Conceptualisation of disability and aged support services –
A right, intrusion or complement to other support
in Australia and Sweden

Carmel Laragy, Karen R Fisher and Elisabet Cedersund
RMIT, SPRC and Jönköping University

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Outline

Research question

Methods

Findings

Implications for social support theory and policy practice
Formal support at home

Formal support in their home

- Formal aged care or disability support in someone’s home
- In addition to their independent activity and informal support

Framework of concepts of formal support

- Right to receive support
- Experience support complementing relationships and activities
- Experience of support as intrusive
Research question

Do people who are ageing or experience disabilities conceptualise formal support services in their home as a right and is it an intrusion or a complement to their informal support?

Illustrate the research question with comparative analysis

- Sweden ageing data – social support program
- Australian disability data – Attendant Care Program NSW
Methods

Interviews with consumers, family members and workers

Sweden

- 11 older people assessed for personal home support and families
- 3 localities
- Discourse analysis using positioning theory
- Framework about rights, intrusion, complementary support

Australia

- 10 people with disabilities receiving attendant care direct funding and families
- 26 comparison people with other attendant care
- Sydney and regional NSW
- Analysis with Swedish framework comparing attendant care types
Swedish ageing data

People viewed home care in three ways

- complement and support to everyday life or
- an intrusion into daily routine and their relationships
- support as a right

People’s concepts in different combinations and ambivalent

- Older person or family member
- Law requires primacy of older person’s voice
Sweden – Complement to everyday life

Older people and families use similar complement concept

- Extend time at home
- Extend independence
- Reduce dependence on informal support
- Enables relationships to remain separate from support
Older people spoke of intrusion

- Unwelcome change of life, deterioration in physical wellbeing
- Threatens integrity
- Wanted relatives to provide all their assistance

Families spoke of intrusion

- They needed more help
- Felt personal failure because they could not meet all the needs
Sweden – Support as a right

Complementary and intrusion groups sometimes also referred to their rights

Older people spoke of rights due from

- law-abiding citizens and had paid taxes
- society has a responsibility to care for older people

Families voiced similar sentiments

- Society has responsibility for aged care in the Swedish system
- Son or daughter who lived away and could not provide daily care
Attendant care program NSW

- High level personal care support in home and community
- Employer, cooperative and direct funding option – choice dependent on degree of control person with a disability prefers
Australia – Complement to everyday life

People with disabilities and families talk of complementing

- Support for tasks of daily living
- Facilitates community and economic participation
- Less stress on family members
- More flexibility for social arrangements with family and friends
- No one wanted all their support to be informal

Not complementary for people without informal support

Similar to older people in Sweden

- Reduce dependence on informal support
- Enables relationships to remain separate from support
Australia – Intrusion

People with disabilities and families spoke of intrusion

- Workers in the family home

Minimise intrusion with direct funding because control

- Direct employer relationship
- Choose the worker, less worker turnover, consistent, predictable care
- Know and trust the worker, children feel safe, privacy
Australia – Support as a right

People did not speak of rights

Instead they expressed

- Good fortune at receiving a rationed service
- Resentment when the support did not meet their needs
  - Poor quality, poor control, insufficient hours, poor organisation

People who chose direct funding did so to

- Maximise control over their support – reliable, flexible, choice
Comparative findings

Reinforces concepts

- Complementing
  - Potential of complementary support to contribute to lives of the person receiving support and the informal carers
  - Irrelevant for people without informal support

- Intrusion
  - Conflicting concepts about intrusion, perhaps due to different expectations for support of older people and people with disabilities
  - Control over support to minimise intrusive impact of workers in home
Implications for social support theory and policy practice

Comparative analysis highlights the effect of different senses of rights and entitlement

- Conflicting concepts about right to support, likely due to social support system
- Right to support not articulated in Australian social support context
- Consistent articulation of right to quality support
- Strong resentment about poor quality support
Implications for social support theory and policy practice

Raises questions for social support theory and policy

- Interface between formal and informal support
- People’s control of formal support arrangements
- Quality of support to facilitate human rights
Resources


Carmel Laragy  carmel.laragy@rmit.edu.au
Karen Fisher  karen.fisher@unsw.edu.au
Elisabet Cedersund  elisabet.cedersund@hhj.hj.se