

The role of natural supports in promoting independent living for people with disabilities



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OVERVIEW OF PRESENTATION

- Context for the study
- Definitions and parameters of literature
- Social Networks
- Initiatives to promote natural supports
- Barriers
- Facilitators
- Policy Implications



REVIEW OF LITERATURE

“What is the role of natural supports in facilitating independent living on the part of people with disabilities?”





CONVENTION on the RIGHTS of PERSONS with DISABILITIES



Time to Move on from Congregated Settings
A Strategy for Community Inclusion

Report of the Working Group on Congregated Settings
Health Service Executive
June 2011



Council of Europe



Disability Action Plan
2006-2015



Plan about how to make
life better for people with disabilities

Easy-to-read version



Number 14 of 2005

DISABILITY ACT 2005

Office for Disability Issues
2011 Guidelines



Independent Living

A cross-government strategy about
independent living for disabled people

DWP Department for
Work and Pensions

Department for
Transport

Department of
Health



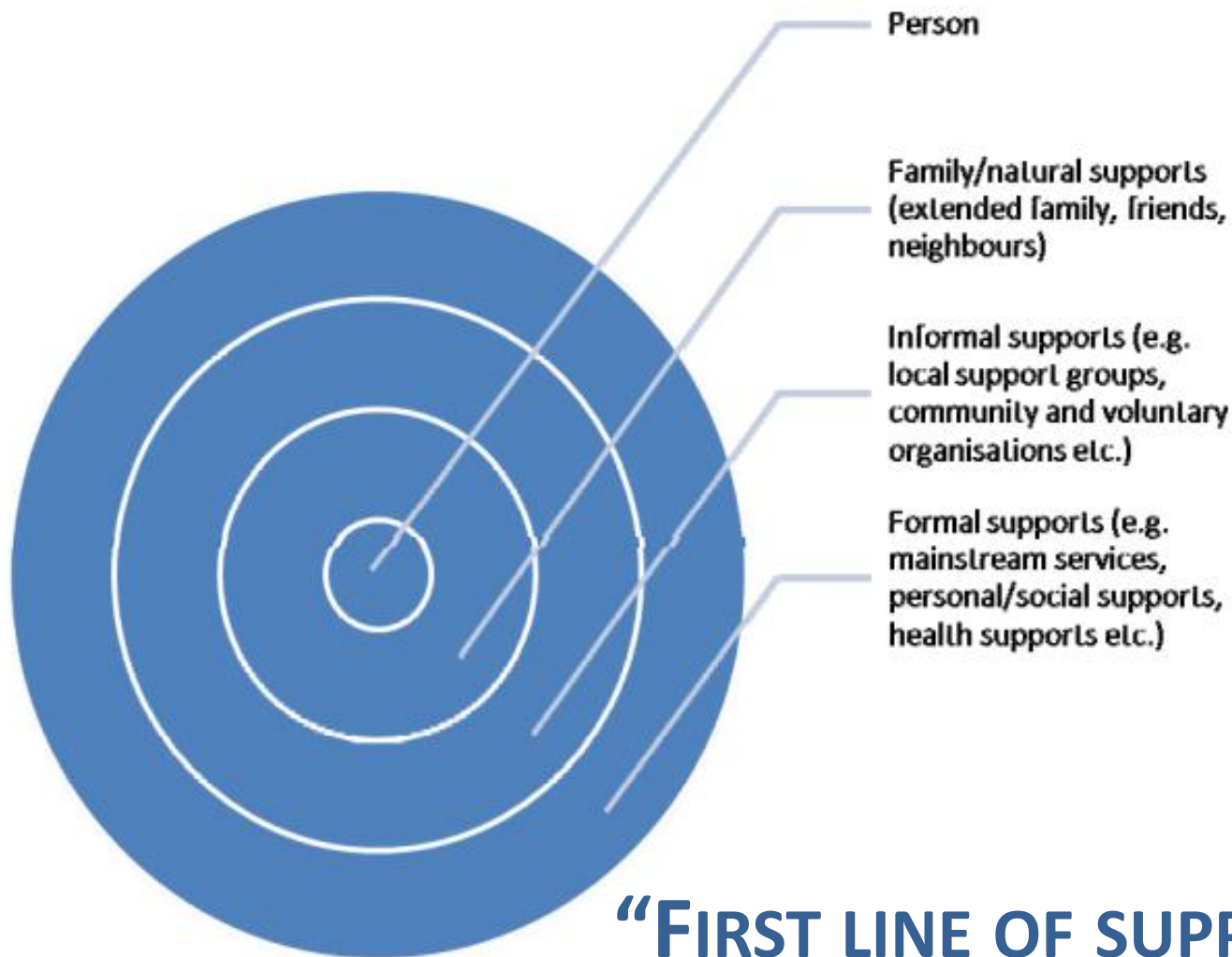
Value for Money and Policy Review of Disability Services in Ireland

**Community
presence is a
necessary, but not
sufficient condition
for social inclusion**





DEFINING NATURAL SUPPORTS



“FIRST LINE OF SUPPORT”

REPORT OF DISABILITY POLICY REVIEW: EXPERT REFERENCE GROUP

The term natural supports refers to the 'resources inherent in community environments including personal associations and relationships, typically developed in the community, that enhance the quality, and security, of life for people'.



REPORT OF DISABILITY POLICY REVIEW: EXPERT REFERENCE GROUP

- Family relationships;
- Friendships reflecting the diversity of the neighbourhood and community;
- Associations with fellow students or employees in regular classrooms and workplaces;
- Associations developed through participation in clubs, organisations and other civic activities.



DEFINING INDEPENDENT LIVING

- Independent living was defined by the NDA as people with disabilities 'having choice and control over the support they need to go about their daily lives and any practical assistance being based on their own choices and aspirations'.
- If formal services have been challenged to support people with disabilities achieve these aims, are natural supports part of the solution?



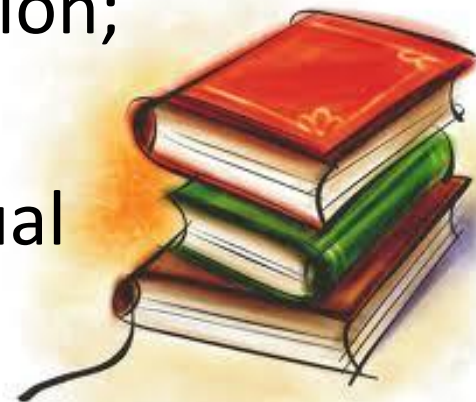


DEFINING PEOPLE WITH DISABILITIES

- The focus of the review was on adults with physical, sensory, intellectual and cognitive disabilities.
- In effect, however, the principal focus is on people with **intellectual disabilities moving to the community** as this is the category of disability most frequently covered in the relevant literature.

SEARCHING FOR INFORMATION

- Initial search revealed very little research evidence of the role of natural supports per se.
- Peer-reviewed and grey literature from 2000.
- Excluding employment literature.
- Natural supports; social networks; social support; social capital.
- Independent living; social integration; community participation.
- 30 core papers found; 16 contextual



FINDINGS FROM THE LITERATURE

- Social Networks
- Initiatives to promote natural supports
- Barriers
- Facilitators
- Policy Implications



SOCIAL NETWORKS

- What is the potential of social networks to provide natural support and facilitate community participation?
- Social networks are deemed key indicators of community participation (Johnson et al., 2010; Milner & Kelly, 2009; Kam-shing & Sung-on, 2002).
- ‘the **least successful aspect** of resettlement when people with disabilities move from long stay to community settings’ (Carson & Docherty, 2002).



COMPOSITION OF NETWORKS

- Most of the research focuses on the social networks of people with intellectual disabilities.
- Social networks are small and comprise a large proportion of people attending or working in services – consistent over 30 years of research (Bigby, 2008; Robertson et al., 2001; Emerson & Hatton, 1996).



SUPPORTING SOCIAL NETWORKS

- People with disabilities report difficulties in receiving adequate supports to maintain their friendships, especially with age (McVilley et al., 2006).
- Life trajectory of people with disabilities may be different to family and friends (Bigby, 2008).



SUPPORTING SOCIAL NETWORKS

- There is evidence that services can limit rather than expand opportunities to develop friendships (Bigby 2008; Clement & Bigby, 2008; Lemoy, 2009).
- Staff prioritise care tasks over social inclusion tasks (McConkey & Collins, 2010; Lemay, 2009; Abbott and McConkey, 2006).
- Have friendships and activities among people with disabilities been devalued in the literature? (Miller & Kelly, 2008).



PROMOTING NATURAL SUPPORTS AND ENHANCING SOCIAL NETWORKS

- (1) support circles, microboards etc. – involve existing natural supports organised formally.
- (2) peer-based advocacy groups, self-authored spaces.
- (3) Promoting social inclusion via individual capacity building, social skills etc.
- (4) Promoting social capital via befriending / community building approaches.



(1) CIRCLES OF SUPPORT

- Model of formalised support which draws on family and friends (not exclusively).
- Established in 1980 by Judith Snow.
- Range from fluid informal arrangements to very formalised arrangements with a quasi-legal structure and long-term objectives (microboards).



(1) CIRCLES OF SUPPORT

- “A circle of support, sometimes called a circle of friends, is a group of people who meet together on a regular basis to help somebody **accomplish their personal goals in life**” [The Circles Network UK](#).
- Support Clusters – don’t aim to directly support the person with a disability but aim to support the social circle around the focus person – includes professionals ([Lord, 1999](#)).



(2) PEER BASED APPROACHES

- Literature indicates that while people with disabilities, particularly intellectual disabilities, value the support and companionship of peers, researchers and others may place greater value on relationships with non-disabled peers (Clement & Bigby, 2009; Johnson et al., 2010).
- Self-advocacy groups, unlike most segregated groups, tend to be widely praised (Johnson et al., 2010).





(2) PEER BASED APPROACHES

- Distinction between **segregated spaces** are seen as shutting people away from the wider community.
- **self-authored spaces** provide protected spaces for people with disabilities (Kendrick, 2009; Hall, 2010).





(3) SOCIAL INCLUSION VIA SOCIAL SKILLS & INDIVIDUAL CAPACITY BUILDING

- Known association between social competencies and social inclusion.
- People with ID recognise the negative impact of low social skills on forming friendships (Abbott & McConkey, 2006).
- Social skills training programmes typically focus on those with milder ID and do not always generalise into the natural environment (Whitehouse et al., 2011).



(4) SOCIAL CAPITAL APPROACHES

- Focus is not on the person with a disability, but rather on people in the community.
- **Befriending Strategies** are a common intervention.
- Friendships mediated by service providers with the support of volunteers.
- Valued by people with disabilities but the evidence-base is poor (Heslop, 2005).

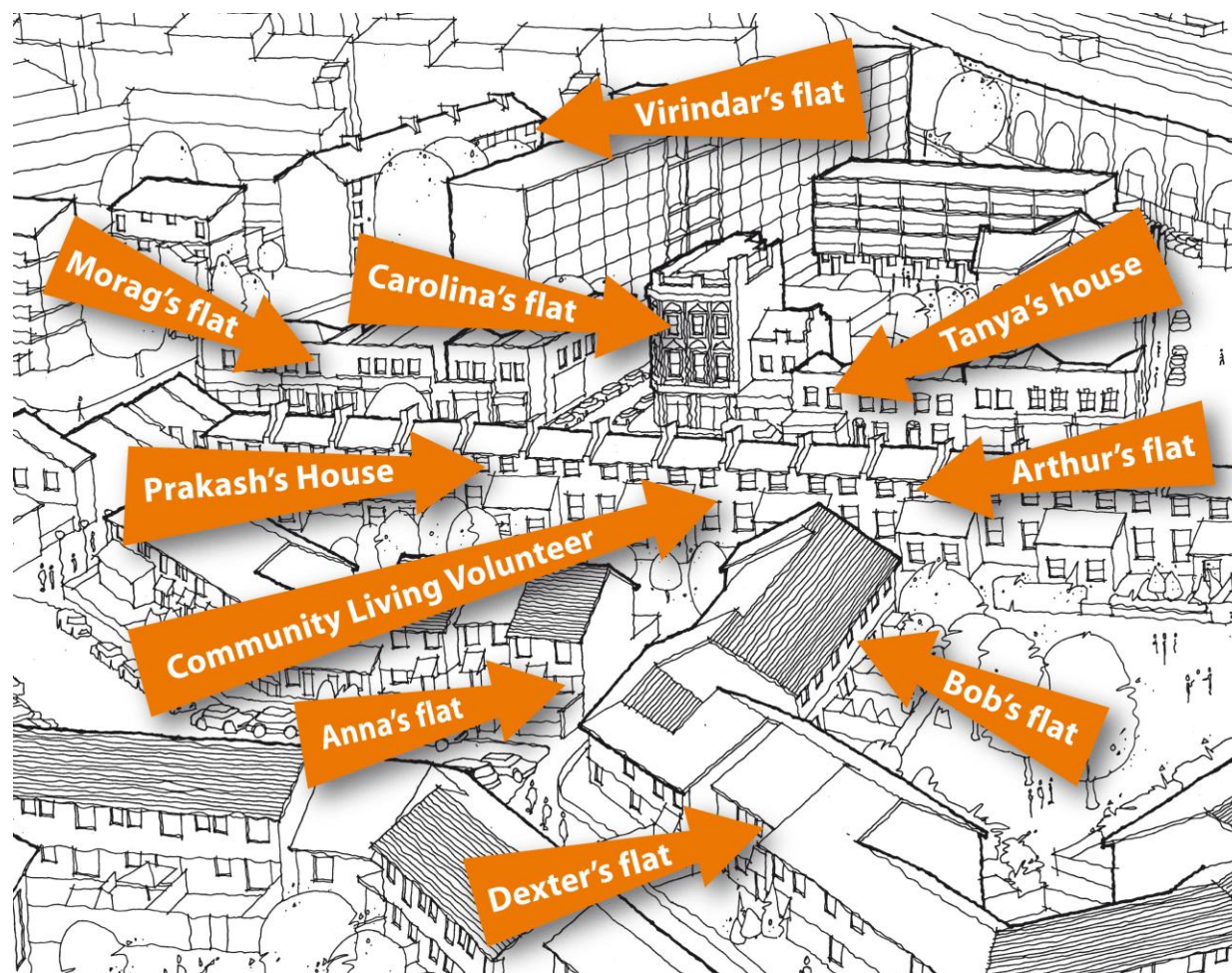
(4) SOCIAL CAPITAL APPROACHES

- **‘Community Connectors’** identify resources within the community where individuals live and try to foster reciprocal relationships e.g. Community Inclusion Officers in Australia.





KEYRING – MUTUAL SUPPORT



(4) SOCIAL CAPITAL APPROACHES

- Some evidence to suggest models that seek to build capacity of people with disabilities to form relationships and support networks are **more effective** than those which rely on formal services to develop links with the community.



“CATCH 22”

- People with disabilities, particularly those with intellectual disabilities, find it difficult to live independently and engage in community activities because they have few friends to support them.
- But these individuals have difficulty making friends because they are not involved in their communities.



BARRIERS TO NATURAL SUPPORTS PROMOTING INDEPENDENT LIVING

- **At individual level** - severity of disability and under-developed social skills.
- **At community level** – lack of community activities and opportunities; location of person's residence; and difficulties in accessing public transport.
- **At service provider level** – ethos, untrained staff, risk averse culture.



FACILITATORS TO NATURAL SUPPORTS

PROMOTING INDEPENDENT LIVING

- Changes at policy development level – not rhetoric, but clear articulation with definitions and measurable objectives.
- Cultural change at service delivery level – indicators and monitoring systems; clear communication to staff; training in best practice.
- Establishment of ‘dedicated’ support workers.



DEDICATED SPECIALISTS

- Interventions reviewed in the report suggest 'dedicated' roles will only succeed if:
 - Role is clearly defined
 - Personnel are sufficiently trained
 - Perhaps, a focus on social capital rather than social inclusion approaches



POLICY CONSIDERATIONS

- **Lack of data** in this area is a serious obstacle to developing and implementing effective policies.
- **Policies** need very clearly stated aims which are measured by valid indicators.
- **Training** in relation to these policies for agency staff , especially if newly ‘dedicated’ posts are to be established.
- The **inclusion of natural supporters** as well as people with disabilities in policy development .



POLICY CONSIDERATIONS

- Need to **pilot and evaluate** a variety of interventions to support the development of natural supports.
- Need to **support the natural supporters** directly and in their role to promote independent living.
- Need to acknowledge that a move to natural supports does have **resource implications**.





WHAT WE HAVE

Policies on de-
institutionalisation
community
participation and
independent living



WHAT WE NEED?

Policies and
services to enable
people develop
real friendships,
real social
networks

Bigby, 2008

A QUOTE TO FINISH....

Thus, for a person with intellectual disability to be **escorted** to a sports club by a volunteer represents a **social inclusion** approach. For the same person to be **actively facilitated** to build a network of friends with whom to go to the sports club represents a **social capital** approach. This distinction has important implications for the development of interventions to support and promote natural supports (**Bates and Davis, 2004**)





THANK YOU