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Final Report

ASAP Project

Meeting the Needs of Ageing Carers of People with Disabilities

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for

PATH & its Dare to Care Sub-Committee

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1. Introduction

Parenting is a life long commitment, both for persons with and without disabilities (Rossi 1980). In acknowledging the relevance of this statement it is important that any research into the needs of ageing carers actively recognises the extensive privileges and challenges associated with caring for an adult child or family member with disability. As ageing carers have revealed throughout this project, attempting to identify a plan for tomorrow requires drawing on a store of practical wisdom while at the same time trying to avoid locking someone into an environment or model which may be inappropriate or restrictive.

PATH with its Dare to Care Sub-committee used the acronym 'ASAP' (*As Soon As Possible*) for their project to indicate the urgency experienced by some older carers[1] who are looking anxiously towards the future for their family member with a disability. The project commenced with the enthusiasm of PATH with its Dare To Care Sub-committee who were passionate about exploring the needs of carers in the Penrith, Blue Mountains and Hawkesbury communities after having been approached on many occasions by parents seeking assurances that their son or daughter would receive appropriate support as they (the carers) became older and less able to look after them. The Sub-committee sought to identify such carers and this project could not have been accomplished without the openness and willingness to share of the families who so kindly shared their stories.

Take for example the story of June[2] who is 84 years old and the sole carer for her daughter Ruth who is 53 years old and has an intellectual disability. Ruth likes to collect toys and does so with enthusiasm. At the time of interview for this project Ruth had collected 10 large boxes of stuffed toys which she had stored in the family home. June explained that Ruth sometimes becomes *aggressive* when she does not get her own way or when she has to help clean

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[1] For the purpose of this project, older carers are self defined i.e. respondents with adult family members who are concerned about the impact of the ageing process for themselves and their family member.

[2] Pseudonyms have been used to ensure the anonymity of individual participants.

their house. Sometimes Ruth impulsively runs away from home and is returned by the police. Sometimes she takes their money and flushes it down the toilet. June receives 4 hours support a week as part of a carer's package. She recently collapsed at home and spent two weeks in hospital. June's other adult children provided limited support for Ruth during this time. June does not like the idea of Ruth living with other people with disabilities and believes that she should be able to remain in her own home with appropriate support and care.

Then there is May who has a 49 year old son Rodney. Rodney has both a psychiatric and an intellectual disability with the added complication of some physical health problems. May is 78 years old and cares for Rodney at home. May is a very strong advocate for Rodney and has historically been able to secure his placement in both a community group home and a day program. He was asked to leave both services after 10 years because *of behavioural problems* and also due to a *lack of attendance at the day program* (his attendance became intermittent due to features of his mental illness). May continued to advocate on his behalf and Rodney was eventually offered accommodation in another group home. After a further 3 year period he was no longer able to stay there because of his health problems and perceived incompatibility within the household. By this time May was already feeling the strain as she was attending the group home daily to administer Rodney's antipsychotic medication. A further placement in a group home was not possible as Rodney did not have access to a day program and therefore did not meet the organisation's entry criteria.

A somewhat different example is provided by Jenny who at 49 years of age provides an example of a younger ageing carer. In her interview Jenny reflected on her daughter's birth and recalled that it was a full six days after she was born before anyone offered her congratulations. She received pot plants and flowers but nothing personal for her baby. Jenny's daughter Lisa has Down syndrome. She leads a full life and was from early childhood involved in a vast range of activities and interests including classical ballet which she studied for many years. She also held down two jobs. At age 25

Lisa suffered a serious stroke from which it was initially thought she would not recover. Jenny immediately took a year off work and commenced the rehabilitation process. She fought tirelessly to obtain the services needed for Lisa (arguing constantly with health care professionals that her daughter's needs were no different from those of any other woman of the same age and that she was entitled to the same quality of intervention). Jenny remains adamant that Lisa should not end up in a group home where one size fits all, nor that she should be treated as though she is a perpetual child.

June, May and Jenny provide just three of the carer examples within this report. They are each strong competent women challenged by their own ageing and continued caring for their much loved family members. Their stories reflect the demands of being carers and the need for targeted service provision to those who require it most. In their instances, were there to be an appropriate and relevant support option available, the caring responsibilities could be more equitably distributed. Neither June nor May want to relinquish the caring role; rather both are seeking some form of respite or support to lessen the load a little. Similarly, Jenny seeks a range of age appropriate community options from which her daughter can eventually choose the way in which she would like to continue to live with the appropriate supports and safeguards in place.

As the report indicates, through both the literature review and the individual case examples, the challenges and demands on caregivers can be influenced significantly by the availability and quality of internal and external resources. Similarly, carers do not often have the opportunity to discuss their plans and preferences for future care-giving or to explore individual possibilities. As another carer put it when asked about the services she thought would be most beneficial- *My son is different from the others- he needs a whole lot of things other people might not understand.* Another parent described herself as *feeling like an agency carer.* She then went on to say that all she really wanted was to be a mother, not a carer.

Concern and debate about the needs and wants of carers of people with disabilities have led to a time of change and uncertainty. New developments have also led to a questioning of assumptions about how support should best be provided. It is hoped that this report will stimulate a range of questions, responses and debate about the needs of carers which will, in turn, generate a range of innovative and responsive solutions.

PATH and the Dare to Care Sub Committee endorse the findings and recommendations of this report and along with its author sincerely thank the participants for so willingly giving of their time and sharing their stories. Special acknowledgement is made of the contribution by Kathleen's family who lost her under tragic circumstances in October 2005. Their caring role continues as they cope with her loss.

2. The ASAP Project

The ASAP Project was developed to:

> *gain a clear picture of the overall situation of ageing carers/parents in the Nepean area and surrounds, to come to grip with the challenges involved, to offer practical suggestions to meet these challenges and then to work with the responsible agents in the community to meet the needs revealed by the research.*

At the first meeting held on September 30th 2004 it was decided to review the feedback from the project in five stages which were:

1. Preliminary feedback regarding the interview results, discussion of any emerging issues and trends, revision of the project aims and process
2. Presentation of draft findings for discussion and review of further interviews proposed and project milestones
3. Tabling of draft report with preliminary findings and recommendations
4. Submission of final report
5. Meeting with relevant community providers and other follow up.

2.1 Stage 1 & 2 Outcomes

Throughout this period the project brief was refined and basic fact finding commenced. The following activities also took place:

- Preliminary meetings with potential participants at a PATH social event
- Establishment of the carer contact line (a designated phone number which carers could use to initiate contact with the researcher at no cost)
- Follow up meetings with PATH President, Joyce Bellchambers, Alison Tredinnick (research associate) and Lynn Houlahan, principal researcher
- Representation at the Nepean Disability Expo
- Distribution of flyers at Community Centres, Neighbourhood Centres, and TAFE (Penrith, Richmond & Blue Mountains)

- Carer advertisements in the Penrith Press, Blue Mountains and Hawkesbury Gazettes
- Brief Literature Review and analysis of the Carers Coalition Draft Issues Paper (June 2004)
- Summary of respondents' preliminary comments
- Discussion of emerging trends and issues in care giver responses provided to representatives of PATH and the Dare to Care Sub-Committee

2.2 Stage 3 Outcomes

- Contact made with the Project Manager for the Motor Accident Authority - Spinal Cord Injury and Acquired Brain Injury project
- Follow up with Carers NSW regarding the variability of specific data reflecting the needs of Carers in the Nepean Area
- Discussion with Spastic Centre Occupational Therapist, Kingswood
- Contact with Respite in Action Co-ordinator - Sunnyfield Association
- Interview with Kincare representative to establish whether there were service users in common
- Distribution and collation of responses from Coordinators of Castlereagh Learning Service and Katoomba Day Program (DADHC operated services for people with developmental disabilities)
- Phone discussion with staff from Baptist Community Services, Penrith
- Further analysis of carer information
- Initial recommendations to *As Soon As Possible* Committee

3. Summary of Selected Literature

A large body of literature exists within Australia and internationally which reflects the issues and challenges particular to the care-giving relationship between older parents (carers) and their co-resident adult son or daughter with disability. In the Report entitled *I hope he dies before me: Caring for Ageing Children with Intellectual Disabilities* commissioned by the Disability Services Sub-Committee of 1997, it was found that it is difficult to calculate the number of people in this group for a variety of reasons. This may be because some are registered with services for aged persons, some are registered with specialist disability services and some may not be known or acknowledged by any generic or specialist services at all. It is also noted by Christine Bigby (2000) in her book *Moving on without parents* that very few writers question the appropriateness of parents formulating plans for the future of their adult child with disability. She and other authors note, however, that caring involves two kinds of involvement: care about the person themselves including, love, concern and anxiety, and the actual work involved including, feeding, washing, protecting and comforting. Subsequent authors have also used similar concepts, although different language, to distinguish between caring *for* and caring *about* people.

Several features emerge from the literature which consider the issues specifically in relation to the needs of ageing carers relevant to the ASAP project. They are that:

1. The duration of the caring relationship is much longer with older carers than for other carers and that the caring role will more than likely be brought to an end by the death or incapacity of the carer
2. Often the move from parental care to another form of support will arise through an ill-prepared plan or crisis transition
3. The challenges and demands on caregivers can be influenced significantly by the availability and quality of internal and external resources

4. Researchers consistently report the use of formal services by older adult caregivers as being low, with the primary reasons for under-utilisation being a lack of awareness of programs and the unavailability of services
5. Many carers do not discuss plans and preferences for care giving in the future out of frustration arising from a lack of seemingly relevant or available services
6. A 1991 study by Heller and Factor considered the support needs of ageing carers and found that the following six areas were considered to be of high priority in terms of carers' ability to maintain their family member at home: emotional support, transportation, daily respite, extended respite, information on formal services and personal care.
7. Several authors (see Llewellyn, Gething, Kendig and Cant's report funded by The National Health & Medical Research Council May 2003) found that older parent carers' views are often driven by their *experiences in the past*. These experiences include a struggle for assistance when their child was younger, dissatisfaction with current or past service providers, a deep sense of personal responsibility, the belief that by asking for help they are admitting failure, a fear of loss of control and a learned response of having to *fall back on their own devices*.

In the Carers Coalition Draft Issues Paper (2004) reference was made to several sources of carer information. The paper drew together relevant issues through a variety of project work and literature obtained from expert sources and daily carer contact. As a result six major questioned were raised. These were:

1. How can the physical and emotional needs of ageing parent carers best be met?
2. How can the social isolation of ageing parent carers be broken down and community participation achieved?

3. What would enable ageing parent carers to access appropriate services for the person they care for and themselves?
4. What are the best ways to financially support ageing parent carers and those they care for?
5. If future planning for the care relationship is a key priority, how can it best be carried out?
6. How can appropriate accommodation options be developed?

The Carers Coalition Project Work plan then *workshopped* these questions and summarised the suggestions which were submitted to address these issues.

In the publication jointly compiled through the University of Sydney and the Spastic Centre of NSW (Supporting Families - family well being and children with disabilities 2003), it was generally acknowledged that much of the literature emphasises the *tragic tenor* of the role of caring for a family member with a disability. Equally it was noted that the vast majority of people with disabilities are cared for in the family home.

Karen Roberto's 1993 publication, *The Elderly Caregiver* found that elderly caregivers confronted a number of changes as they passed through the various stages in the life cycle. She summarised these changes as including indecision and ambivalence about the future care of their family member, the development of an enforced interdependence, high expectations of the state and a culture of maintaining a family tradition. She also cited numerous studies where the impact of providing care had significantly affected the health of the carer, his or her emotional and psychological well being (depression being regularly experienced), restricted use of personal time, limited both social and employment opportunities, strained family relationships (in particular with other adult children without disabilities) and in some instances increased day to day stress about the current and future needs of themselves and the family member for whom they are caring.

4. Ageing Care Giver Interview Findings

Family member's disability	Main concerns of carer	Carer's own needs?	Carer's request for more information	Interviewer Comments
1. Intellectual and medical	Lack of respite care (inadequate funding). Need for better transport to activities. Wants high security facility (to keep family member *safe.)*	Sole carer, multiple health problems, early dementia.	Carer would like more information on *secure nursing homes*. Prefers a facility where parent and child can reside together.	Carer does not like the idea of a supported accommodation model. Likes the concept of communal living.
2. Autism, communication difficulties	Lack of access to high quality day programs. Lack of worker entitlements for people with disabilities. Need for adult casework follow up.	Siblings support needs. Desire to have own life-separate form family member in future.	More information to be compiled re group home and community options. Department of Housing has stated to the carer that tenants need to be capable of caring for the property.	Carer has experienced difficulty with securing personal and medical insurance for her family member. She is also concerned about limited access to information re changes and future directions of the post school options program.
3. Epilepsy and physical disability	Community transport & geographical limitations such as crossing over into different LGAs. Vehicle modifications.			Family have a responsive general practitioner and have been well supported through their local hospital.
4. Autism & epilepsy	Need for high levels of supervision when transporting. Behavioural difficulties. Daily routine & staff continuity seen to be vital. Changes to ATLAS cause anxiety.	Time to enjoy life as a couple.	Alternative respite options (if they exist).	Family report an inability to enjoy spontaneous outings or activities. Limited access to respite and its inflexibility severely limits their options. Family would like a dedicated accommodation service for people with autism.

Family member's disability	Main concerns of carer	Carer's own needs?	Carer's request for more information	Interviewer Comments
5. Intellectual disability	Obsessive behaviours, poor personal hygiene, absconding behaviours. Poor money management skills. Changes to in-house carers which causes disruption.	Single, elderly carer. Health problems and social isolation.		Carer is concerned about spending savings on care for family member, believes her health is suffering as a result of worry over the future. Is unwilling to consider community living options for family member-feels that *home is best.*
6. Acquired brain injury, epilepsy	Lack of community awareness, need for in-home support to enable carers to have a small amount of time to themselves. Housekeeping and meal preparation assistance.			Carers place a high value on the need for a family pet and in- house support without intrusion.
7. Psychiatric disability	Social isolation, community prejudice, changes to his life for example in his case worker. Cost impact of needed services for example, music therapy.	Need to provide daily intensive support to family member.		Carers are not keen on the idea of group home living. Concerned about family member's inability to get along with others.
8. Intellectual disability-Down syndrome	Wants family member to live close to her own home with freedom and access to visit whenever she wants to.	Heart problems. Age related health issues, limited family support.	Details of group home availability in Blue Mountains. Costs of community living.	

Family member's disability	Main concerns of carer	Carer's own needs?	Carer's request for more information	Interviewer Comments
9. Dual diagnosis (psychiatric & intellectual disability)	Better supervised respite care, more attention to medical needs, more understanding of the individual personality, transport to and from services. Changing rules and policies and procedures, better range of and access to day programs.	Age and intermittent health problems, inability to plan for social activities. Worried about family members getting access to needed services in the future.		Carer dislikes the lack of routine and predictability that is associated with accessing several disability support services at the same time.
10. Intellectual disabilities	Lack of day programs, social activities. Wants group home placement in the future (not now). Finds government services to be non-responsive. Sick of changing case workers through DADHC.	Day to day stress associated with caring (although family members do not have challenging behaviours). Needs more flexibility with access to respite care.	Carer concerned re issues of legal guardianship.	Carer has two family members needing support.
11. Intellectual disability uncontrolled epilepsy	Carer would like to have overnight care for her daughter in own home.	Family member accesses a day program two days per week. Is transported there and back.	Carer finds funding package information confusing.	Carer can drive but tends to call an ambulance when her daughter has a seizure. She has carefully considered insurance support and has made a will to provide for her daughter financially.

Family member's disability	Main concerns of carer	Carer's own needs?	Carer's request for more information	Interviewer Comments
12. Schizophrenia	Carer has shared responsibility (her son has a Department of Housing bed-sitter). She would like more communication from mental health providers and better access to hospital when he needs it.	Anxiety disorder. Family member does not want to go to day program or living skills centre and is constantly returning to his carer's home.		Carer would like more control over her son's decision-making ability. He wants to lead his own life. Carer believes he has limited insight into the impact of his disability.
13. Developmental disability/ mild brain damage) following motor vehicle accident	Has good access to day program. Attends a local recreation service. Family member is sometimes impulsive- forms relationships too readily. Carer would like her to share with one or two others (with supervision/ support).	Carers are working and in good health.	Information on making wills (published by Redfern Legal Service) provided.	Carers are relatively young (48 & 51 yrs).They would not like their family member to move out of home immediately but would like to have a plan in place for the future.
14. Down syndrome & associated health conditions (obesity and cardiac)	Would like a *family style* group home. Consistent staff. Has had some one-off respite care in the past (none currently being sought).	Carers have discussed the future with their extended family.		Carers have read about abuse in care. Would like assurance from a future service provider about recruitment and supervision processes in a supported accommodation.
15. Intellectual disability- minor eye problems	Family wants a range of residential options to be available in the Blue Mountains	Two carers- one with hypertension, the other has a heart problem.		

Family member's disability	Main concerns of carer	Carer's own needs?	Carer's request for more information	Interviewer Comments
16. Severe Intellectual disability- some behavioural challenges	Family member is in a group home but has a shared-care arrangement spending part of her week in the family home.	Parents are both mid to late 70's. Family member is an only child.		Carers are worried about how their daughter will adjust *after we are gone*. They admit that they tend to spoil her at home- at the group home she has to share everything. They have a good rapport with group home staff and contribute a great deal.
17. Developmental delay- some autistic tendencies	Family member likes routine- starts to pace and hand-wring when changes occur. Carer would like more respite (non-government service assists at present). Not seeking permanent placement at present.	Family member doesn't drive. Relies on help from her sister (in her 60's also).	Information on community transport.	Family member has difficulty communicating- tends to point and lead carer to what is wanted (eg. Fridge). Respite care changes (both staff & clients) can be disruptive as client dislikes change and reacts to noise.
18. Mild Intellectual disability	Wants to progress to independent living. Attends supported employment. Needs support with activities of daily living, banking and mail.	Family member gets frustrated with siblings who are in relationships and work.	Discussion re Department of Housing eligibility and ability to manage a tenancy	Family member appears to have the potential to live more independently in the future. At 19 years of age she is keen to lead as mainstream a life as possible. Is too capable for supported accommodation but will require educational and life skills support (and monitoring)
19. Intellectual disability-food seeking behaviours	Has had regular respite in DOCS group home. Needs Behaviour Support. Permanent placement being sought. Carer wants someone to take him out regularly although he dislikes walking	Carer experiences stress managing behaviours. Family member is overweight - reacts badly to limit-setting.	Positive behaviour support strategies. Follow up from DADHC psychologist – in-home programs	Family member places some limits on carer's day-to-day activities. He needs constant supervision. Carer has recently been able to arrange a holiday so is feeling better.

Family member's disability	Main concerns of carer	Carer's own needs?	Carer's request for more information	Interviewer Comments
20. Autism and genetic disorder	Carers have two sons with support needs. One is in full-time care, the other has scheduled respite. Carers feel both sons need permanent supported accommodation placement.	Carer has another child and grandchildren would like opportunity to experience more normal lifestyle. One family member is often awake at irregular hours so this causes fatigue in carer.	Carers are very well informed about services. Known to Carer's NSW.	Very active female carer. Contributes to committees and various projects established for people with disabilities. Has been involved in DADHC staff selection processes.
21. Brain haemorrhagic disease, sensory impairments, communication difficulties	Carers want to leave the family home to their family member after their death. They state they would want meals on wheels, assistance with housework and daily supervision.	The need for familiar surroundings is one of the key issues for these carers who are in their late 60's.		Carers are opposed to supported accommodation style accommodation. They are actively pursuing neurological services and are particularly keen to find an empathetic specialist who appreciates the extent of their family member's needs.
22. Psychiatric disability-chronic smoker	Carers and sibling constantly need to encourage interaction and participation. They would like a responsive rehabilitation facility with good supervision.			Active symptoms (suicidality and paranoia) impact on the entire family. Their family member is very demanding when unwell and demands to know their whereabouts at all times. Family is not in favour of a supported accommodation environment because of their family member's personality.

Family member's disability	Main concerns of carer	Carer's own needs?	Carer's request for more information	Interviewer Comments
23. Mental health issues, high blood pressure and anxiety	Family member previously lived in permanent accommodation but could not stay due to behavioural problem and emerging health needs. Carer is concerned that services insist on access to a day program before a permanent bed can be provided.	Financial impact of having to pay to retain a placement that family member cannot take up. Carer has health problems (not disclosed) and is very involved in day-to-day support of her family member (including medication administration)		Carer is a very strong advocate and well informed. She is seeking more accessible day activities and quality long-term supported accommodation
24. Intellectual disability	Lives with one carer and they support each other. There are no immediate plans for permanent placement. Non gov. service provides limited respite. Family member sometimes wants to go and sometimes doesn't. Carer is not interested in someone coming to their home - would eventually like a permanent placement (no specific time frame).	Carer and family member have an extensive social circle and tend to do things together. Carer can drive.	Information regarding respite support close to Londonderry	Household have been mutually dependent for many years (and enjoy each other's company). The family member with disability is well integrated into the local community.

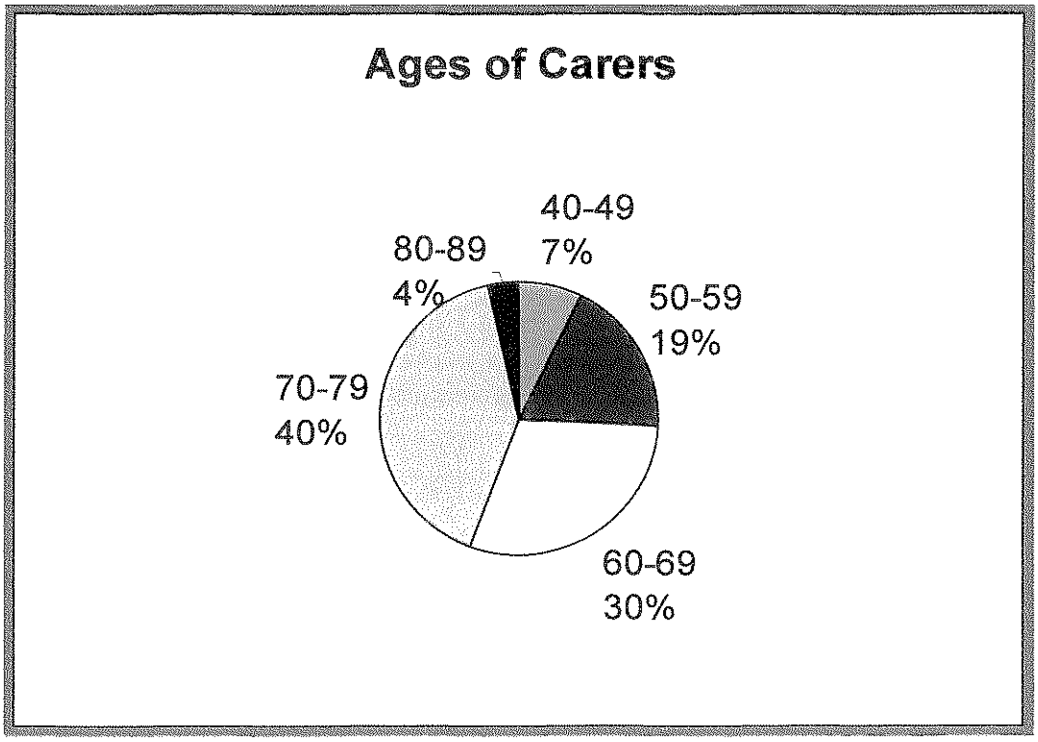
Family member's disability	Main concerns of carer	Carer's own needs?	Carer's request for more information	Interviewer Comments
25. Learning difficulties (attended a school for specific purposes)	Referred to researcher by neighbour. Carers would ultimately like long term placement (but only when she wants to move out). Some conflict within the household about the extent of freedom allowed (and choice of friends).	One carer (aged 61) has diabetes and is insulin dependent). Carers would like to have a plan in place for future.	Would like to place family member's name on a waiting list.	Carers stated that they would not accept out of home care if it was immediately available. Family member would require limited support in the community and a range of shared household options would provide the greatest degree of independence.
26. Intellectual disability, some behavioural issues	Carers would like a secure environment as family member tends to abscond if she is not happy. They would consider a community placement (supported accommodation or hostel). Previously had a placement with a non- government facility which they relinquished.	No known health issues. Carer would like to visit family interstate but family member doesn't travel well.	Discussions re "locked facilities" and safety issues.	Carer wants secure supported accommodation *without violent residents* to ensure family member's safety. Would not be happy if family member were *free to wander the streets*.
27. Uncontrolled epilepsy, physical dependency	Carer's sibling is concerned about the impact of providing care on her parents.	Two parents who are elderly - father has had major heart surgery.	The family have made legal provisions for the future by way of an insurance policy. Both carers have made wills.	Carers would like overnight support to enable their daughter to try living away from home. Carers do not want immediate permanent placement. Would eventually like a *caring environment* with things for family member to do during the day.

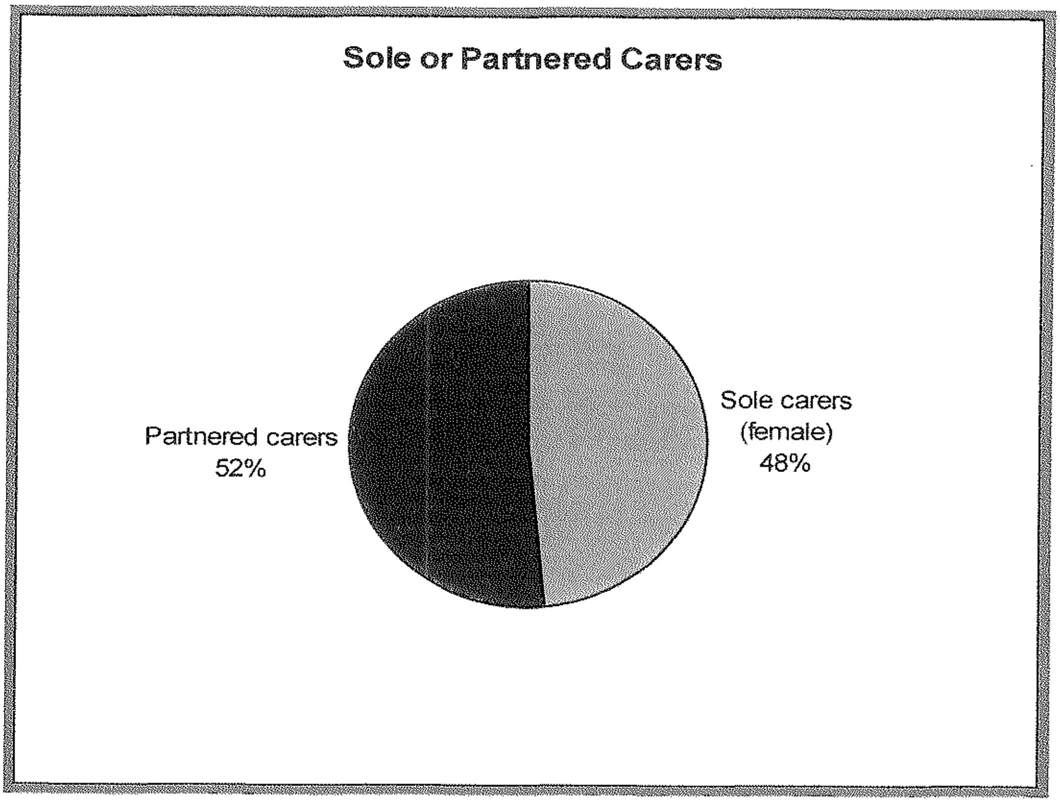
Family member's disability	Main concerns of carer	Carer's own needs?	Carer's request for more information	Interviewer Comments
28. Down syndrome, cerebral accident, Coeliac Disease	Carer is concerned that her adult child is perceived as an extension of her and not as a unique individual with rights and wants. Has had to advocate with services to access intervention that would be available to a non- disabled person e.g. colonoscopy and physiotherapy.	Carer would like more "unstructured" time to meet her own (and her partner's needs). She also has a demanding career which requires travel.	Carer is very well informed and aware of available resources. She has actively initiated service development so as to meet her family member's needs as she ages.	Carer is comparatively young. She is totally dedicated to enabling her family member to have choices that meet her needs. Somewhat disillusioned by lack of responsive living arrangements despite years of advocacy and inclusive planning.
29. Developmental disability, mental illness, acquired brain injury	Carer and her family member cannot live together due to his complex needs. Family member lives in a group home staffed 24hrs a day (which carer believes discourages independence). Family member is required to comply with house rules which are not age appropriate. Carer is concerned about the future for her son when she is not around to promote his interests	Carer lives alone but has daily contact with family member. She also assists him with shopping, medical appointments etc.	Information provided regarding options for secondary consultations and community resources. Carer is a strong advocate for people with disabilities generally.	Carer impressed as sensitive to her family member's need but admits to anxiety about potential withdrawal of support services if she voices a concern about current procedures. Services currently provided to her family member appear regimented and somewhat restrictive. Carer would be open to a range of accommodation options which facilitate greater skill development such as money management while also providing companionship

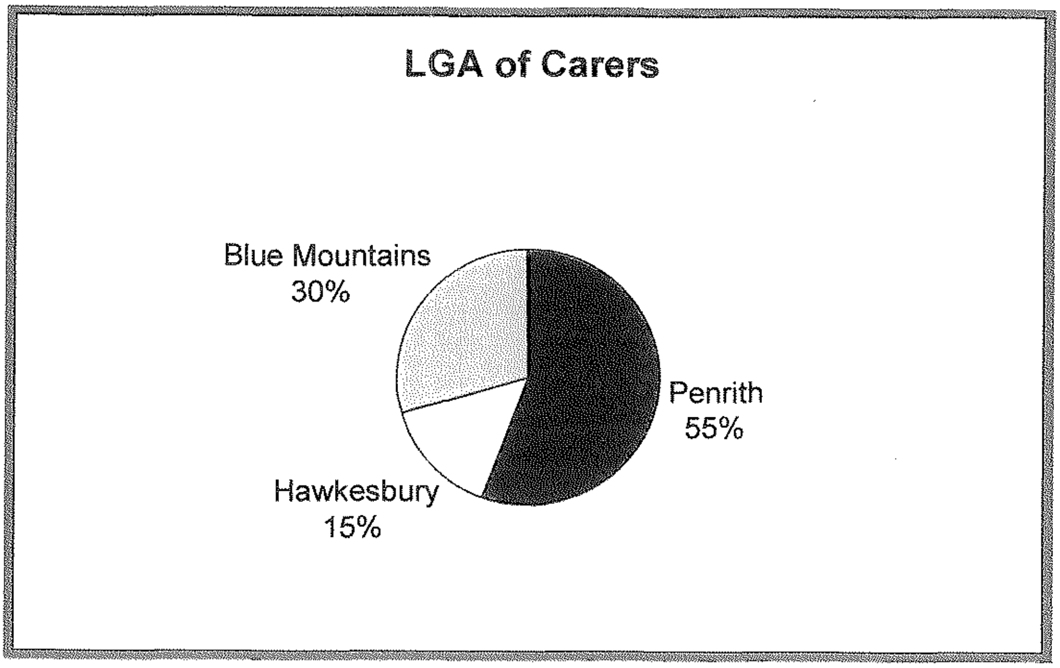
5. Summary of Findings

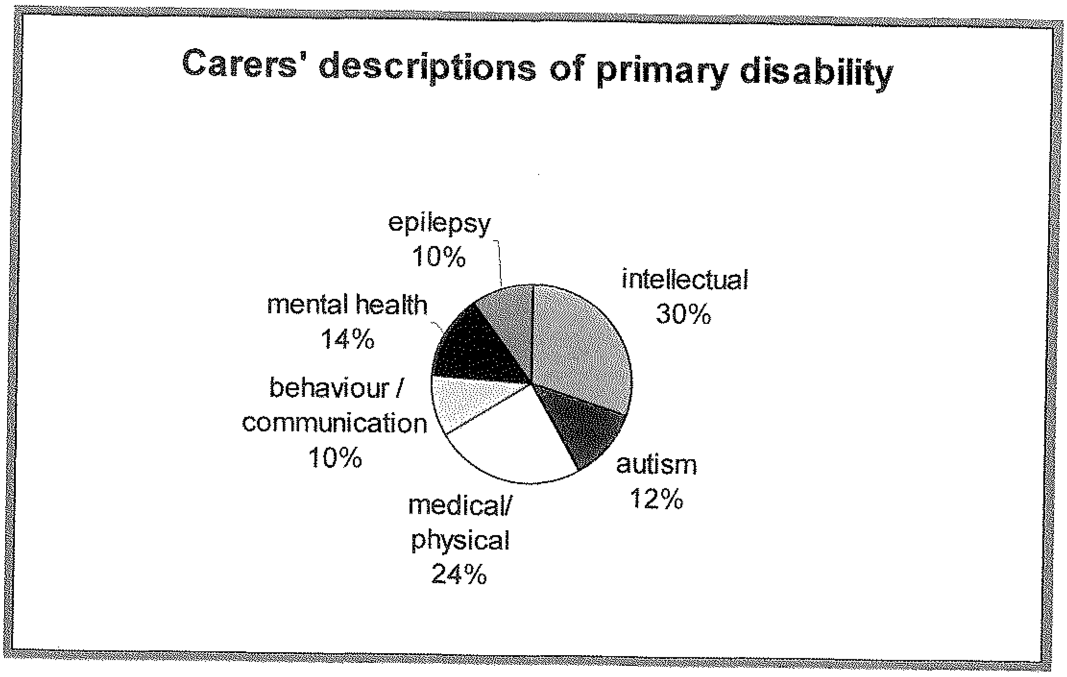
The above is a summary of the formal 29 interviews conducted. Two initial respondents were found to be out of area in that one was a grandmother who lives in Western Sydney (and visits her grandchild rather than providing regular care) and the other lives in the Bankstown local government area and provides her family member with informal shared care. A small number of messages were left on the hot line number wherein the caller failed to leave contact details and therefore could not be contacted by the researcher.

As shown by the figures below, the participant carers ranged in age from 47 – 83 years. The youngest family member with disability being cared for was 16 and the oldest 49 years. As seen in the following graphs, the majority of carers supported people with intellectual disability, followed by carers of those with medical or physical disabilities (including acquired brain injury). A number of people being cared for had multiple and complex needs.




Sole or Partnered Carers
Partnered carers
52%
Sole carers
(female)
48%


LGA of Carers
Blue Mountains
30%
Penrith
55%
Hawkesbury
15%



The figure above reflects the major identified disabilities of those being cared for. Specifically, some carers described difficulties in caring for family members with uncontrolled or difficult to manage epilepsy, and others detailed autism or autistic like features in their overview of their family members. Carers were mostly in favour of the provision of supported accommodation or in-home support: however there were some carers who were opposed to supported accommodation models. With respect to the concept of supported accommodation, carers were most familiar with the idea of community group homes and had formed views (either positive or negative) based on media stories or personal experience. It was also apparent that some carers had misinformation about the scope and availability of community group homes and had been influenced by negative press reviews or the shared experiences of others. No carers mentioned "intentional community" options although several indicated that their preferred option would be to remain living with their family member (in aged care or even a nursing home).

Some of miscellaneous program supports identified by carers under the *other* heading included supervision of medication, modifications to motor vehicle to facilitate transportation and the provision of outings from home. Transport to and from services of all kinds was generally raised in the context of the carer either having lost or anticipating losing their ability to drive in the future as a result of increased age or deteriorating health.

In comparing the interview findings with the findings within the literature review, research findings and in several large studies, there are many similarities and some differences.

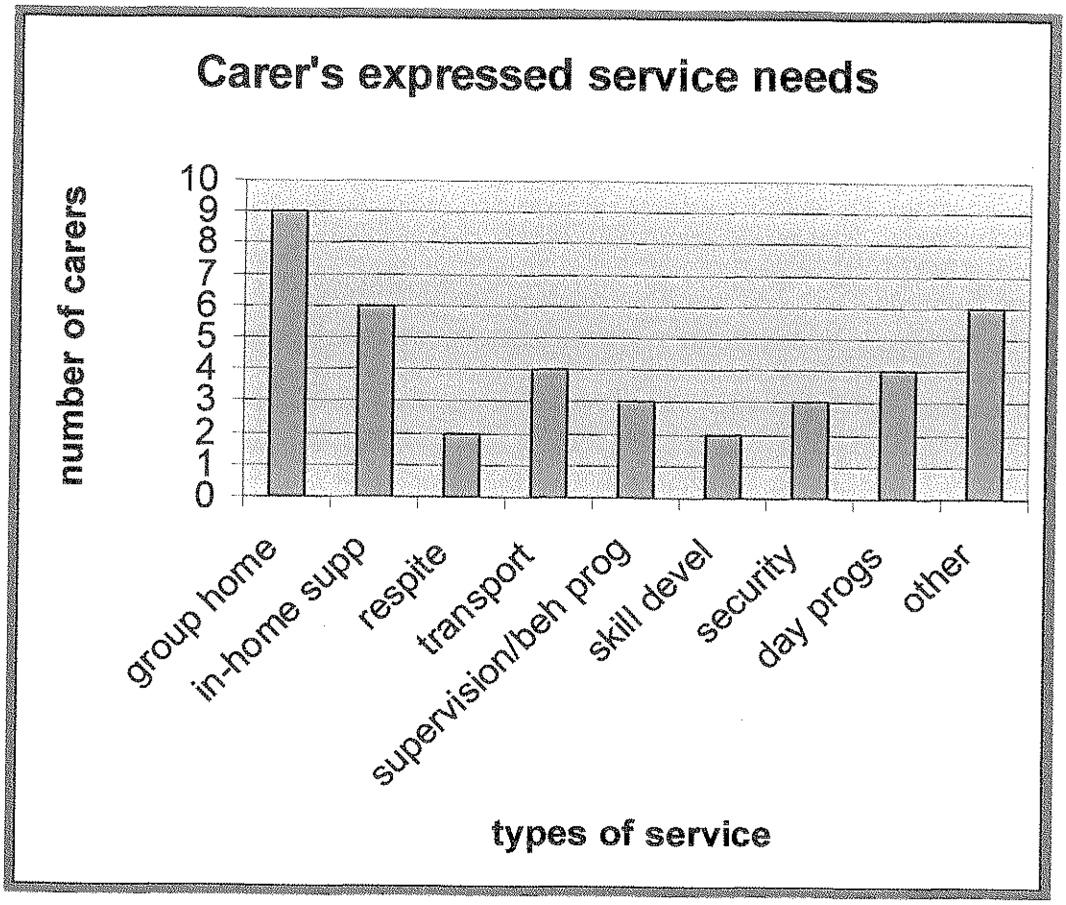
Of interest in the interview findings was that several participants referred to their perceptions of bias or prejudice within the community concerning the person with a disability. Overall however, participants had solid connections with service providers who valued their family member and treated them respectfully. Some participants felt that there was a lack of transparency as to how to enter both supported accommodation options and day programs and noted that often entry and exit guidelines were not freely available. One mother also commented that she felt there was an air of secrecy around some day programs and workshops *as if they have something to hide.*

On a more positive note, while it was reported that caring for a family member with a disability can be stressful, several parents (both mothers and fathers) expressed reluctance to relinquish care of their family member. This appeared to vary depending upon the behavioural demands of the person being cared for and on the health status of the individual carer. The degree of interdependence noted in the literature was reported directly by three carers who felt that their lives would be *empty* without their family member living at home with them and another who stated *we just help each other every day - it suits us both.* It is noted that these carers did not want an immediate placement for their family member but wanted such an option longer term.

Several carers expressed their concerns that staff working in supported accommodation facilities may be poorly trained or inexperienced. Those with experience confirmed that the staff turnover is often high and that people with disabilities may form attachments which are soon broken when the staff member moves on. Another aspect which related to the quality of supervision and monitoring was raised in terms of the potential for exploitation or abuse in community supported accommodation. Food choices, nutrition and access to transport were also discussed. As predicted, the future needs of the person with disability were consistently raised in interviews. Carers did not want their other children to necessarily have the on-going responsibility for their sibling with a disability, and in some instances stated that their other children were unwilling to provide care after their death.

Another common theme among respondents was the need for continuity of case management. Several carers emphasised the negative impact that being *passed on* from worker to worker has on both the person with disability and the family overall. For those carers supporting a family member with mental illness the need for support largely related to the phase of the family member's health. Where the son or daughter lived independently (such as in Department of Housing accommodation), more support was only required when the family member was in an active psychotic or delusional state. The ability to access secure psychiatric inpatient services was seen as a high priority at this time.

All participants were able to identify one or more services for people with disabilities which were either inadequate or lacking in their community and to identify the need (in their own words) for key person succession plans and planned lifetime assistance programs as identified in the Carers' Coalition Project Work Plan.



5.1 A brief comparison of the PATH/ Dare to Care Project Findings and the findings of the Carers Coalition Report

There were six major issues identified by ageing parent carers at the ACROD State conference and the inaugural meeting of ageing carer project officers of the Commonwealth Carer Respite Centres in May 2004. These issues were: ***physical and emotional health, social isolation and participation, access to appropriate services, financial limitations, planning for the future*** **and** ***accommodation options***. When these issues were analysed in terms of the PATH ASAP Project findings there were many common features. Take for example the issue of access to case management and provision of information (*Access to appropriate services*). This report indicates that carers were dissatisfied with changes in case management and often felt that access and exit guidelines were not transparent or freely available from the service provider. Under the heading of *physical and emotional health* this project identified direct links between the carer's own health and support infrastructure and their views about permanent or respite care for their family member. Where a respondent felt healthy and well supported there appeared to be less of an immediate desire to access supported accommodation. While the PATH ASAP Project participants identified the need for more day and transitional programs they also identified behaviour support (where relevant) as being inadequate (a factor not specifically raised in the Carers Coalition Report but no doubt captured under *Access to appropriate services*).

One of the issues of concern for some carers living within the Blue Mountains and Hawkesbury areas was the inevitability as they aged of no longer being able to use private transport to take their family member to and from various services. The need for transport support was not so much raised as a financial limitation but as one of the challenges of living in a large geographical area encompassed by the three LGA's (as well as the relative isolation of some communities within these areas). This factor was identified and expanded upon by the Carers Coalition under *financial limitations for carers* where creative uses of community transport and the development of NSW carer concessions were raised as two of a number of strategies to address this issue.

In reflecting on the issues noted by the Carers Coalition Report under the heading *planning for the future,* the ASAP Project found that most carers had made financial arrangements for their family member via their will or informal arrangements with siblings. The issues of legal guardianship posed concerns for some who were unable to appreciate the difference between legal decision- making and relinquishing care. In one instance a participant who was experiencing early signs of dementia became quite disturbed at the suggestion of guardianship for her daughter (who has limited decision-making ability). This particular participant believed that if she supported guardianship her daughter would be removed from her care as a result.

The inability to access both regular and emergency respite care was raised by participants who had undergone unexpected hospitalisation or treatment. Some participants appeared to have established links with respite services while others had only made contact when a crisis had arisen. As reflected in the Carers Coalition findings, some carers had no links to the established disability system either because of lack of awareness or due to previous negative experiences in which they had felt *let down* by service providers. Overall the PATH ASAP Project findings upheld many of the issues raised within the Carer's Coalition paper and highlighted the six major issues identified. As reported earlier in the report these issues were; *physical and emotional health, social isolation and participation, access to appropriate services, financial limitations, planning for the future* and *accommodation options.*

6. Recommendations to the PATH/ Dare to Care Steering Committee

Throughout the life of this project the researcher was privileged to meet and talk to carers whose stories reflected a lifetime of support, advocacy and often frustration with the inadequacy of current services. Many talked sadly of the gaps in the existing system and their desire to see things *put right* before they as carers, were unable to continue.

The researcher recognises that some of the participant carers in this project have been able to access funded respite packages which include the provision of transport to and from the respite provider. Still others access in-house respite and some of the remainder participate in a limited booking system where it is expected that the carer transports their family member to and from a residential service for an allotted period of respite. Several carers also mentioned having paid for respite camp arrangements to enable both themselves and their family member to have a break from each other.

Concerns about suitable transport arrangements were also raised in a practical sense as, while some participants still drove their own vehicles, many recognised the inevitability of losing their license as they aged further and expressed anxiety as to the impact of this loss. While the numbers may not be statistically significant, the fact remains that carers within the Nepean area require greater access to supported accommodation and respite care choices if they are to continue to be effective in their life long role as carers.

Following feedback from the draft reports submitted in July and September 2005 and further in July 2006, the researcher and the PATH/ Dare to Care Sub-Committee agreed on the following recommendations:

1. PATH and the Dare to Care Sub Committee to use a public occasion, for example, PATH's forthcoming 25th Birthday celebration and AGM to launch this report and emphasise its findings. This report to support further representations to the Minister for Disability seeking enhanced service provision to people with disability and their carers in the Nepean Area.

2. A summary of the project findings to be prepared for publication by newspapers in the three Nepean local government areas so as to further promote the report findings. Press releases to also be forwarded to a range of selected community-based publications as well as to NCOSS and ACOSS.

3. Representatives from PATH/ Dare to Care to prepare a formal submission seeking the Minister's response to the findings and an action plan to address the issues highlighted. In particular, PATH and its Dare to Care Sub- Committee strongly support increased funding and strengthening of local information and advocacy groups in direct response to the concerns raised by carers and highlighted within this report (such as case management, transport and information services).

4. Given the strongly identified need within this report for a greater range of supported accommodation choices, it is crucial that further options be developed and made available to people with disability and their carers within the Nepean Local Government areas. PATH will continue to support the need for enhanced accommodation support within its existing resources as well as by seeking increased recognition and funding to enhance this role and function.

7. Appendix – Questions for Participants

In order to gather the data necessary to consider the issues facing ageing parent carers a set of questions and prompts was developed to explore their needs

ASAP- Meeting the Needs of Ageing Carers *of People with Disabilities*

Introduction & Opening statements:

The project aims to establish the specific needs of older families and carers with a family member with disability. A report will be prepared based on the information provided by you which the Committee will be sending to government. The PATH/ Dare to Care sub committee will make the final report available to all interested parties (on request) upon its completion.

1. Can you tell me about your family member (age, type of disability intellectual, physical, psychiatric etc, personality, preferences etc)? What services does your family member currently access eg respite care, peer support, day programs, aged services etc. (Some families will talk about ATLAS or POST SCHOOL OPTIONS) these are services funded by the Dept of Ageing Disability & Home Care- some get a few hours, others get several days on a regular basis).

2. What are your family member's main needs? What are some of the things you are concerned about as he/she gets older? How does your family member's special needs impact on your lifestyle (now & projected)?

3. If residential care or supported accommodation is identified (a group home for example) what are the particular things that would be important to you (such as transport, health care, supervision with medication, case management, access to a medical specialist, staff training).

4. Does your family member have any particular health problems? (What are they- how are they managed currently?).

5. How does your family member spend his/her leisure time? (Hobbies, social clubs, peer support groups).

6. Depending on the participant's age- is your family member attending a day program (or work placement) at present? What are its strengths and weaknesses? Can you think of suggestions to improve the service or change its approach?

7. Does your family member require transport to and from activities? Is the current service adequate?

8. What are the particular limitations for you as a carer (both now and into the future)?

9. Is there any particular information you would like about relevant issues for example, Legal advice for people with disabilities, making a will, money management, Guardianship, additional services etc.

10. Anything else you can think of?

8. References

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