The Implementation of Policies Supporting Independent Living for Disabled People in Europe: Synthesis Report

Dr. Ruth Townsley with Prof. Linda Ward
Norah Fry Research Centre
University of Bristol
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Background

- Aim: to review frameworks, policies and practice around independent living
- 26 countries responded to questionnaire (varied in scope and detail)
- Definition of independent living: article 19 UN convention emphasises human rights aspect
- Importance of independent living to disabled people's movement

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Policy context and legal framework

- Majority of states have policies with clear statements supporting independent living (but not all do)
- Some groups however may be excluded i.e. people with intellectual disabilities
- In some member states, continued reliance on institutional care/family carers

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Development of policy/approaches

- No one single model of independent living
- Involvement of disabled people and user led organisations varies

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Evidence of commitment

- Few match their strategic commitment to local/practice level and reality. Why?
  - Limited by local resources and/or regional interpretation
  - Lack of policy lead
  - Policy under-developed
  - Focus on assessment procedures rather than meeting needs

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Progress towards independent living

- Limitations of the data and interpretation e.g. what is an institution?
- 3 member states with no evidence of large scale institutions (but going backwards?)
- Where they do exist, reliance on these is diminishing – but are the *practices* still institutional?
- States where there is no change/progress – role of family carers

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Factors impeding progress towards community/independent living

- Perceived expense in current economic climate
- Insufficient community support
- Concerns from carers (about e.g. isolation, bullying)
- Lack of specific safeguards to prevent institutionalisation
- Public opinion

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Winners and losers (where data available)

- People with intellectual disabilities (risk increases with age)
- People with multiple impairments
- In UK – young disabled people going to residential (educational) placements in large numbers

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Support for independent living: personal assistance

- Sweden: self directed personal assistance as the norm
- 12 states: 'twin-track' support
- 9 states: also 'twin-track' but support not self directed
- 2 states: absence of support – service led or otherwise

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Eligibility and how funded

- About half had eligibility criteria which was based on medical model/impairment based assessment. About half has wider eligibility criteria but in practice may exclude.
- Funded in 3 main ways:
  - Via a personal budget or direct cash payment
  - Personal assistance allocated as a service
  - Personal assistance funded by individuals' benefits

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Assistive equipment and adaptations

- Choice about equipment over-ridden by medical assessment of 'functional limitations' and bureaucratic problems
- Centres of good practice
- Availability of funding varies widely
- Separate systems for work-related/home based needs
- Lack of portability between – sometimes within – countries

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Evidence of outcomes and effectiveness

- Very little research which has looked at outcomes (Austria notable exception)
- Little published research on costs and benefits (those that do look at savings rather than costs/benefits)
- No clear examples of involvement of disabled people in research on independent living

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Concluding comments

- Progress is hugely varied with arguably too few countries offering good options/support.
- Progress still risks excluding some groups
- Do we have a clear, shared vision of independent living – above and beyond the detail of how we might make it happen? Are we clear that it is a human rights issue?
- How can disabled people's voices be more central?
- Sharing good practice on what is working
- Recognition of why it matters so much

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Recommendations

- Greater use of European funding (e.g. the European Social Fund) to support the development of initiatives to foster independent living, including personal assistance schemes

- Develop pilot strategies to increase the mobility of disabled people – within and between countries

- Explore ways to monitor and check any trends back towards institutional living

- Improve the collection of relevant data

- Sharing good practice

- Maximising the involvement of disabled people's organisations in the planning, delivery and monitoring of policies and practice to support independent living

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