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

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November 2009

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

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

Development of policy/approaches

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

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

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

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

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

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

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

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

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

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

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