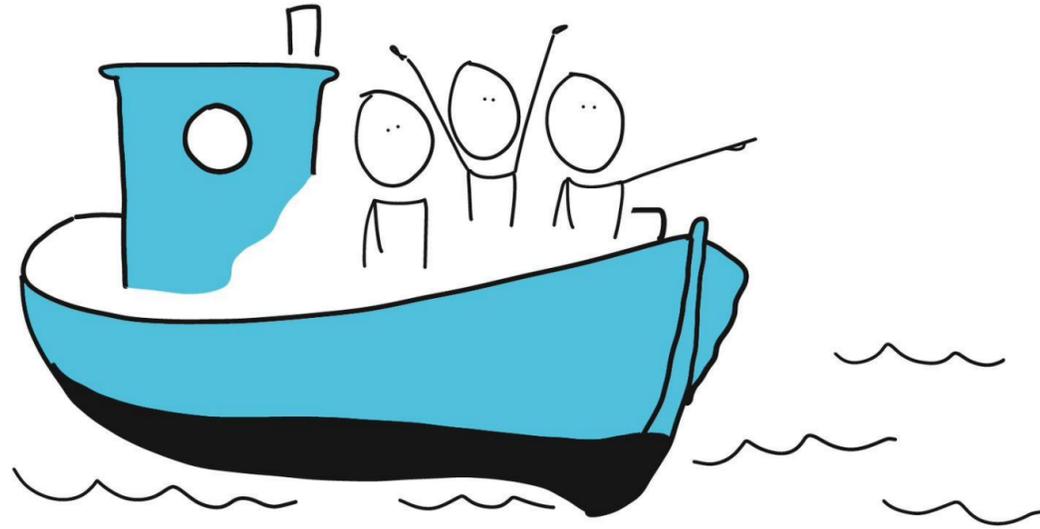
- Services should help people to find their own voice
- Services should support full citizenship, also people with lots of support needs
- Value social relationships and build up meaningful roles in communities
- Managing change with staff is crucial; feeling respected and still finding out new set of skills
- Closing institution is not the vision but a good life and good quality services in the community for people with disability and their families.



Thank you!

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Samassa
-veneessä



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