

Living Options Residential Weekend

National Federation of Voluntary Bodies

Research Review:

1. McConkey, R. (2005). 'Fair Shares? Supporting families caring for adult persons with intellectual disabilities'. *Journal of Intellectual Disability Research*, Vol. 49, part 8, pp 600-612.

1. Context

In the UK and Ireland, natural families continue to provide life-long care for the majority of adults with intellectual disabilities. For the remainder, historically, our services worked in isolation by providing care in service packages with little or no input from the individual's family. Today, in spirit of social inclusion, reintegration and through person centered planning we are reconnecting with families, encouraging and inviting them to become an integral part of the persons life, working together with the person to support them in their vision for the future.

2 Providing current supports and planning future requirements to enable families to care for their loved ones in their own home

2.1 Introduction

'In many countries, families continue to provide a home for their son or daughter with an intellectual disability long into adulthood'. Because adults with intellectual disabilities are living longer, families have a longer period of care-giving responsibility. Older families become less able to provide care as they deal with their own aging, careers, and other natural responsibilities.

2.2 Aims:

1. Describe the characteristics of persons providing family based care for adult persons with intellectual disability. This was usually documented in terms of the characteristics of the person with the disability and rarely in terms of family carer characteristics.
2. The type of support services that families receive and those they may require in the future.
3. Ascertain the variables, if any that determine the allocation of support services to families.

2.3 Method:

Two computer based systems: The Child Health System: Module V and the Soscare System were used to identify all persons with a learning disability aged 20 and above, and living with family carer's. Information was crossed checked to avoid same person being entered twice and staff eliminated people who are now deceased, moved away or moved into residential care.

For each trust, a random selection identified by SPSS package and pro formas were then distributed to trust representatives who were tasked to distribute them to colleagues that best knew the person. 1584 forms returned 26.6% of known population; 61% completed by social workers; 22% key-workers and 17% community learning disability nurses.

2.4 Findings

1. Characteristics of Family Carers

- A. Around half of the people with learning disabilities were being cared for by both parents but with nearly 1/3 living with lone carers; followed by 19.8% living with a relative and .8% living with foster or adoptive parents.
- B. Lone parent carer's were mainly mothers aged 65 years and above and they were more likely to be living in rented accommodation.
- C. Lone carers under 65 years were less likely to be in employment and more reliant on social security benefits.
- D. Characteristics of the carers varied across the trust areas in terms of proportions of lone carers, carers aged over 75 years, carers reliant on social security benefits and those living in rented accommodation

1.1 Characteristics of people with learning disabilities

- A. Over half of the persons with a learning disability were judged to have no extra support needs while 22% had two or more support needs.
- B. People living with two parents tended to have higher support needs than those living with a lone parent
- C. Those living with relatives had the lowest support needs

2.5 Services and Supports received

- A. Day service supports were available to 80% of carers and a further 2.5% were in part-time or paid employment and did not attend a centre. A smaller proportion of carers looking after those 50 years and above had access 68% in comparison to 80% for those under 50 years.
- B. 34% of carers had access to some form of overnight break; residential facility 22%, going on holiday 10.5%, another person's home 6.2% (similar to that reported for the Irish Republic)
- C. Just over one in five carers had domiciliary help at home (higher than that reported for Ireland 9%). Only a small proportion had a befriender for their relative 7.7%
- D. Access to these services varied across trust areas; differences in day services was not statistically significant but for the other three services the differences were significant
- E. Access to these support services was not statically different across the three different carer groupings; two parent, lone parent and relatives

2.6 Future Needs

- A. 34.9% of persons identified by trust staff as requiring a move at some time in the future Distinguishing factors being;
 - relatives high dependency in personal care
 - carer aged 65 or over
 - carer living in inadequate or unsuitable accommodation
 - carer experiencing greater than average stress
 - carer's income solely from social security benefits

IMPORTANCE OF SUPPORTING THE CARER TO MAINTAIN CARE TO THE INDIVIDUAL: Wrap around service - to the family unit / rather than individual: Link to example of P08W

3. Predictors of Service Usage

- A. Three variables were significantly related to the person's attendance at day service; relative more likely to have higher dependency in personal care; relative rated as over-active or relative aged 50 years or under. Reflective of the broad range of needs these centres attempt to meet.
- B. Carer's that were more likely to receive a break had relatives with high dependency, relatives rated as over-active or carer's with greater than average stress.
- C. Carer's more likely to receive domiciliary supports with relatives with high dependency needs, those required nursing care or carers aged over 75, experiencing poor health, or greater stress
- D. Total common predictor - relative higher dependency in personal care. Over-activity and nursing care did make access to certain services more likely. Greater levels of stress amongst carers did increase the chance of respite breaks and domiciliary supports whereas poorer health and old age only influenced domiciliary supports.
- E. Carers living in certain areas were found to be less likely to receive respite breaks and domiciliary supports than those living in other areas.

4. Critical Evaluation

1. Considering the high level of adults remaining in their family homes and social inclusion movement- critical area of research;
2. Highlights the necessity of services to pay closer attention to the characteristics of family carers to overcome present inequalities in supports offered to them;
3. Data obtained based on the view of one member of staff and trust staff rather than family/individual asked to predict needs in the future;
4. Although they predicted the likelihood of requiring a move at some time in the future, they failed to investigate if carers have made arrangements for future and if so, what type of arrangement e.g. on residential waiting list, going to live with relative, going to be supported in the home etc - may inflate predicted service provision
5. Investigation re: unmet needs and obtaining support when not needed - Lack of assessment re: the actual supports meeting the individual's & carers needs?
6. Comprehensive analysis of four types of supports - could be extended e.g. in-home, extended natural supports, assistive technology etc & identifying service(s) that provide the support; 1 agency / number of agencies;
7. Lack of examination of the level and frequency of supports;
8. It would be useful to have a cost-benefit analysis of supports being utilised;
9. Poor generalizability (limited to one region in the UK); include wider sample;
10. Findings reflect historical provision of care outside family home (under-provision of alternative care arrangements results in greater number of lone parents continuing to care for their relative);
11. Not representative of entire population: did not include family carers not known to statutory services;

12. Good recommendations of future research

- Further investigation of the stress experienced by carers and coping strategies they use;
- Explore QOL of people with intellectual disabilities living in family home compared to those living in out of home arrangements;
- Examine the impact of both the carer and person with intellectual disability if they move from the family home

THOUGHTS

Age in Place?

There will be an increased need for services and supports for older adults with intellectual disabilities whether they are living independently, with their families, or in other residential settings.

Some services and supports supporting functioning and providing opportunity to live as independently as possible:

A. Assistive technologies

1. Mobility devices;
2. Communication aids
3. Security aids
4. Medical aids
5. Home modifications

B. In-home Supports; e.g. home help, home support

C. Extended Family, Friends, Neighbours, Community

D. Volunteers

E. Paid Supports

Future Requirements:

Planning for a time when they can no longer care for their relative is a critical common concern felt by the majority of older family caregivers. Future planning involves providing for residential, legal, and financial arrangements in addition to health care, vocational/leisure activities, and community supports.

(a) Information regarding alternative places to live,

(b) Future financial planning,

(c) Legal capacity - guardianship,

(d) Supports.

There has been an increase in funding for family support programs but only represent a small portion of spending for developmental disabilities services, and often target families of children. More needs to be done to support families of adults.