Deinstitutionalisation and Community Living for Adults with Intellectual Disabilities: Progress and Challenges

Agnes Turnpenny

Vilnius
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University of Kent
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Outline

- Definitions of key concepts
- History of deinstitutionalisation (DI) and community living (CL)
- Results and key lessons
- DI in Central and Eastern Europe: some lessons from Hungary

What is an institution?

- Administrative definition:
  Whatever the law defines as an institution.
- Substantive definition:
  "An institution is any place in which people who have been labelled as having a disability are isolated, segregated and/or compelled to live together. An institution is also any place in which people do not have, or are not allowed to exercise control over their lives and their day-to-day decisions. An institution is not defined merely by its size."

(ECCL, http://community-living.info/)

Characteristics of institutions

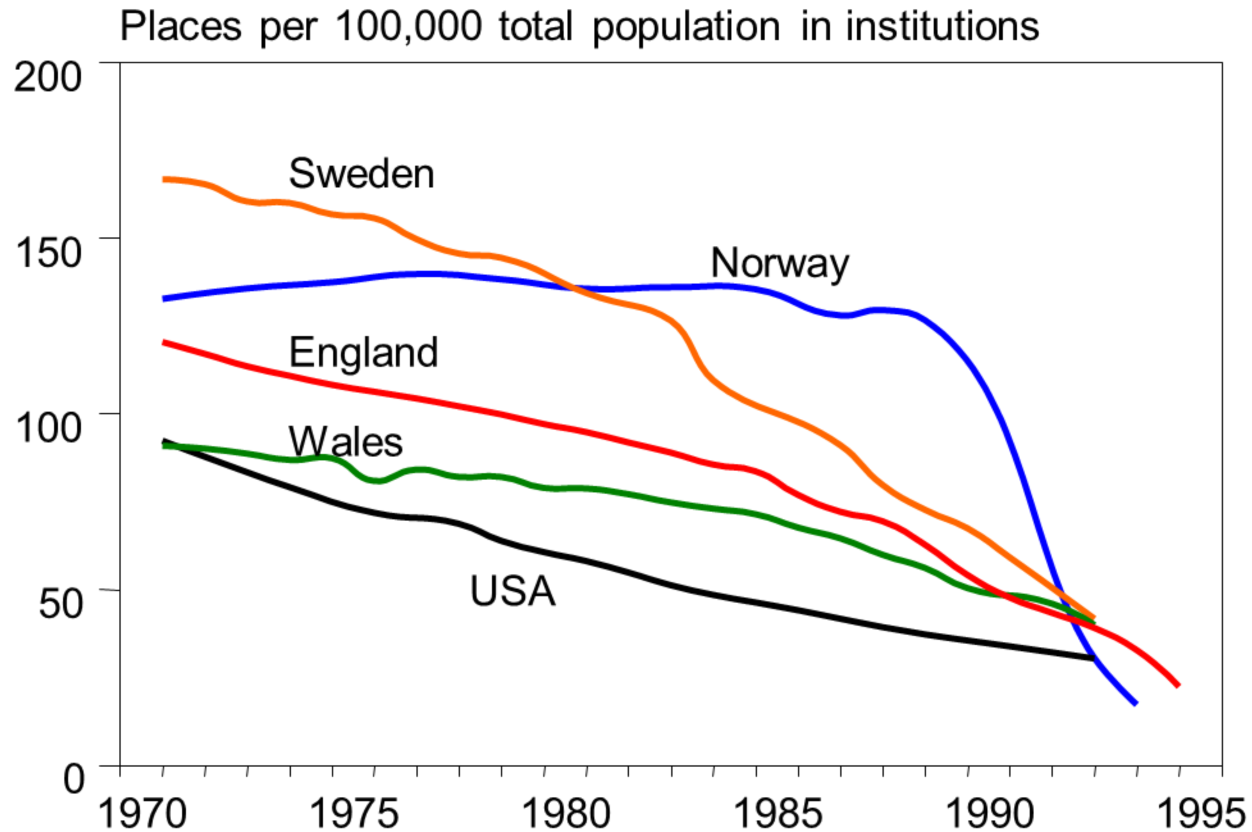
- They are physically and socially segregated from the wider society.
- Residents are not easily able to leave them to live elsewhere (either because of the lack of alternatives or because of legal capacity).
- Material conditions of life are worse than for most people in the wider society.
- They are often large establishments serving large numbers of people, but institutions can be of any size.

What is deinstitutionalisation?

- It is not simply the closure of institutions.
- It is a political and a social process.
- Happens when a person placed in an institution is given the opportunity to become a full citizen and to take control of his/her life (if necessary, with support).
- Essential to the process is the provision of affordable and accessible housing in the community, access to public services, personal assistance, and peer support.
- It is also about preventing institutionalisation in the future.

(ENIL: http://www.enil.eu/policy/)

Decline of institutional care



From Ericsson and Mansell, 1996

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What form has change taken?

- National/regional leadership → local leadership
- Small institutions → group homes → independent (supported) living
- Specialisation → mainstreaming

Current situation for people with disabilities in Europe

- Research* shows at least one million people with disabilities are still in institutional settings
- Most countries don't collect adequate data to allow the monitoring of the situation
- Some good practice in many countries
- Progress appears to have stalled in some countries, perhaps because of economic crisis, perhaps for other reasons.
- New impetus in Central and Eastern Europe by EU funding.
- Even when services are smaller, people are not necessarily having good lives…

* DECLOC (2007): https://www.kent.ac.uk/tizard/research/DECL_network/documents/DECLOC_Volume_2_Report_for_Web.pdf

* Mapping Exclusion (2012): http://www.mhe-sme.org/fileadmin/Position_papers/Mapping_Exclusion_-_ind.pdf

* Included in Society (2004): http://www.enil.eu/wp-content/uploads/2012/07/ECCL_Included-in-Society.pdf

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What has driven this change?

Ideology

Alternatives

Advocacy

Costs

Scandal

Ideology

- Normalisation
- Human rights
  - Litigation and law suits
  - UN CRPD

Ideology clearly very important but on its own isn't enough to explain change…

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Advocacy

- Disabled people's movement:
  - social model
  - independent living
  - direct payments
  - personal assistance
- Self-advocacy

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Scandal

- Public outrage at conditions in institutions in late 1960s
- Important in North America and UK, where it continues to drive policy change (e.g. Winterbourne View etc.)

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Alternatives

- New models demonstrate an achievable vision.
- New models are applied to more and more disabled people over time.
- As momentum builds, new funding and management arrangements are developed.

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Costs

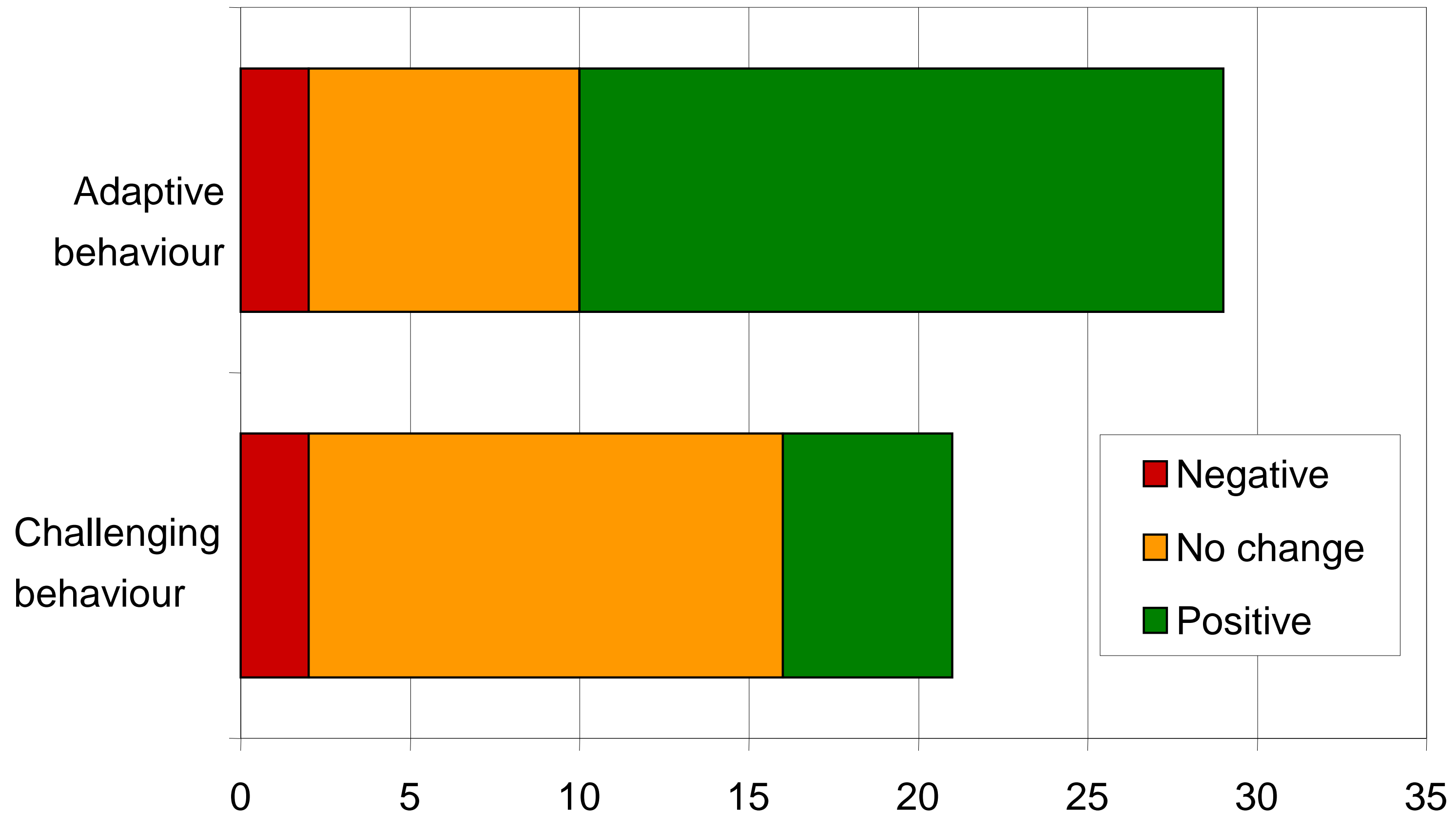
When we talk about costs, we also need to take into account outcomes!

- Relative costs differ in different countries
- Widespread deinstitutionalisation when there are clear cost incentives for decision makers
- Scandinavia/USA – institutional costs higher than community services; In UK, institutional costs lower but extra funding creates incentives for community services
- Elsewhere: ???

What have been the results of deinstitutionalisation?

- Research comes from a relatively small number of countries (mainly USA, Canada, Australia, UK).
- The results of moving from institutional to community care are generally positive, although for some groups they are variable.

American deinstitutionalisation studies



From Kim, Larson and Lakin (2001)

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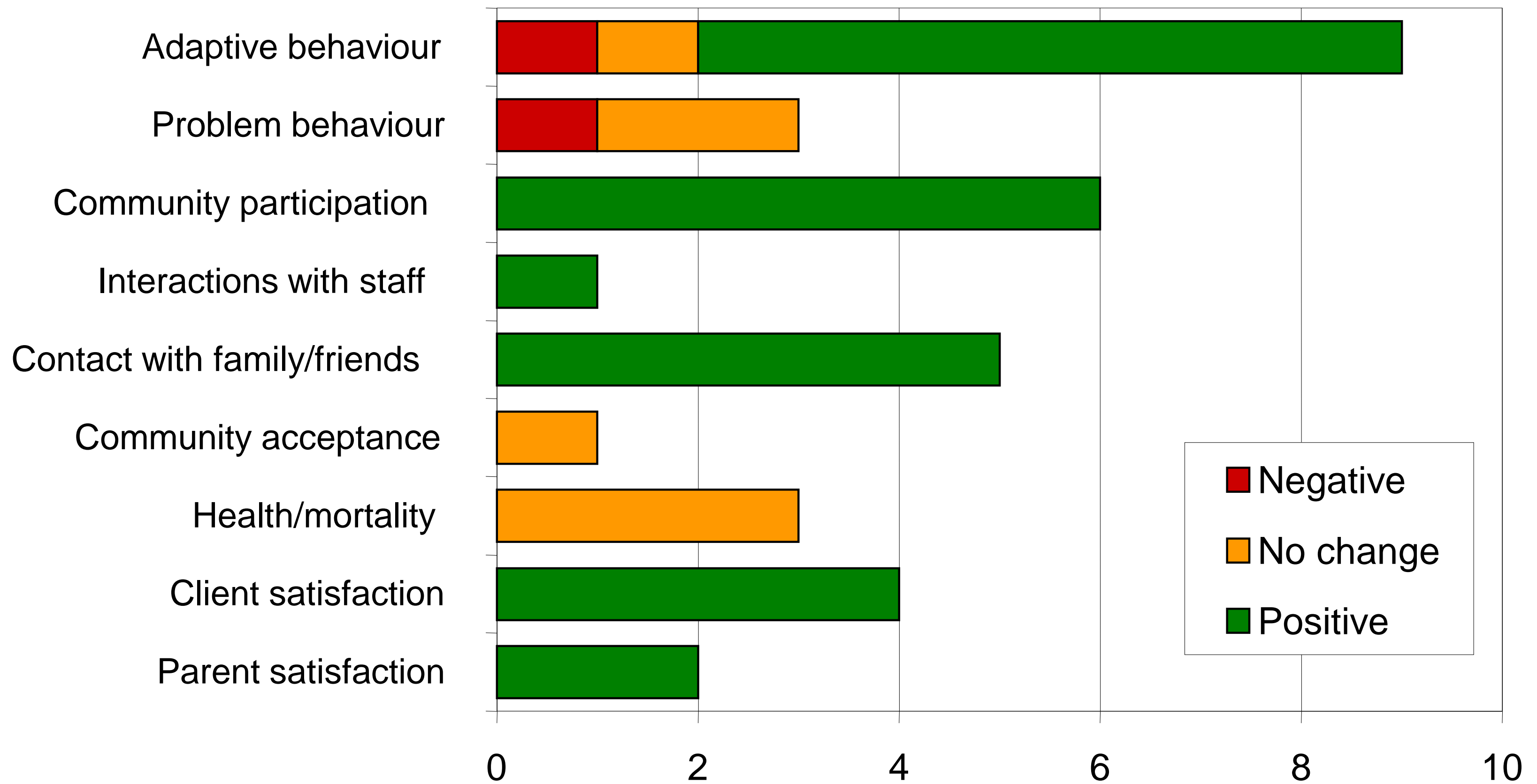
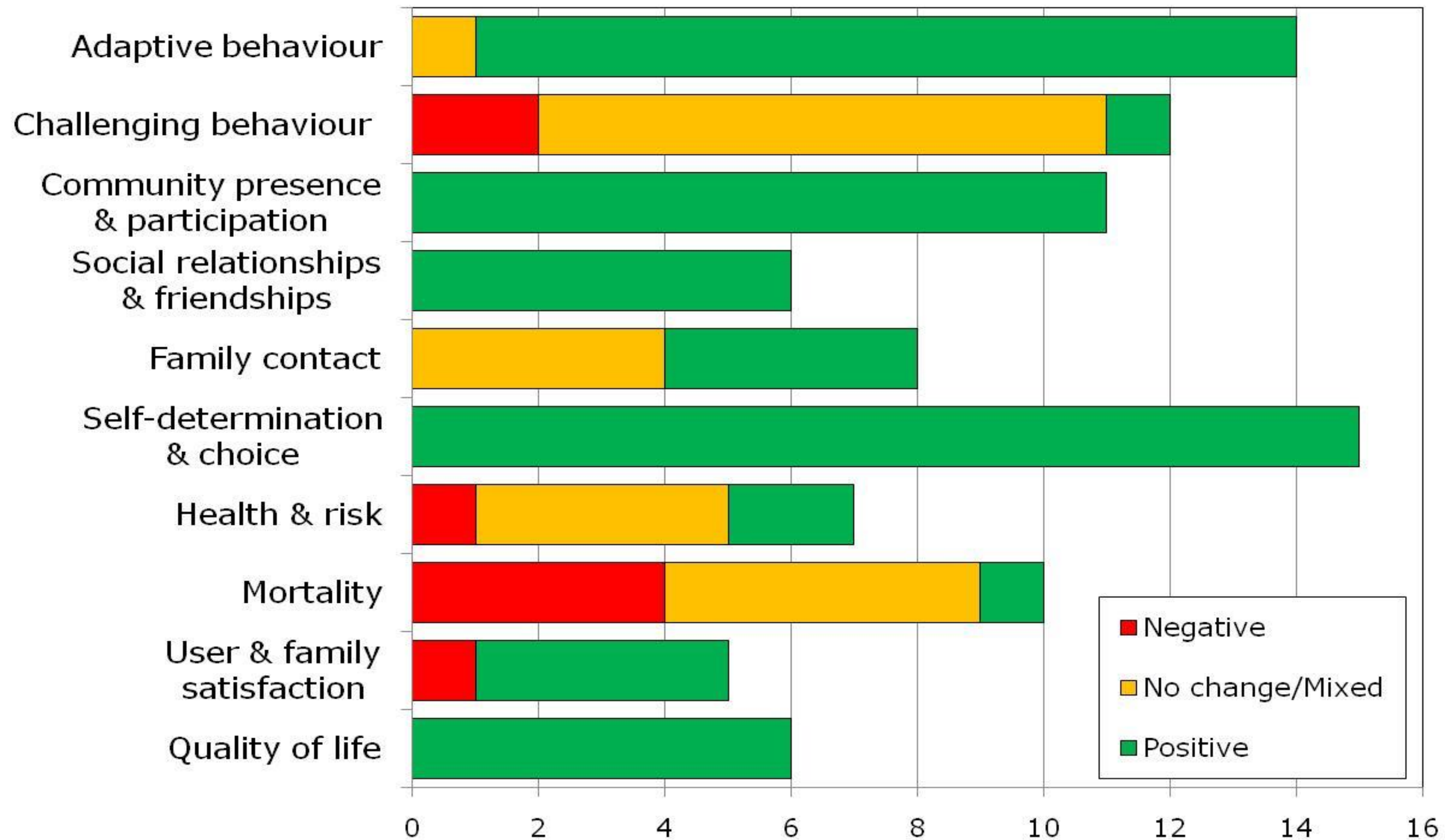
Australian deinstitutionalisation studies



From Young et al, 1998

Latest, international deinstitutionalisation studies



From Kozma, Mansell and Beadle-Brown 2009

Research on size and type of setting

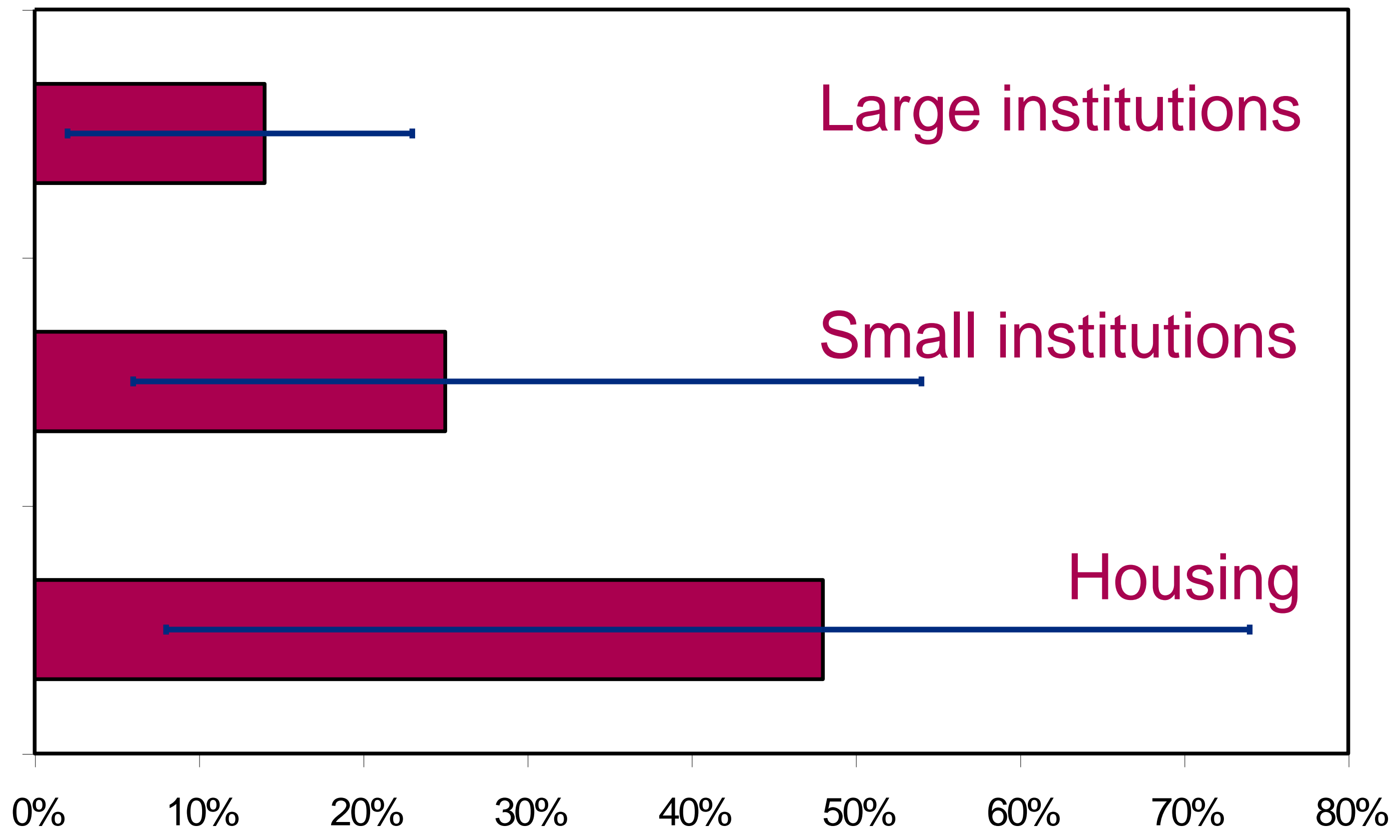
- Size: 1-6 places offer better outcomes but effect is stepped rather than gradual (Tossebro, 1995)
- Type: ordinary and dispersed is best (Emerson et al.; Janssen et al., 1999; Mansell & Beadle Brown, 2009)

  - Dispersed – small supported accommodation 1-6 (housing and support) or supported living 1-3 (separation housing and support)

  - Cluster – 'number of living units forming a separate community from the surrounding population'

    - Residential campuses – institutional in nature
    - Cluster housing – separate housing on same site
    - Intentional villages – separate site, shared facilities, unpaid life sharing, strong ideology (e.g. Camphill)

Comparing service models



From Emerson and Hatton 1994

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Key lessons: quality of life

- Closing institutions and moving people into ordinary homes in the community is an essential but not sufficient condition for an improved life for people with disabilities.
- Institutional practices can exist in small homes, even in supported living.
- Person-centred planning is important, it improves life on some domains, it is less effective in other areas. Not enough on its own.
- Research shows that staff care practices, the way people are supported to live in the community are critical.

Key lessons: dynamics of change

- The dynamics of change are complex and can send out misleading signals about changing costs and outcomes.

  Decision makers must ensure that they take the long view.

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The long view: Independent Living (Article 19)

- Using housing located among the rest of the population, which is adequate, appropriate and accessible to the individual.
- Using the range of housing options ordinarily available to the wider population.
- Enabling people, to the greatest extent possible, to choose where, with whom and how they live.
- Providing whatever help is required to enable people to live independently (with support) in the community.

ENIL Myth Buster on Independent Living: http://www.enil.eu/wp-content/uploads/2014/12/Myths-Buster-final-spread-A3-WEB.pdf

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Incentives for community living

- Individual budgets and personal assistance
- Individual assessment and planning
- Support to own or rent own home
- Availability of advocacy
- Person-centred approaches to support – in particular active support.

From http://discit.eu/

Barriers to community living

- Cost cutting
  - limited availability of good/any community based services.
  - Lack of staff and lack of appropriate staff training
- Guardianship/lack of mental capacity legislation.
- Lack of/Bureaucracy around individual budgets.
- Community acceptance.
- DI overnight.

From http://discit.eu/

What is needed to bring about change?

- Strengthen the vision of new possibilities in the community.
- Create (sustain) public dissatisfaction with current arrangements.
- Create some practical demonstrations of how things can be better.
- Reduce resistance to change by managing incentives for the different actors in the process.

From DECLOC (2007):
https://www.kent.ac.uk/tizard/research/DECL_network/documents/DECLOC_Volume_2_Report_for_Web.pdf

What is needed to develop high quality services?

- Quality should be focused on the outcomes – quality of life - not systems and processes.
- Staff need training to be able to enable people to have a life in the community (not just a house)
- Those running organisations need to provide the right leadership and motivation for staff to support and enable, not care and control.
- Adequate staffing levels are necessary. Those with more severe disabilities will need more support but those with less severe disabilities often just need permission to do things.

DI in Central and Eastern Europe

- Slow progress over the last 15 years but new impetus thanks to EU funding.
- Various countries have started closing down old institutions for people with intellectual and psychosocial disabilities: Croatia, Czech Republic, Hungary, Romania, Slovakia etc.
- There is little information about programmes, lack of evaluation.

The closure of institutions in Hungary: Background

- Some 17,000 people with ID and 8,000 with psychosocial disabilities in long-stay social care settings (over 80% in institutions).
- Over 120 institutions, average size around 100 places, ranging from 30 to 700.
- Idea of community living first appeared in the 1980s. In 1998 there was a vague mandate to reform and move towards community living.
- Very slow (if any) progress until 2010, considerable amount of money invested in institutional infrastructure in this period.
- Recent research compares quality of life in different living arrangements and highlights the difficulties of those living with their family in the community: http://www.tarki.hu/en/news/2016/items/20160408_fszk_en.pdf

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Hungary: 2007-2013

- Attempts to use EU Structural Funds to refurbish institutions → protest from NGOs and the European Commission.
- Legislation to close down 'care institutions' for people with ID with more than 50 places (other types of institutions not included in the legislation) in 2009.
- Strategy to implement closure over a 30-year period → vague, lack of clear vision
- Main source of funding: ERDF and some ESF

Hungary: 2007-2013

- Programme management: Equal Opportunities of Persons with Disabilities Non-profit Ltd. (FSZK; http://fszk.hu/english/).
- Other key actors: Directorate for Social Care and Child Protection (http://www.szgyf.gov.hu/), Ministry of Social Affairs, Coordinating Committee (IFKKOT).
- ‘Mentor-network’ to support the transformation of institutions.
- Closure of 6 institutions (4 ID and 2 MH), 660 people to move out.
- Three types of accommodation created: residential centres (20-25 places), group homes (7-12 places) and supported housing (up to 6 places).

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Hungary: 2014-2020

- Programme set to continue and expand.
- No formal evaluation of previous period → lessons not learnt.
- It is expected that more than 3,000 people will move out of institutions by 2020.
- Strategy and legislation have not been reviewed (i.e. no change in definition of "institution").

Hungary: experiences

- Challenges resulting from the use of Structural Funds: timing, coordination and fragmentation of programmes.
- Projects: lack of leadership and clear vision. Mentor network, although potentially useful, poorly implemented and has had limited benefits. Timing of projects is problematic and training of staff is largely inadequate.
- Challenges of cooperation and coordination between organisations and agencies, distrust is endemic.
- Focus on the creation of infrastructure and residential care. Closure of institutions is not part of a wider reform strategy to develop community living services (e.g. legislative and funding reform, development of support services in the community, direct payments, supported decision making etc.).
- Forthcoming research report: http://tasz.hu/en

Thank you for your attention!

E-mail: a.v.turnpenny@kent.ac.uk
https://www.kent.ac.uk/tizard/