SUPPORTED LIVING: A NEW PARADIGM

Peter Kinsella

1993

National Development Team

United Kingdom

Shifting Paradigms in American Services

Focus	Rehabilitation	Independent living	Support/empowerment
Definition of problem	Physical impairment, lack of vocational skill, psychological maladjustment, lack of motivation and cooperation	Dependence on professionals, relatives and others; inadequate support services; architectural barriers; economic barriers	Attitudinal, political, economic and administrative barriers to societal participation; inadequate supports within society
Locus of problem	In individual	In environment; in rehabilitation process	In society/environment; in rehabilitation process
Social role(s)	Patient-client	Consumer	Co-worker, community member, student, neighbour, so forth
Solution to problem	Professional intervention by physician, physical therapist, occupational therapist, vocational counsellor, and others	Peer counselling; advocacy; self-help; consumer control; removal of barriers and disincentives	Redesign of schools, homes, work places, health-care systems, transportation, and social environments to include everyone
Who is in control	Professional	Consumer	People in alliance with each other
Desired outcomes	Maximum activities of daily living (ADL), gainful employment, improved motivation, completed treatment	Self-direction, least restrictive environment, social and economic productivity	Pluralistic society inclusive of all people; quality lives as defined by people themselves; self-direction embedded in collaborative decision making and problem solving

Change

- John O'Brien states that there are two ways organizations and systems can develop:

1. A **First Order Change** is where there is no change to the basic structure, assumptions and values of the system or organization, simply people learn how to do things better.

2. A **Second Order Change** is where people not only change how the do things, but how they approach, respond to and evaluate situations.

Where we (Just the U.K. and the U.S.A.?) are coming from:

- We moved into the Independent model (From institutionalisation and segregation) in the 70s:

- Peter Kinsella says that the new paradigm in the U.K. since the 80s was a first order change and describes this as: "we created smaller institutions in the community…(and) relocated institutional practices (within the community). Support is still tied to buildings; People live with people they do not necessarily get on with; And staff work to set shifts in houses…Maybe this is not such a good way of doing things after all"

The Current Paradigm, since the 80s:

- America moved into the community membership, support and empowerment model in the 80s, The U.K. trailed this shift.

- "…people as community members not clients"

- "People with learning disabilities are asserting themselves more, through collective action, and the best examples of person-centred planning are giving individuals a full say in the supports that they receive and the things that they do".

The transition to person-centred community-based supports requires four major paradigm shifts:

From	To
Programs	Flexible Support
Facilities	Community Membership
Management	Leadership
Mechanical Change	Spiritual Change

What is Supported Living?

- Supported Living is people choosing where they live, who they live with, which supports they get and the lifestyle they lead (Kinsella 1993).

- NDT (1993) state that Supported Living is:
  - Separating Housing and Support
  - Focusing on one person at a time
  - Full user choice and control
  - Rejecting no-one
  - Focusing on relationships; making use of informal supports and community resources

Roommate Guidelines from 1993

A 'room mate' can be

1. A friend
2. A confident
3. A source of support
4. Someone to celebrate with
5. Or someone to despair with
6. Or sometimes a practical arrangement

⦿ Sometimes a roommate will help a person get involved in their local community and they will participate in some activities together.

⦿ "Not liking the roommate who lives with you is good enough reason for them to be told to leave"; "… the most important factor is that both people must want to live with each other.

THE CHOICE BETWEEN A REAL HOME AND A PROGRAM (SUMMARY)

Kendrick, Michael

1993

Progress, Volume 2(I)

USA

Q: When is a home not a home?

A: When it is a facility

- The qualities of a home vary but they are based on a rich cultural heritage that underlies the true concept of a "real" home. These features may include:
- A place where we can be ourselves and feel comfortable
- A place that expresses our personality
- A place we choose that has a sense of family, intimacy and privacy
- A place to contain our personal relationships and social life
- A place of our own where we can feel safe and secure

How to Make a Home

1) The residents served should <u>assist in the selection and location</u> of the home.

2) They should help to <u>decorate and furnish </u>their home environment.

3) They should decide who they want to live with.

4) They should have a voice in staff selection.

5) Agencies should hire <u>staff</u> whose personal orientation, commitment, and attributes are <u>targeted</u> towards <u>helping people make a home </u>for themselves.

6) <u>Programming, treatment</u>, and related practices are either kept out of the home setting, or if necessary blended carefully into the home-life so they <u>do not disturb </u>the home setting.

7) Agencies should <u>not bring their bureaucracy into the home</u>. This means agency materials, meetings, offices, or equipment.

How to Make a Home (Continued)

8) Home sites should be integrated into their neighborhoods. The houses should be attractive, well cared for, and similar in appearance to neighboring households.

9) The home should be close to work, family, recreation and convenient to other interests of the people who live there.

10) Intimacy, sharing, personal ownership and possessions should be encouraged.

11) Regulatory concerns of funding agencies should be addressed in such a way that the home remains a home.

12) The house is at all times, legally and otherwise the home of the residents, and not the staff or the agency.

13) The agency should stress in its mission, and in its communication to staff, consumers and families that the concept of home in its residences is a worthy and preeminent goal of the organization.

AGGRESSION, SOCIABILITY, AND ROOMMATE FRIENDSHIP: NEW FINDINGS TRANSLATED INTO A RESOURCE FOR SELF-DETERMINED CHOICES

James Wiltz and Tracy Kalnins

Friendships and People with an Intellectual Disability

1 "Almost half of 3,630 people with an intellectual disability had no friends, "while it is nearly certain that many of these individuals had roommates"

2 "Maintaining at least some friendships has been identified as a possible protective factor against developing psychological disorders"

3 "Not having friends can have negative psychological implications"

4 "Particularly important may be close relationships, such as those with roommates"

"...practical information not only can improve outcomes, it also can increase self-determination"

"…rely too heavily on self-determination as the ultimate solution to problems"

+

"….simply use the method and ignore the individual"

=

"…integrate relevant data into a self-determined selection process for better informed-choices"

From college literature reviews – "…roommate similarities were associated with compatability"

2 Independent samples:

186 (93 pairs) adults with intellectual disabilities

26% were in the moderate to sever or profound category

In community based housing, across three cities

52 adults (26 dyads) with intellectual disabilities

84% were in the moderate to sever or profound category

Living in a large congregate-care settings

Study 1 Hypothesis

1. "Roommate similarity on the need for "Order" is associated with greater friendship" - **Rejected**

2. "Roommate similarity on the need for "**Social Contact**" (sociability) is associated with greater friendship" - **Supported**. "Sociable people prefer sociable roommates, and nonsociable individuals want to live with nonsociable others, *r=0.302 (p<0.01, two-tailed)*

3. "Roommate similarity on the need for "Independence" is associated with greater friendship" - **Rejected**

4. "The need for "**Vengeance**" , which theoretically is related to aggression, is a hindrance to roommate relationships whether pairs are similar or not" - Supported. *r=-0.479 (p<0.01, two-tailed) between vengeance and friendship scores*

Study 2 Hypothesis

1. Roommate friendship is associated with similarity on the need for "**Social Contact**" (sociability), but not to overall sociability – **Supported**, *r=0.429 (p<0.05, two-tailed)*

2. Roommate friendship is associated with similarity on the need for "**Order**", but not to overall orderliness - **Rejected**

3. Roommate friendship is negatively correlated to overall **vengeance** in the relationship (**Supported**) and that high-high vengeance dyads will have lower friendship scores than low-high vengeance pairs (**Not Supported**)

4. Reiss's vengeance scale is associated with the index of aggression score – **Supported**, *r=0.840 (p<0.01, two-tailed)*

5. Roommate friendship is negatively correlated to the index of aggression score – **Supported**, *r=-0.522 (p<0.01, two-tailed)*

Main points from the study

1) "One way that advocates can appropriately support people with ID is by providing them with information that is relevant to their choices, such as selecting a roommate"

2) "…similarity in both communities in sociability was correlated to higher levels of friendship"

Guidelines: when supporting people to choose their roommates (Condensed)

1) Determine the person's level of aggression.

2) Determine the person's sociability

3) Screening
   - A highly aggressive individual will be incompatible as a roommate. The author recommends they do not share living spaces without supports in place to handle crises and to facilitate positive relations with others in the home.
   - Highly sociable people should be encouraged to select people with similar sociability levels and vice-versa for non-sociable individuals.

4) Arrange get togethers before the final decision on the selection of roommates.

5. "It is important for teams to assist in self-determined roommate selection. But the individual makes the final choice

6) Provide follow up and checks for satisfaction

End