

Futures Planning for Older Carers of Adults with a Disability

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 - Project Coordinators: Lesley Pope; Janet Pope
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Background - 1

- Issues for older carers who have an adult son or daughter with disabilities have been identified as a concern over many years (DADHC, 2006:3). Issues include:
 - carer anxiety about what will happen when parents or carers are no longer able to provide the current level of care (Bigby, 2000);
 - who will speak for people with developmental disabilities when they do not have close family members to do so (Bigby and Johnson, 1995); and
 - who will question/challenge ... family members/others who may not be acting in the best interests of the person with the disability (ibid).
- “...an ageing carer’s incapacity or death can precipitate a crisis rather than a careful transition to planned and sustainable alternative care arrangements” (Bigby and Johnson, 1995).

Background - 2

- Carers have lowest wellbeing index score for any large group in Australia, scoring 58.5 cf average Australian population between 73-76 (Cummins & Hughes et al 2007)
- Having plans in place for a time of future incapacity can relieve anxiety of older people about their future and allow them to live well now (Cartwright & Parker, 2004).

Aims/Objective

- **AIM:** to empower carer/s to plan ahead for a future time when they may not be able to continue to provide the level of care required for the adult with disabilities, because of the death or incapacity of the carer or carers.
- **OBJECTIVE:** to assist older carer/s (and their adult family member with disabilities, where possible) to reach a level of certainty with respect to future care needs.

Methodology - 1

- The project:
 - Recruited ten families committed to planning for the future of the person they care for;
 - Developed a Model suitable for use by government, service providers and carer/s.
 - Developed family 'Futures Plan' setting out arrangements for a planned transition to a new care situation when older carer/s are no longer able to provide care
 - Developed a Personal Portrait to "tell a story" about the person with a disability (PWD)

Methodology - 2

- This was a descriptive study, using Action Research methods, to allow flexibility within a structured framework.
- Processes:
 - review current literature
 - model identification and development
 - establish inclusion/exclusion criteria,
 - identify/recruit 10 families to participate
 - conduct a series of four interviews
 - hold an information session in each area
 - develop individual Personal Portraits for each PWD
 - write a Futures Plan for/with each family.

Participants

- 10 families:
- Location
 - 4 in the southern North Coast area; 6 in the northern area.
- Age range
 - 57-84 years for carers
 - 18-54 years for PWD.
- Gender
 - Carers incl. 8 males and 9 females;
 - PWD: 6 males and 4 females.
- Type of disability
 - All 10 PWD had an intellectual disability; 2 also had a physical disability.
- Relationship of carer/s to PWD
 - one or both parents and a grandmother.

Model and Futures Plan - 1

- Guidelines for developing a vision and a plan
 - The vision (of the family and PWD for the future of the PWD) is what drives the planning;
 - Important that families are in control;
 - Important that families include others in their planning;
 - The Plan should be realistic and achievable; and
 - Each Plan should be unique and reflect the needs and aspirations of the specific family.

Futures Plan - 2

- Issues for consideration in a Futures Plan for the Person with a Disability (PWD):
 - Financial & Legal (for carer, or both carer and PWD):
 - wills, assets tax implications
 - Centrelink implications financial management
 - Enduring Power of Attorney Enduring Guardianship;
 - testamentary trusts.
 - Housing for where PWD may live in the future :
 - carer's expectations
 - is where they live now suitable?
 - design/layout
 - Are changes required?

Futures Plan - 3

- Issues for consideration in a Futures Plan (cont.)
 - Health/Medical:
 - current level of personal care required for PWD; who provides it? time required to perform this?
 - Contact details of doctors, specialists, dentists, allied health professionals PWD sees;
 - transport to these appointments;
 - private health cover, ambulance/ hospital cover;
 - Guardianship orders.
 - Leisure/Recreation:
 - activities that PWD currently participates in;
 - future activities they would like to be involved in;
 - cost of such activities;
 - availability of suitable activities within the community.

Personal Portrait: Content

- “Who is this person?” The PWD’s story (provided by carer and PWD where possible) including:
 - Factual information, e.g. name, address, date of birth
 - current carer details; emergency contact details and relationship of that person to PWD
 - medical and dental history incl. contact information of health care providers; current medications/allergies
- Also, personal information – photos, friends, activities, likes/dislikes, achievements, favourite things

Personal Portrait: Particular Needs

- Particular information on daily activities, specialised equipment/aids used and a list of topics under which the PWD was rated as:-
 - Independent and does not require help
 - Fairly independent and only requires some supervision
 - Fairly dependent and requires supervision
 - Dependent and needs lots of help
- Topics
 - Communication Diet Food preparation
 - Eating Toileting Showering
 - Dressing/Grooming Mobility Travelling:
 - Managing Money Housekeeping:

Personal Portrait: General

- Activities and Interests
 - things the person likes to do
 - contact details of activity centres/support people
- Behaviour
 - patterns of behaviour
 - “tips” for managing difficult behaviour or soothing the PWD
- Social events
 - who does the PWD like to have around, do things with?
 - Are there things s/he regularly attends/ enjoys
- Likes / Dislikes
 - Foods
 - Music and Entertainment
 - Clothes
 - Special Possessions (incl. those that give personal security)
 - Going Out

Interviews & Information Sessions

- These will be addressed in the following presentation

Outcomes - 1

- All 10 families stayed in the project, even though some found it challenging and stressful
- All completed a Futures Plan to some extent – some more detailed than others
- Most said that they felt that the Personal Portrait would allow someone who had to take over the care in an emergency to really “know” the PWD.
- Comments from carers moved from statements such as:
 - “I’m not going to live forever and I think ‘Goodness, what will happen to him?’” and “It’s not easy to think about (the future)” at Interview 1 to
 - This project ... (provided) ... knowledge that we never knew we didn’t have”; “I wish we could have done this 20 years ago”; and “We (now) have direction” by Interview 4.

Participant Satisfaction

- Family 3: “It is a great idea ... its covered everything ... it was just something we didn’t talk about ... it was just something we didn’t want to bring up. Because of this project, (name) is finally going to Respite ... he just wasn’t allowed ... he loves it.”
- Family 4. “We had no idea about all the things that can come up ... or where to take the next step”.
- Family 9: “We feel lucky and appreciative even though we have found it threatening at times to think of these things. The whole project has made me think and to realise the reality of our situation”.
- Family 10: “The project has been very helpful and informative ... there was so much we didn’t realise. The Personal Portrait is excellent ... even though I sweated blood getting it done ... it is good to have that information all in one place ... it will be very useful. We have direction ... before, it was all too much and we just didn’t know what we could do or what should be done.”

Discussion

- This one year project was a response to the concerns of older carers of adults with disabilities, to help address the question “Who will care for them when I am not here?” It was also a response by DADHC to the concerns of carers and concern for the future of the people with disabilities.
- Some interviews took longer than expected because of the need to build rapport and establish trust with the families. The major issues discussed had the potential to cause distress to families and great care and sensitivity was needed to ensure that the families and the person being cared for were provided with support, even if not formal counselling.
- Supporting families through the Futures Planning process will hopefully alleviate both their short term and long term anxieties about the future.