



**Aged Services Learning and Research Centre (ASLaRC)**

# **Futures Planning for Older Carers of Adults with Disabilities**

## **Phase 2**

**Report to NSW Department of Human Services  
Ageing, Disability and Home Care  
January 2010**



**Human Services**  
Ageing, Disability & Home Care



*home and community care*

A JOINT COMMONWEALTH AND STATE/TERRITORY PROGRAM  
PROVIDING FUNDING AND ASSISTANCE FOR AUSTRALIANS IN NEED



## ACKNOWLEDGEMENTS

The Research Team wishes to acknowledge the advice and support of Jane Roser, Senior Project Officer, NSW Department of Human Services, Ageing Disability and Home Care (ADHC).

The Team wishes to specifically thank those people who gave of their time and expertise at the Information Sessions:

- Stuart Garrett – Solicitor, S+P Lawyers
- Paul Ryan – NSW Trustee and Guardian
- Rick Rutten – Financial Advisor, Retireinvest
- Deborah Goodger – Manager, Information, Referral and Intake – ADHC
- Paul Tipper – Solicitor, Paul Tipper and Associates
- Linda Ingelby – Financial Advisor, Kerry Albert & Co
- Merilyn Purton - Centrelink

The Team also wishes to thank the service provider organisations who provided considerable staff resource to ensure the success of the project:

- Tweed Valley Respite Services
- Multitask
- Realise Every Dream Incorporated (R.E.D. Inc.)
- Northcott Disability Services
- Ageing, Disability and Home Care (ADHC)
- Valleys to Plateau Community Support Services Incorporated
- Clarence Valley Community Programs
- Life without Barriers
- Respite and Recreation Incorporated
- Accommodation Network Pty Ltd

Finally, we wish to acknowledge the cooperation and input of the families who willingly gave up their time to participate in this project.

Funding for the study was provided by the NSW Department of Human Services Ageing Disability and Home Care.

The Chief Investigator for this study was Professor Colleen Cartwright, Director, Aged Services Learning and Research Centre (ASLaRC), Southern Cross University.

The Project Coordinator/Research Officer was Marie Gale; assistance with the study was also provided by Cath Cosgrave, Research Assistant and Leanne Carpenter, Jenny Smith and Jocelyn Craig, Administrative support.



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## **LIST OF ACRONYMS**

ABS – Australian Bureau of Statistics
AHCD – Advance Health Care Directive
ARAFMI – Association of Relatives and Friends of the Mentally Ill
ASLaRC – Aged Services Learning and Research Centre
ADHC – NSW Department of Human Services Ageing Disability and Home Care
EG – Enduring Guardian
EPA – Enduring Power of Attorney
FaHCSIA – Department of Families, Housing, Community Services and Indigenous Affairs
PLAN – Planned Lifetime Advocacy Network, Canada
PWD – Person with a disability
SCU – Southern Cross University

## GLOSSARY OF TERMS

*Carer* – A relative or friend who provides or organises day-to-day care for a person with a disability.

*Consent* – Agreement by carer/s and, where possible, person with a disability to participate in the project.

*Disability* – A physical or mental incapacity, either congenital or resulting from an injury or illness etc, that curtails to some degree a person's ability to carry on his/her normal pursuits.

*Family* – Carer/s and the person with a disability, may also include other family members or others providing on-going non-professional personal support to the person with a disability.

*Futures Planning* (In relation to this study) – A structured process whereby families (a) developed a written document outlining the arrangements they have made for the care and support of the person with a disability, including but not limited to: accommodation; finances; person to oversee care; and (b) put in place various binding and legal vehicles to cover dispersal and management of assets and decision making around health and well-being relating to the person with a disability.

*Geographical Area* – The boundary for the project/location of families.



## **EXECUTIVE SUMMARY**

### **INTRODUCTION**

The Aged Services Learning and Research Centre (ASLaRC) of Southern Cross University is involved in research, education and the promotion of evidence-based practice and community engagement in relation to the development and delivery of aged services for rural and regional communities.

The NSW Department of Human Services, Ageing, Disability and Home Care (ADHC), provides support and services to more than 1 million older people, people with disabilities and their carers, to assist them to lead independent lives and participate in community life.

In June 2006, ADHC (then DADHC) invited tenders for a one-year project to undertake Futures Planning for Older Carers of Adults with Disabilities; ASLaRC was the successful tenderer. Phase 1 of the project was undertaken in 2007. The outcomes for Phase 1 of the project are detailed in the ASLaRC report *'Futures Planning for Older Carers of Adults with Disabilities Phase 1'*: a copy can be downloaded from the ASLaRC website (<http://aslarc.scu.edu.au/downloads>).

Following the successful outcomes of Phase 1, ADHC provided funding to ASLaRC to conduct a second phase of the project, working with service providers and the families they support, to investigate whether the project was viable within existing service delivery processes. Phase 2 of the project was undertaken in 2009.

### **AIM**

The overall aim of the Project (Phases 1 and 2) was 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 a disability, because of the death or incapacity of the carer or carers.

### **OBJECTIVE**

The main objective of this project was to assist older carer/s (and their adult children or family member with disabilities, where possible) to reach a level of certainty with respect to future care needs. In addition Phase 2 sought to test the viability of expanding the project to

reach a wider number of carers, in a cost-and time-effective way, by working through service providers active in the sector.

## **EXPECTED OUTCOMES, PHASE 2**

It was expected that the project would:

- Train and equip personnel from participating service providers to enable them to facilitate Futures Planning with older carers;
- Develop a 'Futures Plan' for each person with a disability involved in the project, setting out arrangements for a planned transition to a new care situation when older carer/s are no longer able to provide care;
- Assist carers and persons with a disability to develop a comprehensive Personal Portrait that would enable support to be provided to the person with a disability with minimal disruption to preferred and normal routines;
- Reduce the need for a crisis response in the event of the death or incapacity of older carer/s.
- Provide carers with a level of certainty about the future and help to allay their fears about what will happen when they are no longer able to provide support.

## **BACKGROUND**

An extensive literature review was undertaken as part of Phase 1 (see Phase 1 Report), the key themes, from which, are summarised below. Also included is information from research undertaken since the conclusion of Phase 1.

Issues for older carers who have an adult son or daughter with disabilities, identified in Australian and international literature, 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 older people with developmental disabilities when they do not have close family members to do so (Bigby and Johnson, 1995) and who will question and challenge the roles played by family members who may not be acting in the best interests of the person with the disability (ibid).

Cummins and Hughes et al (2007) found that carers have the lowest wellbeing index score for any large group in Australia, scoring an alarmingly low 58.5, compared to the average Australian population between 73 and 76. Research has demonstrated that 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). It is expected that a similar psychological process would apply in relation to carers, who could maximise the quality of the time they have left with the person for whom they care without the constant worry and anxiety of “what will happen when I am not here”.

The Australian Government's Discussion Paper on Succession Planning for Carers (2007) identified a number of key barriers to planning, including that: Families don't know where to start; it is a sensitive issue; it is a complex and time-consuming task; and many ageing carers may not have expected their son or daughter to outlive them and may have unrealistic expectations around what governments, services and family members can provide when they need to relinquish care.

## **METHODOLOGY**

**Ethics Approval:** Ethics Approval was provided by the Southern Cross University Human Research Ethics Committee.

**Methods:** The project used Action Research methodology and built upon the experience gained from Phase 1. The methodology process involved a review/up-dating of current literature, identification and recruitment of service providers to participate, development of a training manual for service providers, provision of a training day for service providers, identification and recruitment of families to participate, a series of three interviews between the service provider participant and the family, an information session, development of individual Personal Portraits for each person with a disability and development of a Futures Plan with each family. Reporting and monitoring took place at each stage and a final evaluation session was conducted with service providers at the end of the project.

**Target Group:** For this project, the target group comprised families where the primary carer/s was aged over 65 years (reduced to 60 years as the project progressed) or an indigenous carer/s aged over 45, caring for a person aged over 18 years with a mild-to-moderate disability. In Phase 1, the interviewer had no existing relationships with any of the families and found that it took time to develop sufficient rapport and trust to be able to discuss some of the sensitive issues that are intrinsic to Futures Planning. Phase 2, therefore, sought to capitalise on the existing relationships that service providers have with the families with whom they work. Initially 23 families expressed interest in participating in the project, 9 on the Far North Coast of NSW and 14 on the Mid North Coast. However a number of families withdrew over the course of the project, primarily for health reasons, resulting in full completion of the project by 10 families, 5 on the Far North Coast and 5 on the Mid North Coast.

**Model/Guidelines Development:** The project model developed for Phase 1 was based on existing literature and programs. The model for Phase 2 was amended by the findings of Phase 1. The project sought to integrate best practice principles, functions and guidelines.

A Futures Plan was developed, based on projects in New South Wales, Queensland and Victoria while the Planned Lifetime Advocacy Network (PLAN) in Canada provided an international perspective. This Plan was used in both phases.

**A set of Principles** was developed as part of Phase 1, which underscored the team values in conducting the project and these related to working with the carers and with the person with a disability. In Phase 2 these principles were incorporated into the service provider training manual and course.

**Guidelines for developing a Vision and a Plan** (developed for Phase 1) included the importance of families being in control and including others in their planning, the necessity for the Plan to be realistic, achievable, unique and to reflect the needs and aspirations of the family.

**Issues to be considered in a Futures Plan** included financial and legal matters, housing, health, leisure/recreation and the roles of other family members.

**Questionnaire Development:** In Phase 1, a set of questions for each interview was developed, drawn from the literature and varied to suit the aims of the project. In Phase 1 four interviews were undertaken with the families. In Phase 2 this was condensed into three interviews, in anticipation that the existing relationships between service provider personnel and families would negate the need for time to be spent on initial introductions and the establishment of a basis for rapport.

**Service Provider Engagement, Phase 2:** Invitations to participate in the study were sent to the senior Executive Officer in 27 service provider organisations, 15 in the Lismore area and 12 in the Coffs Harbour area. The letters provided an overview of this second phase of the Futures Planning project and an invitation to attend a two hour Introduction Session, aimed at enabling these senior officers to assess the relevance and capacity of their organisation to participate in the project. The service providers were selected in consultation with a Project Officer from the Department of Ageing, Disability and Home Care (DADHC, now ADHC) and were targeted at those service providers most likely to be working with families who met the selection criteria for the project.

Introductory Sessions were held in Lismore and Coffs Harbour. Service provider organisations which agreed to participate signed an Agreement letter and nominated a staff member/s to work with the families. Staff members signed Consent Forms agreeing to participate.

**Training Process:** There were 14 participants from 7 organisations at the Lismore area training workshop. At the Coffs Harbour training workshop there were 14 participants from 9 organisations.

Attendees were provided with a detailed Training Manual and templates for the Personal Portrait, Futures Plan, Interview Reports, Information Sheets and Consent Forms. These were also provided electronically.

The training workshop: (a) provided information on Phase 1 and the objectives, aims and rationale for Phase 2; (b) systematically worked through the format and rationale of each of the interviews and the project requirements; and (c) discussed how best to engage the person with a disability and how to manage the sensitivity of the matters to be raised in the interviews.

**Interview Process:** At the commencement of each interview, the Interviewer confirmed that the family were comfortable with the conversation being recorded and that the recorder could be switched off at any time if they so wished.

*Interview 1:* At the first interview the family was provided with information about the project and if they wished to proceed they were asked to sign the consent forms.

Following consent the second part of the interview began the process of developing a background picture of the family and some understanding of planning completed to date, if any, for inclusion in the Futures Plan. Each family was provided with a template of the Personal Portrait of the person with the disability, for them to continue working on between interviews.

*Interview 2:* The second interview took place after the Information Sessions. Some families who had attended asked a number of questions relating to the topics discussed at the sessions, which proved challenging for some interviewers. It is recommended that, in future, a special session be held for interviewers to ensure that they have sufficient understanding to be able to support the families. This interview continued the process of reviewing and discussing the Futures Plan and the ongoing development of the Personal Portrait.

*Interview 3:* The third interview was an opportunity for the family to review the prepared Futures Plan and Personal Portrait to check for accuracy and to request any relevant changes. The final Futures Plans and Personal Portraits were given to the families in hard copy and, where someone in the family was computer literate, in electronic format.

**Information Sessions:** An Information Session was held in each area to give carer/s (and the persons with the disability where appropriate) the opportunity to further understand their rights and options with respect to Futures Planning. A range of relevant professionals provided information on issues such as Wills, Powers of Attorney, Guardianship, family trusts, housing, Centrelink payments and financial planning. Follow-on appointments with the professionals were paid for from the project funds. Three families took advantage of this opportunity, to meet with a solicitor.

## **RESULTS**

**Participants:** Eight families on the Far North Coast and eleven families on the Mid North Coast participated in the first interview, resulting in 19 people with a disability and 24 carers. Of those eleven families on the Mid North Coast, only five completed all three interviews and of those eight families on the Far North Coast, five completed all three interviews. Ages ranged from 60-79 years for carers and from 24-59 for persons with a disability. Carers included 5 males and 19 females; 13 persons with a disability were males and 6 were females. All persons with a disability had an intellectual disability. Relationship of carer/s to the person with a disability included one or both parents and, in two instances, a sister. Single carers were all females and where the carer role was shared, it was shared by both parents.

**Interviews:** The interviews focussed on looking at what steps families had already taken with regard to Futures Planning, identifying what steps they needed to take and working on development of a Personal Portrait which would provide detailed information about the person with a disability. The majority of families stated that they did not feel they were prepared for the future and whilst many had at times thought about it, they lacked the time, knowledge and resources to take action. In some cases it was simply too confronting.

Primary issues of concern identified in the interviews in Phase 2 were essentially the same as those identified in Phase 1. These included: that the person they cared for would be able to continue with the same standard of living that they had always experienced; that they would continue to have secure care and accommodation; and that they would have financial security and be protected from financial exploitation. There was also concern to ensure that there would be someone to oversee the support networks for the person with the disability. All of the families found the development of the Futures Plan and the Personal Portrait to be a positive and useful process.

**Participant Satisfaction:** Despite numerous challenges for families, particularly in making time available to participate and dealing with sensitive and, in some cases, contentious issues, everyone involved felt that the process had been of substantial benefit.

## **DISCUSSION**

This one-year project came about in response to the evident need, as identified by ADHC, by service providers and during the implementation of Phase 1. The methodology was developed in response to one of the recommendations made in Phase 1, namely: *“a well known and trusted person who already works with the family ...would be better placed to work through the process with the families”*.

### Training

The training successfully provided the service provider staff with sufficient knowledge and a sound framework from within which to: identify and recruit carers who met the participation criteria; undertake the interviews; report on the interviews; and assist families to prepare the Personal Portrait and a comprehensive Futures Plan.

### Interviews

The interview structure proved to be effective and the service provider staff felt comfortable with the process. The existing relationships that the majority (84%) of staff had with the carers proved to greatly assist with the establishment of trust and rapport within the first interview and to enable discussion around the sensitive issues of mortality and family relationships that needed to be addressed (thus confirming recommendation from Phase 1).

### Information Sessions

The Information Sessions were well received by all the families who attended. The sessions enabled carers to identify the gaps in their knowledge and to take steps to rectify this.

### Personal Portrait

The Personal Portrait was embraced by all of the families and proved to be a very important means of providing carers with security and peace of mind.

### Futures Plan

As with the Personal Portrait, the development of the Futures Plan provided carers with a level of certainty and helped allay their fears about what will happen when they are no longer able to provide the level of care required for the person with a disability.

## **PROJECT LIMITATIONS/BARRIERS**

- A lack of resources within service provider organisations placed additional workload pressures on those staff participating.
- The feedback from attendees at the Information Sessions highlighted the need for these sessions to be longer and to provide more opportunity for small group interaction.
- The availability of suitable speakers for presentation at the Information Sessions meant that the content and quality of the information presented varied.
- The time constraints of the project meant that in those families where the carer/s became ill during the project there was insufficient time to wait until they were well enough to continue. Sadly, these carers were the ones most urgently in need of Futures Planning.

## **RECOMMENDATIONS**

- Delivery of Futures Planning would be greatly enhanced if resources were made available for participating service providers. Given the aptness of Futures Planning to existing funded programs for older carers, funding an extension to those services could provide a cost-effective delivery mechanism. Futures Planning would also be compatible with case management services.
- Information Sessions would be more effective if held over a full day with separate panels and small working groups for families to be able to ask targeted and specific questions of professionals within a safe environment. (Note: this may require additional care/respite to be provided for the person with a disability).
- Carers would benefit if Information Sessions were held on a regular basis across the area, irrespective of whether or not they were part of a Futures Planning program.
- Specific training needs to be provided to service provider staff to ensure they have sufficient knowledge to assist families.
- Opening the program up to carers who are aged in their fifties to enable people to start the planning process whilst they are in good health and more physically able to do so would improve outcomes.

## **CONCLUSIONS**

One of the greatest concerns that older carers have expressed is “who will care for him/her when I am gone?” The aim of this project was to begin to address this fear and to establish a model of Futures Planning which could assist carers to put in place arrangements which would negate the potential need for emergency (unplanned) responses at a time of future crisis. Emergency responses also have a cost and resource implication for ADHC.

In addition this project set out to explore the viability of expanding the implementation of a Futures Planning process to service providers in the disability sector. Service providers were able to identify gaps in their service delivery and to expand their views on how they can best service the needs of clients and their families. This has the potential to stimulate a move towards a more responsive, integrated and whole-of-family approach to service delivery.

The project highlighted the fact that carers, on the whole, do not know where to start or how to access the information they need to start planning for the future. It was also evident that whilst most carers were aware of the need to attend to such matters they were impacted by a lack of time, resources and energy. This project therefore provided the participating carers with the information, guidance and assistance that they needed to overcome the challenges they were facing.

The project was very successful for the 10 participating families who remained involved to the end. All these families completed a Personal Portrait and either completed or were well advanced with a Futures Plan. Service providers involved in the project reported that this has given families a sense of relief, peace of mind and had wide-ranging benefits for the family unit. Some service providers have incorporated the Futures Plan and Personal Portrait into their “Standard toolkit” for working with carers / families of an adult with a disability.



## **CHAPTER ONE – INTRODUCTION**

The Aged Services Learning and Research Centre (ASLaRC) of Southern Cross University is involved in research, education and the promotion of evidence-based practice and community engagement in relation to the delivery of aged services for rural and regional communities.

The NSW Department of Human Services, Ageing, Disability and Home Care (ADHC), provides support and services to more than 1 million older people, people with disabilities and their carers, to assist them to lead independent lives and participate in community life.

In June 2006, ADHC (then DADHC) invited tenders to undertake a one-year project for Futures Planning for Older Carers of Adults with Disabilities; ASLaRC was the successful tenderer. Phase 1 of the project was undertaken in 2007. Phase 2 of the project was undertaken in 2009. The outcomes for Phase 1 of the project are detailed in the ASLaRC report *'Futures Planning for Older Carers of Adults with Disabilities Phase 1'*.

A copy can be downloaded from the ASLaRC website (<http://aslarc.scu.edu.au>).

### **AIM**

The overall aim of the Project across both Phase 1 and Phase 2 was 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 a disability, because of the death or incapacity of the carer or carers.

### **OBJECTIVES**

The main objective of both Phases of the project was to assist older carer/s (and their adult children or family member with disabilities, where possible) to reach a level of certainty with respect to future care needs. In addition, Phase 2 sought to test the viability of expanding the project to reach a wider number of carers, in a cost-and time-effective way, by working through service providers active in the sector.

### **TIMEFRAME**

The project had a 12 month timeframe.

## **EXPECTED OUTCOMES, PHASE 2**

It was expected that the project would:

- Train and equip personnel from participating service providers in the use of the Futures Plan and Personal Portrait to enable them to facilitate Futures Planning with older carers;
- Develop a 'Futures Plan' for each person with a disability involved in the project, setting out arrangements for a planned transition to a new care situation when older carer/s are no longer able to provide care;
- Assist carers and persons with a disability to develop a comprehensive Personal Portrait that would enable any appropriate person to step in and provide support to the person with a disability with minimal disruption to preferred and normal routines;
- Reduce the need for a crisis response in the event of the death or incapacity of older carer/s.
- Provide carers with a level of certainty about the future and help to allay their fears about what will happen when they are no longer able to provide support.

## CHAPTER TWO – BACKGROUND

An extensive research review was undertaken and reported for Phase 1. (See Report ‘*Futures Planning for Older Carers of Adults with Disabilities: Phase 1*’ which is available for download on the ASLaRC website (<http://aslarc.scu.edu.au/downloads>). As part of Phase 2 a further review was undertaken to identify recent research of relevance.

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). The Australian Institute of Health and Welfare (AIHW: 2009) estimates there will be 1.5 million people with profound or severe disabilities by 2010, increasing to almost 2.3 million by 2030.

Issues identified in Australian and international literature 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 older people with developmental disabilities when they do not have close family members to do so (Bigby and Johnson, 1995) and who will question and challenge the roles played by family members who may not be acting in the best interests of the person with the disability (ibid).

*“... ageing carers often face the end of a lifetime of caring with anxiety and uncertainty as to the future support arrangements for their adult son or daughter. This not only causes considerable stress for the family, but also means that 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).

Cummins and Hughes et al (2007) found that carers have the lowest wellbeing index score for any large group in Australia. The index score considers many life issues including economic, environmental and social conditions. Carers scored alarmingly low, 58.5, compared to the average Australian population between 73 and 76, reflecting the strain and challenge that carers face everyday.

Research into Advance Care Planning has demonstrated that 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). It is expected that a similar psychological process would apply in relation to carers, who could maximise the quality of the time they have left with the person for whom they care without the constant worry and anxiety of “what will happen when I am not here”.

The Australian Government's Discussion Paper on Succession Planning for Carers (2007) identified the following key barriers to planning:

- Families don't know where to start; who to go to; where to find information or what to do.
- The costs of disability and caring are such that many parents may not have accumulated many assets in their lifetime and may not be able to financially provide for their child's future, without significant government assistance.
- Future planning is a sensitive issue, challenging family assumptions and requiring people to face their own mortality and discuss personal issues and information.
- A planned transition is not considered feasible whilst services and governments continue to place only those people with disabilities in crisis or emergency situations.
- Many carers are too busy or tired from day to day responsibilities to be able to find the energy to undertake the complex and time-consuming task of planning for the future.
- Many ageing carers may not have expected their son or daughter to outlive them and may have unrealistic expectations around what governments, services and family members can provide when they need to relinquish care.

## **GOVERNMENT INITIATIVES**

In September 2007, the Department of Families, Community Services and Indigenous Affairs (FaCSIA) advised that Centrelink’s “transition support workers” would interview over 4,000 carers across Australia during September – December 2007. The actual implementation varied from the original announcement and is summarised in Centrelink’s Annual Report 2008 -2009, (Chapter 4, p. 90).

In July 2008, the Disability Assistance Package for Older Carers administered by the Department of Families, Housing, Community Services and Indigenous Affairs, was transferred from the Australian Government to state and territory governments, in line with the 2007 election commitment. The package contained a number of measures for older carers of severely disabled adult children, including additional respite and transition support that were delivered by Centrelink until this transfer was completed in October 2008.

Centrelink's Social Work Service provided transition support to carers, aged 65 years and older, of children aged 40 years and older. Many of these older parents had spent years caring for a significantly disabled child. However, as they became older and more frail, they were facing some difficult decisions about future care arrangements for the child/ren. Transition support and assistance is provided to these older carers dealing with a transition to a new care arrangement. Originally envisaged as a five-year plan, this was shortened with the change in governance arrangements.

By October 2008, Centrelink Social Workers completed their work with the 1613 carers who had accepted this offer of support and made arrangements for the handover of transition support to relevant state/territory government departments.

On 23 November 2009, the Prime Minister, Kevin Rudd, announced that the Australian Government would engage the Productivity Commission to carry out an Inquiry into a National Long-term Care and Support Scheme. The report is due in July 2011. This insurance scheme has been strongly supported by the Parliamentary Secretary for Disabilities, Bill Shorten, who recognises that existing funding arrangements result in large numbers of people living with a disability and their families struggling to meet adequate care needs. (*Prime Minister's Address to the National Disability Awards Ceremony, Parliament House Canberra 23 November 2009*)



## **CHAPTER THREE – METHODOLOGY**

### **ETHICS APPROVAL**

This research project was approved by Southern Cross University's Human Research Ethics Committee, (Ethics approval ECN-08-145).

### **METHODS**

The project utilised Action Research methodology. *“Action research is a flexible spiral process which allows action (change improvement) and research (understanding, knowledge) to be achieved at the same time”* (Dick as cited in Costello, 2003).

The methodology process involved: an updated review of current literature, building on that already undertaken in Phase 1; developing a service provider implementation program; developing a service provider training manual and running a one day training workshop; assisting service providers to identify and recruit families to participate; assisting service providers to undertake a series of three interviews; organising and holding information sessions; assisting service providers to develop individual Personal Portraits for each person with a disability and to write a Futures Plan for each family.

Reporting and monitoring occurred at regular intervals, thereby enabling reflection of actions taken to date to be reviewed before proceeding to the next step in the process.

The project also undertook to test the viability of expanding the provision of Futures Planning to a great number of older carers through the use of existing service providers in the sector.

### **TARGET GROUP**

For this study the target group comprised families, which included a carer/s aged over 65 years (reduced to 60 years as the project progressed) or aged over 45 for indigenous carers, caring for a person aged over 18 years with a disability. Carers were not necessarily the parent of the person with a disability. In Phase 1, the interviewer had no existing relationships with any of the families and found that it took time to develop sufficient rapport and trust to be able to discuss some of the sensitive issues that are intrinsic to Futures Planning. Phase 2, therefore, sought to capitalise on the existing relationships that service providers have with the families with whom they work.

Initially 23 families expressed interest in participating in the project, 9 on the Far North Coast of NSW and 14 on the Mid North Coast. However a number of families withdrew over the course of the project resulting in full completion of the project by 10 families, 5 on the Far North Coast and 5 on the Mid North Coast. A further 3 families participated up until the final interview, 2 on the far North Coast and 1 on the Mid North Coast and were well positioned to complete their Futures Plan and the Personal Portrait on their own.

Of those families who withdrew, 4 withdrew before Interview 1. One family expressed concern about the protection of their personal and financial privacy, citing a previous experience, which had undermined their confidence. Another family experienced a change in personal circumstances, which resulted in their inability to make time to participate and 2 families changed their minds about participating for reasons unknown. A further 6 families withdrew before Interview 2. One carer requested to withdraw because she found the process too distressing for herself and her adult son. Two families withdrew due to time constraints and a further 4 were forced to withdraw due to health issues. One the carers in the latter category had to undertake emergency surgery in Sydney, which served to further highlight the importance of Futures Planning.

**Selection of Family Participants:** In this Phase 2 project, the eligibility criteria used by service providers was based on that developed in Phase 1, as follows:

- Carer/s aged 60 or over or 45 or over for indigenous carers;
- Carers caring for a person with a disability at least 18 years of age;
- The person with the disability does not necessarily need to be living with the carer/s
- The carer/s does not necessarily need to be full-time carer;
- The family consent to participating in the project;
- The family have an existing relationship with the Service Provider (added for Phase 2).

In Phase 2 the eligibility criterion requiring families to be able to commit a minimum of \$100,000 to a Futures Plan was removed. It was excluded on the grounds that it precluded many carers, particularly those most in need. It was apparent through both Phases that asset dispersal was only one factor of relevance in Futures Planning and that the establishment of an Enduring Guardian, Enduring Power of Attorney, alternative accommodation and carer arrangements were of equal importance.

## **MODEL/GUIDELINES DEVELOPMENT**

This Phase of the project used the model and Guidelines developed for Phase 1. The process for their development was extensively reported in the Phase 1 Report and is not repeated here.

### Core functions of the Model Developed for this Project included:

- Provision of the initial contact/front line information and advice to families about assistance available for Futures Planning.
- Facilitation of the family's vision of a new future.
- Matching the family's needs with community resources/expertise.
- Converting the family vision into an implementation-based plan.
- Assisting families to focus on pivotal planning decisions about ageing, frailty or death of carer/s and the transfer of existing family caring responsibilities to others.
- Identification of informal and formal services for the future life plan of the person with the disability.

The Futures Plan and Personal Portrait developed for Phase 1 were used for Phase 2.

## **PRINCIPLES**

Principles on which the project was based were both general and specific to carers and persons with a disability:

### General

- Deal with participants in the project in a fair and ethical manner and take steps to resolve any issues or differences that may arise;
- Emphasise people's own ability to bring about change;
- Seek to create conditions that enable people to mobilise their strengths in the process of change;
- Promote a positive attitude about the dignity, capacities, rights and uniqueness of all participants;
- Demonstrate respect for the carer/person with a disability and his/her family members;
- Respect the values and preferences of both the carer/s and person with a disability.

### Relating specifically to Carer/s

- Focus on the strengths of the family, promoting respect and empowerment of the carer, with recognition of the carer's experience and expertise;

- Acknowledge the strength and resources a carer brings to the situation and try to harness this in finding solutions to issues that the carer identifies;
- Acknowledge that Futures Planning, dealing, as it does, with planning for a time when the carer is no longer alive, can be an emotionally confronting process and bring to the forefront issues and concerns that are complex and distressing;
- Remember that the responsibility for the final decision belongs to the carer/family.

#### Relating specifically to the Person with a Disability

- Where appropriate encourage and facilitate, participation in the planning process by the person with a disability;
- Acknowledge that family and friends play an important role in the life of any person; and
- Acknowledge that planning for the future in an open and honest way can be empowering for the person with a disability and can contribute to that person's wishes and hopes being accommodated.

### **GUIDELINES FOR DEVELOPING A VISION AND A PLAN**

Guidelines to be used by staff in the project were underpinned by the following concepts:

- The vision is what drives the planning;
- Important that families are in control;
- Important that families include others in their planning;
- The views of the person with a disability were to be included, as appropriate;
- The Plan should be realistic and achievable; and
- Each Plan should be unique and reflect the needs and aspirations of the specific family.

Issues to be considered in a Futures Plan included:

- Financial and Legal: wills, dispersal of assets (of carer/s and persons with a disability), tax implications, Centrelink implications, financial management, Enduring Power of Attorney, Enduring Guardianship and testamentary trusts.
- Housing: expectations about where the person with the disability may live in the future. Are changes required? Has the person been placed on the ADHC Accommodation Needs Register?
- Health/Medical: the current level of personal care required for the person with the disability; who provides it - lists of doctors, specialists, dentists and allied health

professionals; transport to these appointments; private health cover, ambulance/ hospital cover; and Guardianship orders.

- Leisure/Recreation: activities that the person with the disability currently participates in; any future activities they would like to be involved in; cost of such activities; availability of suitable activities within the community.

### Families Familiar with Project Boundaries

As the project was a research project with limited resources it was explained to participating families that:

- The purpose of the project was to develop Futures Plans in relation to financial, legal, accommodation, support and health/medical needs of the person with the disability to the extent that was possible within the timeframe and context of the project;
- The project was concerned with the long term security of carer/s and persons with a disability in relation to the future and not the current, day-to-day issues that they face;
- The service provider staff would work alongside the family to help develop the Futures Plan and Personal Portrait; and
- The intention of the project was to assist the families to make preparations for the future care needs of the person with the disability.

### **SERVICE PROVIDER ENGAGEMENT**

Invitations were sent to the senior Executive Officer in 27 service provider organisations, 15 in the Lismore area and 12 in the Coffs Harbour area. The letters provided an overview of this second phase of the Futures Planning Project and invited them to attend a two hour Introduction Session to enable them to assess the relevance and capacity of their organisation to participate in the project. The service providers were selected in consultation with a Project Officer from ADHC and were targeted at those service providers most likely to be working with families who met the selection criteria for the project.

The Project Coordinator then contacted the service providers by telephone to provide further information, answer any questions and ascertain whether they would be attending. The Coffs Harbour session was held at the Southern Cross University campus on the 12 March 2009 and 14 people attended from 8 organisations. The Lismore session was held on 13 March 2009 at the Goonellabah Community Centre and 20 people attended from 11 organisations.

One of the attendees at the Lismore session was from the Coffs Harbour area but had been unable to attend the Coffs Harbour session.

Following the Introduction Sessions service providers were sent an Agreement letter to be signed and returned. Consent Forms for the staff members who were going to work with the families were also sent for signing and return.

At the Introduction session in Coffs Harbour it became evident that a number of service providers work with the same families and that there was the potential for some families to be approached twice. It was decided therefore to ask staff to provide the family name and street name of the family they wished to work with to avoid families being contacted twice.

Of the service provider organisations represented at the Introduction Sessions, eight did not proceed. Reasons for withdrawal included: unable to attend the training workshop x 1; unable to identify a suitable family to work with x 1; the project was outside their service delivery focus x 2; lack of resources associated with uncertainty around further funding of another program x 2; organisational changes and a lack of resources x 1; no reason was given for the non-participation of the 8th organisation.

## **TRAINING PROCESS**

A one-day training workshop was held for all service provider staff participating in the Project. The Lismore area, training workshop was held on 8 April 2009 at the Lismore Workers Club. There were 14 participants from 7 organisations. The Coffs Harbour training workshop was held on 14 April 2009 at the Southern Cross University campus. There were 14 participants from 9 organisations.

Attendees were provided with a detailed Training Manual and templates for the Personal Portrait, Futures Plan, Interview Reports, Information Sheets and Consent Forms. These were also provided electronically.

The training workshop: (a) provided information on Ph 1 and the objectives, aims and rationale for Ph 2; (b) systematically worked through the format and rationale of each interview and the project requirements; and (c) discussed how best to engage the person with a disability and how to manage the sensitivity of the matters to be raised in the interviews.

**TRAINING EVALUATION**

Service Providers were asked to complete an Evaluation Form at the end of the training workshop. The participants were asked to rate how well the training had met the following objectives.

Objectives of Training:

- 1. To enable participating service providers to gain a clear understanding of Phase 1 of the Futures Planning Project;
- 2. To enable participating service providers to gain a clear understanding of Phase 2 of the Futures Planning Project;
- 3. To enable participating service providers to gain a clear understanding of the requirements and constraints of the Futures Planning Project;
- 4. To enable participating service providers to gain a clear understanding of how to complete research documentation;
- 5. To assist service providers to be able to conduct Future Planning interviews consistently and reliably; and
- 6. To ensure participating service providers are able to develop Future Plans and Personal Portraits with families consistently.

Participant Ratings: In response to the statement “Today’s training has successfully met the above objectives”, participants scored as follows:

<b>Objectives</b>	<b>Strongly Agree</b>	<b>Agree</b>	<b>Unsure</b>
<b>1</b>	13	14	1
<b>2</b>	16	12	
<b>3</b>	11	17	
<b>4</b>	13	15	
<b>5</b>	13	15	
<b>6</b>	11	16	1

### Participant Comments

*“The day was comfortably paced and well presented. Information presented was clear and manual set out well”.*

*“Good layout of training manual – easy to follow”.*

*“Training session was clear and concise”.*

*“Would like to have a glossary of terms ie OPG, EPA etc”.*

*“(Would be good to have) a flow chart of process with rough timeframes”.* (Note: This comment was made in the first training workshop and a flow chart was incorporated into the second workshop.)

*“Co-location of relevant documents (would have been easier) than going between appendix documents and interview documents”*

## **INTERVIEW PROCESS**

**Questionnaire Development:** In Ph 1, a set of questions for each interview was developed, drawn from the literature and varied to suit the aims of the project. Four interviews were undertaken with the families in Phase 1. In Ph 2 this was condensed into three interviews, in anticipation that the existing relationships between service provider personnel and families would negate the need for time to be spent on initial introductions and the establishment of rapport.

The questions were modified for Ph 2 as a result of the findings and recommendations emanating from Ph 1. (see Appendix 5)

**Interview Framework:** At the commencement of each interview, the interviewer confirmed that:

- The family had no objection to the conversation being recorded;
- The family was aware that the recorder could be switched off at any time if they so wished.
- The family could ask for the interview to stop at any time if they felt distressed or unable to continue; and
- The family could ask for counselling support at any point.

The interviews varied in length but in general averaged 2 hours duration.

### **Interview 1**

The first interview consisted of two parts. In the first part the interviewer provided the family with information about the project both verbally and in writing, including; the number, expected duration and focus of visits; the rationale for the project; the information session; what costs the project could meet; the potentially sensitive nature of the questions and the opportunity for people to request a break if they found the discussion too upsetting; the process for lodging a complaint about the project or seeking support around any other issues; the importance of including input from the person with a disability, where appropriate; and the limitations of the project. The families were then asked to sign the Consent Forms.

Following consent the second part of the interview began the process of developing a background picture of the family, their hopes and dreams, concerns or fears and some initial understanding of planning already completed to date, if any, for inclusion in the Futures Plan. Each family was provided with a template of the Personal Portrait of the person with the disability, for them to continue working on, in between interviews.

### **Interview 2**

The second interview took place shortly after the Information Sessions. Feedback on the Information Session was sought and many of the families who had attended asked a number of questions relating to the topics discussed at the sessions. This proved to be problematic for interviewers as the topics covered were new for most of them and some aspects of the legal and financial information was complex. It is recommended that, in future, a special session be held for interviewers to ensure that they have sufficient understanding to be able to support the families.

The interview continued the process of reviewing and discussing the Futures Plan and in particular looked at legal and guardianship issues; Wills, Enduring Guardianship, Appointed Guardian and financial security; Trusts, assets, financial management, Power of Attorney. The interviewers also offered families an opportunity to meet with a solicitor to discuss legal issues. The project funded these appointments. Three families took up the offer. The ongoing development of the Personal Portrait was also discussed.

### **Interview 3**

The third interview was an opportunity for the family to review the prepared Futures Plan and Personal Portrait, check for accuracy and to request any relevant changes. It also provided an opportunity for families to provide feedback on the project.

The final Futures Plans and Personal Portraits were given to the families in hard copy and, where someone in the family was computer literate, in electronic format.

Refer to Appendices 3 and 4 for a sample de-identified Futures Plan and Personal Portrait.

### **INFORMATION SESSIONS**

Two Information Sessions were held, one in Lismore and one in Coffs Harbour. The Information Sessions were found to be invaluable for families during Phase 1 and were incorporated in Phase 2 to follow the first interview. The aim of the Information Sessions was to give carer/s, service provider personnel and, where appropriate, the person with a disability the opportunity to further understand their rights, options and recommended practices with respect to Futures Planning.

Information was provided to participants by a:-

- Solicitor;
- Financial Planner;
- Advance Care Planning Expert;
- Representative from ADHC;
- Representative from Centrelink Financial Information Services, and
- Representative from the Office of the Public Trustee.

Participants were offered the opportunity to consult with a solicitor or financial planner after the Information Session, to follow up on legal and/or financial issues. Three carers took advantage of this offer and consulted a solicitor; the appointments were paid for from project funds.

The organisation of the information sessions entailed:

- Venues – booking appropriate venues;
- Contacting solicitors in both areas to find a suitable person willing to provide their time and advice on a pro bono basis;
- Contacting financial planners in both areas to find a suitable person with specific knowledge relevant to the target group;
- Inviting the ADHC speakers, which included the Manager of Information, Referral and Intake (responsible for managing the Accommodation Register and the point of first contact for families within the Department) and the ADHC Project Manager.
- Contacting Centrelink Financial Information Services for an introduction to local staff;
- Contacting the Office of the Public Trustee to organise a suitable speaker.
- An invitation and schedule was sent to all participating parties.

Centrelink was unable to provide a speaker for the Information Session held in Lismore and the Office of the Public Trustee was unable to send a representative to the Information Session held in Coffs Harbour although they provided an informative DVD, which was shown to participants.

### **SERVICE PROVIDER EVALUATION**

An evaluation session was held in each area with service provider staff participating in the project to review the process and provide an opportunity for debriefing and discussion. Representatives from all but two participating organisations attended the Coffs Harbour session and in Lismore, representatives from all but one participating organisation attended. These sessions provided a valuable forum for analysis, comparison and discussion. It would have enhanced the implementation of this program had group sessions been held following each interview.

Following completion of the interviews and development of the Futures Plans and Personal Portraits, a Service Provider Evaluation Form was sent to the senior management of the nine organisations remaining in the project. Results of the evaluation are provided in Chapter Four.



## CHAPTER FOUR – RESULTS

### PARTICIPANTS

- Eight families in the Far North Coast area and eleven families in the Mid North Coast area participated .
- Age range:-
  - Carers: Far North Coast 61 – 76 years
  - Carers: Mid North Coast 60 – 79 years
  - Person with a disability: Far North Coast 24 – 59 years
  - Person with a disability: Mid North Coast 33 – 55 years
- Gender:-
  - Carers: Far North Coast 1 male, 8 female
  - Carers: Mid North Coast 4 male, 11 female
  - Person with a disability: Far North Coast 5 male, 3 female
  - Person with a disability: Mid North Coast 8 male, 3 female
- All 19 persons with a disability had an intellectual disability.

### Relationship of Carer/s to person with disability

- In five families both mother and father were carers, although in one family the father was seriously ill and the mother was the principal carer.
- In one family the person with a disability lived with his father, however his father was ill and his sister was the principal carer for both him and his father.
- In one family the person with a disability lived with his sister, who was his principal carer.
- There were 12 families where the person with a disability was cared for solely by his/her mother. In one case the son had been adopted.

### INTERVIEWS

In most cases the person with a disability did not participate in the interview sessions because families were concerned about upsetting them. Of the 19 families participating in Interview 1, five of the people for whom they care were present.

From the interviews it was evident that many of the persons with a disability have been ‘protected’ from the process of grieving and the reality of death, with the majority having not attended family funerals. This was considered by a number of service provider staff to be an

issue as they felt that the person with the disability was likely to find the loss of their parent/ carer even more confronting. The following comment from one interviewer is indicative of the comments made by the majority of carers.

*(The carer )said that (name) is worried and has concerns if any thing should happen to her and she felt that it was better that he was not at the first interview and that she will take a 'slowly, slowly' approach to his involvement in the Futures Planning. (Name) will be involved in developing the Personal Portrait. [Family 4]*

Of the 19 families participating, service provider staff had an existing relationship with 16 of them and in the other three cases the family was known to the organisation. Everyone felt that this assisted the process; one staff member commented: "I feel I have a good relationship with the family. If I had not had this relationship the interview could have been quite difficult for all parties."

Primary issues of concern identified in the interviews in Phase 2 were essentially the same as those identified in Phase 1. These included: that the person they cared for would be able to continue with the same standard of living that they had always experienced; that they would continue to have secure care and accommodation; and that they would have financial security and be protected from financial exploitation. There was also concern to ensure that there would be someone to oversee the support networks for the person with the disability. All of the families found the development of the Futures Plan and the Personal Portrait to be a positive and useful process.

### Interview 1

The focus of the first interview was to establish what plans, if any, people had in place and to discuss what the family's hopes and concerns for the future were. The majority of families stated that they did not feel they were prepared for the future and whilst many had at times thought about it, they lacked the time, knowledge and resources to take action. In some cases it was simply too confronting.

Even though each family's situation was unique, there were common themes identified during the first interview that applied to a number of carers:

- Carers on the whole lack knowledge about alternative accommodation options.
- Carers do not wish to burden others and are particularly conscious that their other children have their own lives and commitments.

- Most families are keen to stay living together in the same house for as long as possible and would prefer to have care and support come in for both themselves and the person with a disability. A few even suggested that the person with a disability could move with them into an aged care facility.
- However, some carers are keen to have established a transition for the person with a disability to supported accommodation/independent living before their ability to care for that person is compromised. This was particularly evident amongst carers who are or have been actively working or engaged in the disability sector and hence are better informed of their options.
- Most carers have not spoken to other family members in any concrete terms about the role that the other family member may take in the future, for example, as Person Responsible or Guardian for the person with a disability.
- Carers are concerned about the vulnerability and safety of the person with a disability.
- Whilst some carers have discussed with the person with a disability the possibility of him/ her moving into independent or supported accommodation none of them had directly discussed the inevitability or implications of their death.

#### Quotes from Interview One

##### **With regard to planning:**

*“I haven’t done any planning”* [Family 10]

*“We do not wish any member of our family to take (name) as we are not confident that they will implement what we have placed in our will for the benefit of (name)”*. [Family 11]

*“I want to do some future planning ....I’m looking forward to probably 10 years of good health and then after that probably decline and I’d like to see (name) really secure by then”*. [Family 8]

##### **With regard to accommodation:**

*“I really don’t know what’s available here on a permanent basis”*. [Family 1]

*“If she could go into a home situation with other people like herself”*. [Family 10]

*“Currently involved in trying to set up a home for (name).... I’ve bought a little house in town. (There are) good neighbours around who I know would keep an eye on her. My hope is that one of the services would put in some drop-in support”*. [Family 7]

*“At present filling in Department of Housing forms for (name) and I’ve had discussions with DADHC about flexible respite options ....made an appointment with ...DAISI to talk about Trusts and Wills”. [Family 8]*

*“We (hope) we can live as long as possible so we can look after her for as long as possible”. [Family 11]*

## Interview 2

The second interview took place shortly after the Information Session. The focus of the interview was to further the progress of families towards preparing their Futures Plan. It was scheduled to take place following the Information Session so that families could build on the information they had gathered at the session. Whereas the first interview provided an opportunity for families to think through the bigger picture and identify what planning they needed to focus on, the second interview was aimed at helping families to action specific tasks.

The key themes emerging from Interview 2 were:

- The information provided at the Information Sessions, particularly regarding guardianship and other legal matters made people realise that they needed to either put in place legal structures or make changes to their current Wills and documents;
- People found the information about legal matters and the information from Centrelink to be of the most value;
- The Information Sessions were too short given the amount of information to be absorbed and the complexity of it;
- The Personal Portrait was proving to be a valuable document with most families reporting that it gave them peace of mind to know that the information was available to someone else and that should there be an emergency they did not need to worry about whether the support being provided was appropriate;
- Carers were concerned about the quality of care that the person with a disability will receive in the future;
- Planning around future accommodation options was split across three models.
  - Carers either have or are intending to place the person for whom they care on the ADHC accommodation register for supported accommodation funded through the State Government.

- Carers were working with other family members to have them take on the role of primary carer and for the person with a disability to reside with them. In most cases these were siblings.
- Some carers have purchased accommodation or plan to leave the family home to the person with a disability and are seeking to have support come in either from service providers or from family members.

### Quotes from Interview Two

*“(The Personal Portrait has given me) peace of mind that someone else knows the information”. [Family 2]*

*“(The Information Session) not only provided information that will be very helpful in planning (name’s) future, but also allowed me to initiate conversations about the future with my parents that I have been very nervous about starting previously.” [Family 12]*

*“(The Information Session was) not so much about learning as about motivating us and letting us know that time is short and we need to put in place what we had in mind for (name). Having attended the seminar...we will be updating (our will) and we will be talking to our solicitor ...and to our family” [Family 11]*

### Interview 3

The final interview focussed on reviewing the Futures Plan and the Personal Portrait. Most families had completed the Personal Portrait and found the process to be invaluable. It provided families with a chance to work with the person with a disability to identify their interests and preferences in a formal way and it gave carers considerable peace of mind. Most families had made good progress with the Futures Plan.

Interview 3 also sought feedback on the planning process. All of the participating families reported that they had found the process interesting and helpful. The interviewers recorded the following comments.

- The Futures Planning process encouraged the family to update their Will which they said they needed to but didn’t know how to or who to see.
- As a result of the Futures Planning, (name’s) parents discussed his future with his sister who is currently home from overseas, which they hadn’t done before.

- Going through the process as a family has resulted in the ability to have important conversations in relation to (name's) future. This has included (name's) parents making a Will, and what will happen (sic) when her parents are no longer able to care for her. There has been a general understanding, but family members have been reluctant to bring these issues up in conversation even though they were aware they needed to be dealt with.
- (The most helpful aspect of the process was) the ability to confront those unknown aspects of the future, and to put in place strategies that will ensure some certainty regarding the future for (name).
- The carers expressed throughout the whole process that this has been an opportunity for them to cement their wishes for their daughter's future whilst they are of the right frame of mind and knowing that she will be cared for with the plans done, has made this project the easier for them to undertake.

## INFORMATION SESSIONS

The Information Sessions were well attended with all of the 8 staff working with families and 6 of the family members attending in Lismore. In Coffs Harbour all 11 staff working with families and 7 family members attended. In Lismore, 2 families were unable to attend due to ill health and in Coffs Harbour, 2 families were unable to attend due to ill health and 2 families were isolated due to flooding.

The feedback from participants was very positive. The majority found the sessions extremely informative and of value, although most people felt that the sessions would have been better if they had been spread over a day instead of a few hours. The general view was that there was so much new information, much of it complex to absorb and they needed more time to assimilate the information and ask questions. One of the staff members who attended the Coffs Harbour session made the following comment.

*“The family member I brought along had been reluctant to attend as she is so busy but afterwards thanked me a number of times for pushing her to go”.*

A staff member participating in the Lismore session commented:

*“The Information session was so vital for her but it was over ...by the time she thought of the questions to pose.”*

A carer attending one of the Sessions commented:

*“(It was) excellent, really, really good. It opened my eyes up to a lot of things that I hadn’t really thought about. I had a lot of questions when I got home.”* [Family 6]

The sessions provided participants with the motivation, the guidance and the information to be able to formalise their plans. As was the case in Phase 1, the Information Sessions proved to be pivotal to the success of the project and identified the extent of the gap in knowledge that older carers have with regard to future planning.

## **SERVICE PROVIDERS**

### Feedback relating to participants

The final review sessions with service provider staff provided an opportunity to review, analyse and compare experiences. It was apparent that whilst there were issues or concerns common to all families there was also considerable diversity. This highlighted the very personal and individual nature of the project.

Observations and feedback of particular note included:

- The health issues facing many of the carers, in addition to their daily workload meant that finding extra time and emotional strength to invest in this program was difficult for a significant number of participants;
- There was widespread agreement amongst service provider staff that it would be better for older carers to start Futures Planning earlier;
- The Personal Portrait was very popular with families;
- The project provided an impetus for people to do something about planning; many people were aware of the value but were unsure of where and how to start;
- A number of people reported that the project created the opportunity for carers to bring the whole family together and to get “all those things that had been assumed or presumed, hammered out”;
- And the majority felt that the Futures Planning process was invaluable and provided a vehicle for their organisation to offer a more holistic service. One staff member commented, *“This is part of what I do now, it is an ideal adjunct for organisations working with carers”*.

- Feedback relating to the project process
- The tape recording of the interviews was problematic for the majority of both staff and carers. A number of carers requested that the taping cease; in at least one case this was due to concerns that financial information would not be secure. A number of service provider staff had difficulty with taping and subsequently failed to tape some of their interviews successfully.
- Many found the interview format repetitive and a number did not like the check box aspect of the Futures Plan template.
- A number of people felt that there was too much time between interviews and that this impacted on the momentum of moving forward with the planning process. Others however found that the timeframe gave families the time needed to get the whole family together.
- Resources were an issue, with the majority of staff feeling that the project had impacted on their time with a few giving up their days off.
- A number felt that the project would fit well with case management and in those cases where case management was outside their organisation's focus they felt that they did not have enough time to offer a more integrated case management approach.

#### Feedback from Service Provider evaluation questionnaires

A Service Provider Evaluation Form was sent to the senior management of the nine participating organisations remaining in the project to the end. Five organisations completed the form. Of these, three organisations rated the project as being moderately successful and two rated it as very successful. All five organisations reported a cost impact. The costs incurred related to additional staff wages, travel expenses and in some instances the purchase of recording devices. The majority of service providers plan to use the tool on an ongoing basis.

Comments from service providers included:

- “(Futures Planning) is essential for minimising stress for the carer and client about being organised for the future, it values and validates the past and present and it's an enhancement to a more holistic service provision”.
- “I would hope that there would be the flexibility within current contracts to integrate Futures Planning functions and of course, what would be even better is if this function could be recognised through some additional resources”.

- “It has provided a very useful tool for the organisation to be able to put into practice with other clients that (organisation name) provides services to. The tool is user-friendly and is easily understood by family members. The Case Worker involved has been able to enhance her skills in many areas”.
- “The case worker provided a presentation to the other team members; this was well received and will be a tool that the organisation will use with clients who choose to participate in Future Planning”.
- “Heightened organisation’s awareness around the value of having a ‘Futures trainer’ or ‘family liaison person’ to assist with the development of a solid documented plan for future reference”.
- “Brought to the forefront of our minds the ‘gap’ there is with many families in Futures Planning and the need for (organisation name) to assist families to address this”.
- “I am very keen ... to integrate Futures Planning as part of our service to carers. We have just received extended funding through the DADHC Ageing Carers program and this would be a complementary and valid service to provide as part of this program”.

## **FAMILY PARTICIPANT SATISFACTION**

Despite numerous challenges for families, particularly in making time available to participate and dealing with sensitive and, in some cases, contentious issues, everyone involved felt that the process had been of substantial benefit. As one parent commented: “*Through sitting down with all the family we have come up with a solution that will work*”. [Family 11]



## CHAPTER FIVE - SUMMARY

### DISCUSSION

This one-year project came about in response to the evident need, as identified by ADHC, by service providers and during the implementation of Phase 1. The methodology was developed in response to one of the recommendations made in Phase 1, namely: *“a well known and trusted person who already works with the family ...would be better placed to work through the process with the families”*.

#### Training

The training successfully provided the service provider staff with sufficient knowledge and a sound framework from within which to: identify and recruit carers who met the participation criteria; undertake the interviews; report on the interviews; and assist families to prepare the Personal Portrait and a comprehensive Futures Plan.

However, the training did not include sufficient information on the particular aspects of Futures Planning that were discussed at the Information Sessions. This proved to be an issue and staff reported that they felt ill-equipped to handle the questions from carers following those sessions.

#### Interviews

The interview structure proved to be effective and the service provider staff felt comfortable with the process. The existing relationships that the majority (84%) of staff had with the carers proved to greatly assist with the establishment of trust and rapport within the first interview and to enable discussion around the sensitive issues of mortality and family relationships that needed to be addressed, (thus confirming the recommendation from Ph 1).

#### Information Sessions

The Information Sessions were well received by all the families who attended. All but one of the carers participating found the information to be invaluable. The sessions enabled carers to identify the gaps in their knowledge and to take steps to rectify this. The sessions also proved to be invaluable for service provider staff, many of whom knew very little about the matters covered.

### Personal Portrait

The Personal Portrait was embraced by all of the families and proved to be a very important means of providing carers with security and peace of mind. It has reassured carers that in the event of an emergency, or at the time when they are no longer able to continue in the role of principal carer, that the needs, interests and personal wishes of the person with a disability will, potentially, be adequately understood by another person undertaking their care.

### Futures Plan

As with the Personal Portrait the development of the Futures Plan has provided carers with a level of certainty and helped allay their fears about what will happen when they are no longer here.

## **PROJECT LIMITATIONS/BARRIERS**

- A lack of resources within service provider organisations placed additional workload pressures on those staff participating.
- The feedback from attendees at the Information Sessions highlighted the limitations of a holding these sessions over a few hours. The sessions would have been of far greater value both for carers and for service provider staff had they been full day interactive workshops.
- The issue of availability of suitable speakers for presentation at the Information Sessions meant that the content and quality of the information varied; not all types of speakers were available at both Information Sessions. Some of the reasons included:
  - Unavailable on the particular day the Information Session was held;
  - Did not have the range of expertise relevant to the client group;
  - The need for the professionals to provide their services on a pro bono basis;
  - Did not respond to letters or messages of request
- The time constraints of the project meant that in those families where the carer/s became ill during the project there was insufficient time to wait until they were well enough to continue. Sadly, these carers were the ones most urgently in need of Futures Planning.

## **RECOMMENDATIONS**

- Delivery of Futures Planning would be greatly enhanced if resources were made available for participating service providers. Given the aptness of Futures Planning to existing funded programs for older carers, funding an extension to those services could provide a cost-effective delivery mechanism. Futures Planning would also be compatible with case management services.
- Information Sessions would be more effective if held over a full day with separate panels and small working groups for families to be able to ask targeted and specific questions of professionals within a safe environment. (Note: this may require additional care/respice to be provided for the person with a disability).
- Carers would benefit if Information Sessions were held on a regular basis across the area, irrespective of whether or not they were part of a Futures Planning program.
- Specific training should be provided to service provider staff to ensure they have sufficient knowledge to assist families. Many staff were hearing about Wills, Enduring Powers of Attorney, Trusts and the like for the first time.
- Opening the program up to carers who are aged in their fifties to enable people to start the planning process whilst they are in good health and more physically able to do so would improve outcomes.

## **CONCLUSIONS**

This project aimed to provide older carers with the security of knowing that clear plans were in place to provide for the support, guardianship and accommodation needs of the person with a disability for whom they cared. One of the greatest concerns that older carers have expressed is “who will care for him/her when I am gone?” The motivation to conduct the project was the need to address this fear and to establish a model of Futures Planning which could assist carers to put in place arrangements which would negate the potential need for emergency (unplanned) responses at a time of future crisis. Emergency responses also have a cost and resource implication for ADHC.

In addition this project set out to explore the viability of expanding the implementation of a Futures Planning process to service providers in the disability sector. The success of the project proved the considerable value in having service providers involved with this aspect of carer support. Service providers benefited from their involvement and were able to identify gaps in their service delivery and to expand their views on how they can best service the

needs of clients and their families. This has the potential to stimulate a move towards a more responsive and whole-of-family approach to service delivery.

The project highlighted the fact that carers, on the whole, do not know where to start or how to access the information they need to start planning for the future. It was also evident that whilst most carers were aware of the need to attend to such matters they were impacted by a lack of time, resources and energy. This project therefore provided the participating carers with the information, guidance and assistance that they needed to overcome the challenges they were facing.

The project was very successful with the 10 participating families who remained involved to the end all completing a Personal Portrait and either completing or being well advanced with a Futures Plan. The project also provided a critical role in facilitating discussion amongst family members and providing families with the impetus and structure from within which to tackle some of the unspoken and difficult questions that had been avoided for many years. Service providers involved in the project reported that this has given families a sense of relief, peace of mind and had wide-ranging benefits for the family unit.

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## APPENDIX 1 – Invitation to Project Introductory Meeting for CEOs/General Managers of Service Provider Organisations



Date

[Click [here](#) and type recipient's address]

Dear (Service Provider X),

The Aged Services Learning and Research Centre of Southern Cross University is currently undertaking research on Futures Planning for Older Carers of Adults with Disabilities on behalf of NSW Department of Ageing Disability and Home Care (DADHC). The project is a response to substantial fears and anxieties ageing carers have commonly expressed around the issue of "Who will care for them, when I am gone?" It also aims to better equip staff in disability service provider organisations to support families where there is an older carer(s) looking after an adult person with a disability (PWD).

Phase 1 involved the development of a Futures Planning model and worked with 10 families to trial the model and determine its effectiveness and acceptability to carers - and the PWD where possible. All 10 families were supported to develop a Futures Plan and a Personal Profile of the PWD. Phase 1 was deemed successful by all project stakeholders (a full report can be accessed at <http://aslarc.scu.edu.au/downloads.html>).

We would like to invite your organisation to participate in the second Phase of the project. The main objectives of Phase 2 are: to test the effectiveness of the model when it is implemented by trained service providers; to involve a broader target group of families caring for a PWD; and to introduce service providers to using the Model and encourage its wide-spread use within the community-care sector on the NSW North Coast. We propose to work with 15-20 North Coast service providers and to train one or two staff members from each organisation to undertake Futures Planning with families who meet the selection criteria and consent to taking part in the project..

To assist you in deciding if you would like to participate, we invite you and/or one or two of your staff members to attend a Project Introductory Meeting:

(details of Meeting)

Date:XX

Time:XX

Place:XX

Duration: XX

RSVP: XX

The purpose of this Meeting will be to:

- outline what was done in Phase 1;
- explain what is planned for Phase 2;
- outline what will be required from participating organisations;
- outline what will be required from participating Support Workers;
- clarify what benefits/resources will be available to participating organisations;
- identify which service providers are interested in participating and the next steps.

Please note that attendance at the Meeting is completely voluntary and your or your staff's attendance will in no way commit your organisation to participate in this project. After the Meeting, only those service provider organisations that have agreed to participate or have advised that they are agreeable to be approached again will be contacted by ASLaRC's Project Coordinator to discuss further their organisation's possible participation. Organisations which then consent to participate will be sent a Letter of Agreement that will outline the commitments and requirements from ASLaRC and the participating organisation.

This research has been approved by the Southern Cross University Human Research Ethics Committee. The approval number is ECN-08-145. If you have any concerns about the ethical conduct of the research, please contact:

Ethics Complaints Officer  
HREC  
Southern Cross University  
PO Box 157  
Lismore NSW 2480  
Tel: (02) 6626 9139  
Email: [sue.kelly@scu.edu.au](mailto:sue.kelly@scu.edu.au)

All information is confidential and will be handled as soon as possible

Should you wish to discuss further this Project, please do not hesitate to contact me or the DADHC Project manager (see contact details below).

Yours sincerely

---

Professor Colleen Cartwright  
Director, ASLaRC

**Chief Investigator**  
Professor Colleen Cartwright  
Director, ASLaRC  
Southern Cross University  
Ph: 02 6659 3382  
Email: [colleen.cartwright@scu.edu.au](mailto:colleen.cartwright@scu.edu.au)

**DADHC Project Manager**  
Ms Jane Roser  
Senior Project Officer-Performance &  
Quality Improvement  
Dept Ageing Disability & Home Care  
Ph: 02 6659 1335  
Email: [jane.rosier@dadhc.nsw.gov.au](mailto:jane.rosier@dadhc.nsw.gov.au)

## APPENDIX 2 – Service Provider Letter of Agreement



DATE

[Click [here](#) and type recipient's address]

Dear (Service Provider X),

Thank you for agreeing to participate in the research project, Futures Planning for Older Carers of Adults with Disabilities, being undertaken by the Aged Services Learning and Research Centre (ASLaRC) of Southern Cross University on behalf of the NSW Department of Ageing Disability and Home Care (DADHC). Attached please find two copies of the Letter of Agreement which details the expectations and responsibilities of ASLaRC and your organisation. Could you please have the appropriate person sign both copies of this letter and return one copy to the ASLaRC office no later than 3 April 2009. The other copy is for your records.

This research has been approved by the Southern Cross University Human Research Ethics Committee. The approval number is: ECN-08-145. If you have any concerns about the ethical conduct of the research, please contact:

Ethics Complaints Officer  
HREC  
Southern Cross University  
PO Box 157  
Lismore NSW 2480  
Tel: (02) 6626 9139  
Email: [sue.kelly@scu.edu.au](mailto:sue.kelly@scu.edu.au)

Should you wish to discuss further this Project, please do not hesitate to contact me or the Project Coordinator (see contact details below).

Yours sincerely

---

Professor Colleen Cartwright  
Director, ASLaRC

**Chief Investigator**  
Professor Colleen Cartwright  
Director, ASLaRC  
Southern Cross University  
Ph: 02 6659 3382  
Email: [colleen.cartwright@scu.edu.au](mailto:colleen.cartwright@scu.edu.au)

**DADHC Project Manager**  
Ms Jane Roser  
Senior Project Officer-Performance &  
Quality Improvement  
Dept Ageing Disability & Home Care  
Ph: 02 6659 1335  
Email: [jane.rosier@dadhc.nsw.gov.au](mailto:jane.rosier@dadhc.nsw.gov.au)

## Letter of Agreement

This letter of Agreement is between the Aged Services Learning and Research Centre of Southern Cross University and \_\_\_\_\_

(please insert your organisation name) hereinafter referred to as ASLaRC and The Organisation.

It is agreed that The Organisation shall:

- Select suitable staff member/s to participate in the research project;
- Ensure that the selected personnel attend the one day Training Workshop in April 2009;
- Identify suitable family/ies to participate in the project and provide the family/ies with the *Information Sheet – Carers* and the *Information Sheet – Person cared for*;
- Seek consent from the family/ies and the person cared for as per the *Carer Consent Form* and the *Person Cared for Consent Form*;
- Support selected personnel to undertake a series of three (3) interviews with the family/ies;
- Facilitate selected personnel attending an Information Session and supporting families to attend,
- Support selected personnel to enable them to complete the research documentation following each interview and to prepare the Personal Portrait and Futures Plan for each family;
- Ensure that the confidentiality of participants is respected at all times in line with the Organisation's Confidentiality policy.
- Ensure that all reports and tape recordings of interviews are returned to ASLaRC within the stipulated timeframes.

ASLaRC agrees to:

- Provide The Organisation's selected personnel with training and support to undertake the interviews, complete the Personal Portraits and Futures Plans and to complete the research documentation;
- Ensure that all identifying information pertaining to selected personnel, The Organisation and participating families is kept secure and confidential at all times;
- Ensure that the tape recordings are kept securely and confidentially at the ASLaRC office;
- Ensure that all electronic information is password protected and securely stored;
- Store all information for a period of seven (7) years in accordance with Section 2.3 of the joint NHMRC/AVCC Statement and Guidelines on Research Practice (1997);
- Organise the Information Sessions for families and selected personnel;
- Provide assistance to families if required, on a case by case basis, with regard to the provision of substitute care to enable participation in the Information Sessions and attendance at an initial meeting with relevant professionals;
- Provide a written report on the project to DADHC and with consent from DADHC provide copies of the report to the participating organisations and publish the report on the ASLaRC website.

## Letter of Agreement

### Agreed to and signed on behalf of The Organisation

\_\_\_\_\_  
Title                      First Name                      Surname

\_\_\_\_\_  
Position                      Organisation

\_\_\_\_/\_\_\_\_/\_\_\_\_\_  
Date

### Agreed to and signed on behalf of Aged Services Learning and Research Centre

Professor                      Colleen                      Cartwright  
Title                      First Name                      Surname

Director                      ASLaRC  
Position                      Organisation

\_\_\_\_/\_\_\_\_/\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature



## APPENDIX 3 – CONSENT FORMS



### CARER CONSENT FORM

(This consent form is based on the National Statement on Ethical Conduct in Human Research)

Title of research project: **Futures Planning for Older Carers of Adults with Disabilities – Phase 2**

NOTE: This consent form will remain with the Southern Cross University researcher for their records.

**Please tick the box that applies for each statement, then sign and date the form and give to the researcher**

	Yes	No
I agree to take part in the Southern Cross University research project specified above.	<input type="checkbox"/>	<input type="checkbox"/>
I have been provided with information at my level of comprehension about the purpose, methods, demands, risks, inconveniences and possible outcomes of this research, including any likelihood and form of publication of results.	<input type="checkbox"/>	<input type="checkbox"/>
I agree to participate in three Futures Planning interviews with the Support Worker.	<input type="checkbox"/>	<input type="checkbox"/>
I agree to have all interviews audio-recorded.	<input type="checkbox"/>	<input type="checkbox"/>
I agree to attend the Information Session on Futures Planning.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that my participation is completely voluntary.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that I can choose <u>not</u> to participate in part or all of this research at any time, without negative consequence to me.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that any information that may identify me will be <u>de-identified</u> at the time of analysis of any data. Therefore, any information I have provided cannot be linked to me. ( <i>Privacy Act 1988 Cth</i> ).	<input type="checkbox"/>	<input type="checkbox"/>
I understand that neither my name nor any identifying information will be disclosed or published.	<input type="checkbox"/>	<input type="checkbox"/>

I understand that all information gathered in this research is confidential. It will be kept securely and confidentially for 7 years at the University.	<input type="checkbox"/>	<input type="checkbox"/>
I am aware that I can contact the researchers at any time with any queries.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that the ethical aspects of this research have been approved by the SCU Human Research Ethics Committee.	<input type="checkbox"/>	<input type="checkbox"/>

**Participant**

*I have read the information above and agree to participate in this study. I am over the age of 18 years.*

Name of Participant: .....

Signature of Participant: .....

Date: .....

### PERSON CARED FOR CONSENT FORM

(This consent form is based on the National Statement on Ethical Conduct in Human Research)

Title of research project: **Futures Planning for Older Carers of Adults with Disabilities – Phase 2**

NOTE: This consent form will remain with the Southern Cross University researcher for their records.

**Please tick the box that applies for each statement, then sign and date the form and give to the researcher**

	Yes	No
I agree to take part in the Southern Cross University research project specified above.	<input type="checkbox"/>	<input type="checkbox"/>
I have been provided with information at my level of comprehension about the purpose, methods, demands, risks, inconveniences and possible outcomes of this research, including any likelihood and form of publication of results.	<input type="checkbox"/>	<input type="checkbox"/>
I agree to participate in three Futures Planning interviews with the Support Worker.	<input type="checkbox"/>	<input type="checkbox"/>
I agree to have all interviews audio-recorded.	<input type="checkbox"/>	<input type="checkbox"/>
I agree to attend the Information Session on Futures Planning.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that my participation is completely voluntary.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that I can choose <u>not</u> to participate in part or all of this research at any time, without negative consequence to me.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that any information that may identify me will be <u>de-identified</u> at the time of analysis of any data. Therefore, any information I have provided cannot be linked to me. ( <i>Privacy Act 1988 Cth</i> ).	<input type="checkbox"/>	<input type="checkbox"/>
I understand that neither my name nor any identifying information will be disclosed or published.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that all information gathered in this research is confidential. It will be kept securely and confidentially for 7 years at the University.	<input type="checkbox"/>	<input type="checkbox"/>

I am aware that I can contact the researchers at any time with any queries.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that the ethical aspects of this research have been approved by the SCU Human Research Ethics Committee.	<input type="checkbox"/>	<input type="checkbox"/>

**Participant**

I have read the information above and agree to participate in this study. I am over the age of 18 years.

Name of Participant: .....

Signature of Participant: .....

Date: .....

**OR**

I have given permission for ..... to sign this Consent Form on my behalf.

Name:

Date:

Relationship to me:

**Person signing**

Name of Person Signing on Behalf of Participant: .....

Signature of Person Signing on Behalf of Participant .....

Date: .....

### CASE MANAGER/ SUPPORT WORKER CONSENT FORM

(This consent form is based on the National Statement on Ethical Conduct in Human Research)

Title of research project: **Futures Planning for Older Carers of Adults with Disabilities – Phase 2**

NOTE: This consent form will remain with the Southern Cross University researcher for their records.

**Please tick the box that applies for each statement, then sign and date the form and return to the researcher.**

	Yes	No
I agree to take part in the Southern Cross University research project specified above.	<input type="checkbox"/>	<input type="checkbox"/>
I have been provided with information about the purpose, methods, demands, risks, inconveniences and possible outcomes of this research, including any likelihood and form of publication of results.	<input type="checkbox"/>	<input type="checkbox"/>
I agree to undertake the Case Manager/ Support Worker tasks as specified in the Information Sheet.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that my participation is completely voluntary.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that I can choose <u>not</u> to participate in part or all of this research at any time, without negative consequence to me.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that any information that may identify me will be <u>de-identified</u> at the time of analysis of any data. Therefore, any information I have provided cannot be linked to me. ( <i>Privacy Act 1988 Commonwealth</i> ).	<input type="checkbox"/>	<input type="checkbox"/>
I understand that neither my name nor any identifying information will be disclosed or published.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that all information gathered in this research is confidential. It will be kept securely and confidentially for 7 years at the University.	<input type="checkbox"/>	<input type="checkbox"/>
I am aware that I can contact the researchers at any time with any queries.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that the ethical aspects of this research have been approved by the SCU Human Research Ethics Committee.	<input type="checkbox"/>	<input type="checkbox"/>

Participant name: \_\_\_\_\_

Participant signature: \_\_\_\_\_

Date: \_\_/ \_\_/ \_\_

If you wish to receive a copy of the Final Report, please provide contact details and tick this box:

.....  
.....

## APPENDIX 4 – INFORMATION SHEETS



### INFORMATION SHEET - Carers

#### **Title of Study: Futures Planning for Older Carers of Adults with Disabilities**

You are invited to participate in a research project that seeks to work with families in which the primary carers (parents, grandparents or others) of a person with a disability are becoming older and may require support to ensure that plans are in place for the care of the person with the disability when the carer(s) can no longer provide that care.

The aim of this project is for you to work together with a Support Worker from a disability service provider organisation, who you already know, to develop a Plan outlining what support you can organise for the person you care for, in case at some time in the future you can no longer provide that support yourself. You will also be assisted to put together a Personal Profile of the person you care for, which will provide information about them to someone who may need to care for that person in an emergency.

This is the second phase of a research project that is being undertaken by Prof Colleen Cartwright, Director of Aged Services Learning and Research Centre of Southern Cross University on behalf of NSW Department of Ageing Disability and Home Care (DADHC). In the first phase we worked with ten families to trial a Futures Planning model to see if it was acceptable people with a disability and their carers. The report of Phase 1 includes examples of a Family Futures Plan and a Personal Profile. If you would like a copy of this Report, please contact Professor Cartwright (contact details next page) and she will send one to you.

#### **Procedures to be followed**

##### **Providing you with information about the project**

This Information Sheet will have been given or sent to you by your Support Worker/ Case Manager. She/He will be someone that you already know who has regular contact with you and understands your family's situation.

##### **What is involved for participating carers?**

Your participation in this project will primarily involve participating in three in-depth interviews with your Support Worker and attending an Information Session on Futures Planning presented by planning experts, in order to develop a Futures Plan for the care and support of the person for whom you care. If you would like to participate in the project, your Support Worker will make a time with you for the first interview.

Each interview should take between 1.5-2 hours and, with your permission will be audio-recorded, to assist your Support Worker to develop your family's Futures Plan. You may ask for the recorder to be switched off at any time during an interview. You are also free to stop an interview at any time and ask the Support Worker to come back at another time, or you may choose to totally withdraw from the project, with no questions asked and no negative impact of any kind on you or the person for whom you care.

The Information Session with planning experts will be held at a convenient location in your local area, should take about 2 hours and will also be attended by other participating families, Support Workers and Case Managers.

*Involving Others:* If you wish, you may invite other family members or close friends who provide care and support to the person with the disability to also be present at any interviews. In addition, if the person you care for is able to understand the issues to be discussed, we strongly advise that she or he also takes part in the discussions about his or her future care.

*Participation is entirely voluntary:* You are free to say yes or no to participating, and that will in no-way affect any on-going support you receive from your Support Worker or the organisation for whom they work. You can also choose to discontinue your participation and you will not be asked for an explanation, nor will there be any negative consequences for you or for the person you care for.

### **Other important information about the project**

*Costs for Services of Planning Professionals:* There will be no financial cost to you for the planning work undertaken by your Support Worker or for attending the Information Session. However, if you decide to take further steps in the Futures Planning, such as setting up Trusts, you will need to privately pay the professionals for those services. Depending on individual circumstances, in some cases the project may be able to provide a small amount of financial assistance for this.

*Financial assistance:* To assist you to attend the Futures Planning Information Session, if necessary we will pay for substitute care for the person with the disability, either in your own home or in another location that is convenient for you and we will also pay any travel costs associated with your attendance.

*Possible Discomforts and Risks:* It may be that you find taking part in the interview somewhat distressing, as we are asking you to think about a time in the future when you may not be able to continue providing care for the person with the disability. The Support Worker will do all that she/he can to ensure that such distress is kept to a minimum. However, if you (or the person you care for) do experience any distress a qualified counsellor will be available for you to talk to. At the beginning of Interview 1, the Support Worker will provide you with a list of Counsellors and their contact details.

*Feedback:* In addition to providing a hard copy and CD of the Futures Plan and Personal Profile for you to continue to update them as your family's circumstances change over time, your family will also receive a copy of the Final Report.

### **Responsibilities of the Researcher**

*Obtaining consent:* It is essential that you sign the Consent Form for Carers before you participate in this project. All signed Consent Forms and other records from the project will be stored in a locked filing cabinet in the office of the Chief Investigator and then stored securely and confidentially at Southern Cross University for a period of seven years.

*Confidentiality:* The information collected from you will be required for use by your Support Worker in drafting your family's Futures Plan. The Research Team will require access to such information in order to support your Support Worker in this drafting process. The Project Reference Group will also have access to any information necessary to properly progress and oversee the project. With your consent, information collected may also be passed on to

appropriate professionals (e.g. lawyers, financial advisors and medical practitioners) to assist them to support your family's Futures Planning. In these cases the professionals will only receive the information required to allow them to assist with Futures Planning.

Your family will be given an ID code, which will be used to de-identify the information collected before inclusion in any reports and/or publications. No identifying details about you or the person you care for will be used in any reports or other publications from the study. If information about, or a direct quote from an individual Support Worker or particular family is used to illustrate an issue, particular care will be taken to ensure that they cannot be inadvertently identified.

This research has been approved by the Southern Cross University Human Research Ethics Committee. The approval number is: ECN-08-145. If you have any concerns about the ethical conduct of the research, please contact:

Ethics Complaints Officer<sup>1</sup>  
HREC  
Southern Cross University  
PO Box 157  
Lismore NSW 2480  
Tel: (02) 6626 9139  
Email: [sue.kelly@scu.edu.au](mailto:sue.kelly@scu.edu.au)

All information is confidential and will be handled as soon as possible.  
Should you wish to discuss further this Project, please do not hesitate to contact The Chief Investigator or the DADHC Project Manager (see contact details below).

Yours sincerely



Professor Colleen Cartwright  
Director, ASLaRC

**Chief Investigator**  
Professor Colleen Cartwright  
Director  
ASLaRC  
Southern Cross University  
Ph: 02 6659 3197  
Email: [colleen.cartwright@scu.edu.au](mailto:colleen.cartwright@scu.edu.au)

**DADHC Project Manager**  
Ms Jane Roser  
Senior Project Officer- Performance  
& Quality Improvement  
Dept Ageing Disability & Home Care  
Ph: 02 6659 1335  
Email: [jane.rosier@dadhc.nsw.gov.au](mailto:jane.rosier@dadhc.nsw.gov.au)

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<sup>1</sup> All complaints, in the first instance, should be in writing to the above address. All complaints are investigated fully and according to due process under the National Statement on Ethical Conduct in Research Involving Humans and this University. Any complaint you make will be treated in confidence and you will be informed of the outcome.

## INFORMATION SHEET – Person Cared For

### **Title of Study: Futures Planning for Older Carers of Adults with Disabilities**

You are invited to participate in a research project that seeks to work with families in which the primary carers (parents, grandparents or others) of a person with a disability are becoming older and may require support to ensure that plans are in place for the care of the person with the disability when the carer(s) can no longer provide that care.

The aim of this project is for you and your carer(s) to work together with a Support Worker from a disability service provider organisation, who you will all already know, to develop a Plan outlining support that can be organised for you, in case at some time in the future your carer(s) can no longer provide that support. You and your carer(s) will also be assisted to put together a Personal Profile about you, which will provide information about you to someone who may need to care for you in an emergency.

This is the second phase of a research project that is being undertaken by Prof Colleen Cartwright, Director of Aged Services Learning and Research Centre of Southern Cross University on behalf of NSW Department of Ageing Disability and Home Care (DADHC). In the first phase we worked with ten families to trial a Futures Planning model to see if it was acceptable to people with a disability and their carers. The report of Phase 1 includes examples of a Family Futures Plan and a Personal Profile. If you would like a copy of this Report, please contact Professor Cartwright (contact details next page) and she will send one to you.

### **Procedures to be followed**

#### **Providing you with information about the project**

This Information Sheet will have been given or sent to you by your Support Worker. She/He will be someone that you already know who has regular contact with you and understands your family's situation.

#### **What is involved for participating persons cared for?**

Your participation in this project will primarily involve participating with your carer(s) in three in-depth interviews with your Support Worker and attending an Information Session on Futures Planning presented by planning experts, in order to develop a Plan for your future care and support. If you and your carer(s) would like to participate in the project, your Support Worker will make a time with you all for the first interview. If you do not want to participate in the project but your carer(s) does, that is also acceptable.

Each interview should take between 1.5-2 hours and, with you and your carer(s) permission will be audio-recorded, to assist your Support Worker to develop your Futures Plan. You may ask for the recorder to be switched off at any time during an interview. You are also free to stop an interview at any time and ask the Support Worker to come back at another time, or you may choose to totally withdraw from the project, with no questions asked and no negative impact of any kind on you or your carer(s).

The Information Session with planning experts will be held at a convenient location in your local area, should take about 2 hours and will also be attended by other participating families and Support Workers.

#### *Involving others*

If you wish, you may invite other family members or close friends who provide care and support to you to be present during the interviews and at the Information Session.

*Participation is entirely voluntary:* You are free to say yes or no to participating, and that will in no-way affect any on-going support you receive from your Support Worker or the organisation for whom they work. You can also choose to discontinue your participation at anytime and you will not be asked for an explanation, nor will there be any negative consequences for you or your carer(s).

#### **Other important information about the project**

*Costs for Services of Planning Professionals:* There will be no financial costs to you or your carer(s) for the planning work undertaken by the Support Worker or for attending the Information Session. However, if your carer(s) decide to take further steps in Futures Planning, such as setting up Trusts, they will need to pay the professional(s) for those services. Depending on individual family circumstances, in some cases the project may be able to provide a small amount of financial assistance for this work.

*Financial assistance:* To assist you to attend the Futures Planning Information Session we will pay for any travel costs associated with you or your carer(s) attending. If your carers wish to attend the Information session but you are not able to do that and you require care for the time your carer(s) are away, we will pay for substitute care for you, either in your own home or in another location that is convenient for you.

*Possible Discomforts and Risks:* It may be that you find taking part in the project somewhat distressing, as we are asking you to think about a time in the future when your carer(s) may not be able to continue providing care for you. The Support Worker will do all that she/he can to ensure that such distress is kept to a minimum. However, if you [or your carer(s)] do experience any distress because of this project, a qualified counsellor will be available for you to talk to. At the beginning of Interview 1, the Support Worker will give you and your carer(s) a list of Counsellors and their contact details.

*Feedback:* In addition to providing a hard copy and CD of the Futures Plan and Personal Profile for you and your carer(s) to continue to update as your family's circumstances change over time, your family will also receive a copy of the Final Report.

#### **Responsibilities of the Researcher**

*Obtaining consent:* It is essential that you sign (or your carer signs on your behalf) the Consent Form for the Person Cared For before you participate in this project. All signed Consent Forms and other records from the project will be stored in a locked filing cabinet in the office of the Chief Investigator and then stored securely and confidentially at Southern Cross University for a period of seven years.

*Confidentiality:* The information collected from you and your carer(s) will be required for use by your Support Worker in drafting your Futures Plan. The Research Team will require access to such information in order to support your Support Worker in this drafting process.

The Project Reference Group will also have access to any information necessary to properly progress and oversee the project. With your and your carer(s) consent, information collected may also be passed on to appropriate professionals (e.g. lawyers, financial advisors and medical practitioners) to assist them to support your Futures Planning.

Your family will be given an ID code, which will be used to de-identify the information collected before inclusion in any reports and/or publications. No identifying details about you or your carer(s) will be used in any reports or other publications from the study. If information about, or a direct quote from an individual Support Worker or particular family is used to illustrate an issue, particular care will be taken to ensure that they cannot be inadvertently identified.

This research has been approved by the Southern Cross University Human Research Ethics Committee. The approval number is: ECN-08-145. If you have any concerns about the ethical conduct of the research, please contact:

Ethics Complaints Officer<sup>2</sup>  
HREC  
Southern Cross University  
PO Box 157  
Lismore NSW 2480  
Tel: (02) 6626 9139  
Email: [sue.kelly@scu.edu.au](mailto:sue.kelly@scu.edu.au)

All information is confidential and will be handled as soon as possible.

Should you wish to discuss further this Project, please do not hesitate to contact The Chief Investigator or the DADHC Project Manager (see contact details below).

Yours sincerely



Professor Colleen Cartwright  
Director, ASLaRC

**Chief Investigator**  
Professor Colleen Cartwright  
Director  
ASLaRC  
Southern Cross University  
Ph: 02 6659 3197  
Email: [colleen.cartwright@scu.edu.au](mailto:colleen.cartwright@scu.edu.au)

**DADHC Project Manager**  
Ms Jane Roser  
Senior Project Officer- Performance & Quality  
Improvement  
Dept Ageing Disability & Home Care  
Ph: 02 6659 1335  
Email: [jane.roser@dadhc.nsw.gov.au](mailto:jane.roser@dadhc.nsw.gov.au)

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<sup>2</sup> All complaints, in the first instance, should be in writing to the above address. All complaints are investigated fully and according to due process under the National Statement on Ethical Conduct in Research Involving Humans and this University. Any complaint you make will be treated in confidence and you will be informed of the outcome.

## **INFORMATION SHEET – Case Managers / Support Workers**

### **Title of Study: Futures Planning for Older Carers of Adults with Disabilities**

You are invited to participate in a research project that seeks to train Case Managers and Support Workers from disability service provider organisations to undertake Futures Planning with client-families in which there is an older carer(s) (parents, grandparents or others) caring for an adult person with a disability (PWD). As these carers age, they frequently have concerns and anxieties about “Who will care for them when I die or can no longer provide care?” and may require support to ensure that plans are in place for the care of the PWD when this situations eventuate.

This is a two phase research project being undertaken by Prof Colleen Cartwright, Director of Aged Services Learning and Research Centre (ASLaRC) of Southern Cross University (SCU) on behalf of NSW Department of Ageing Disability and Home Care (DADHC). Phase 1 involved the development of a Futures Planning model and saw ASLaRC staff working with 10 families to trial the model and determine its effectiveness and acceptability to carers and where possible people with a disability. Phase 1 was deemed successful by all project stakeholders (a full report can be accessed at <http://aslarc.scu.edu.au/downloads.html>). The aim of phase 2 is to work with Support Workers from disability service provider organisations operating in the NSW North Coast, to train them to undertake Futures Planning and to support them as they do this with families with whom they work.

### **Procedures to be followed:**

#### **Providing you with information about the project**

Your organisation has agreed to participate in the project and has nominated you as a potential person to join the project. This Information Sheet will have been given to you by your employer. Your organisation has agreed to support and adequately resource their staff who agree to participate; we encourage you to discuss this further with your employer. The purpose of this Information Sheet is to help you to decide if you would like to participate. You are free to say yes or no, and we have your employer’s assurance that your decision will in no-way affect your ongoing relationship with your employer.

A key finding of Phase 1 of the project was that, because Futures Planning can be very confronting for carers, carers need to feel trust in and have rapport with the person with whom they undertake Futures Planning. As building trust and rapport usually takes time, it was decided that a person who already works with the family (e.g. a Support Worker from a service provider organisation) should undertake Futures Planning work with families in Phase 2. The main objectives of Phase 2 are: to test the effectiveness of the Futures Planning model with a broader target group of families caring for a PWD; and to introduce the Model to the community-care sector by training Support Workers in its application and to encourage its wide-spread use across the NSW North Coast.

### **Role of Support Worker participants**

If you choose to participate in the project you will work with 1 or 2 nominated families to develop a Futures Plan (see attachment A ) and support the family to develop a Personal Profile of the PWD (see attachment B). Participating staff will attend a full-day training session to assist you to undertake Futures Planning with your nominated families. It is expected that your participation in this project will take approximately 8-10 hours per month for one family or approximately 15 hours per month if working with two families, over a 5-month period.

### **What is involved for participating Support Workers?**

If you decide to participate you will be asked to sign a Consent Form (see attached). You will then attend a 1 day Training Session which will be held at a central venue in either Lismore or Coffs Harbour. You will be asked to nominate families which you think meet the inclusion criteria and may be interested in participating in the project. Once the Project Reference Group has selected the families to be invited you will contact “your” family(s) and explain the project to them; if the family(s) is interested, you will send/provide an Information Sheet for both carer(s) and the PWD and set up a meeting time for the first interview. At the first interview, if the family still wishes to proceed you will ask them to sign the appropriate Consent Form(s) and begin the Futures Planning and Personal Profile process.

You will conduct three semi-structured interviews with each family, using questions from the Model developed in Phase 1. Each interview should take between 1.5-2 hours and, with the permission of the interviewee(s), will be audio-recorded, to assist you in developing the Futures Plan. You will also be required to attend three feedback and support meetings of approximately 2 hours each throughout the project and attend a 2-hour Information Session with planning experts to be held in each local area for the families.

### **Responsibilities of the Researcher**

#### *Obtaining consent*

It is essential that you sign the Consent Form for Case Managers/ Support Workers before you participate in this project and ensure that your family(s) members also sign their Consent Forms. All signed Consent Forms and other records from the project will be stored in a locked filing cabinet in the office of the Chief Investigator and then stored securely and confidentially at Southern Cross University for a period of seven years.

#### *Confidentiality*

The information collected by you from participating families will be required for use in drafting the family’s Futures Plan. The Research Team will require access to such information in order to support you in the drafting process. The Project Reference Group will have access to any information necessary to properly progress and oversee the project. With the consent of the family, information you collect may also be passed on to appropriate professionals (e.g. lawyers, financial advisors and medical practitioners) to assist participating families to undertake Futures Planning. In these cases the professionals will only receive the information required to allow them to assist with Futures Planning.

You will be asked to give each family an ID code, using the same system as DADHC MDS, which will be used to de-identify the information collected before inclusion in any reports and/or publications. No identifying details about you or the participating families will be used in any reports or other publications from the study. If information about, or a direct quote from an individual Support Worker or particular family is used to illustrate an issue, particular care will be taken to ensure that they cannot be inadvertently identified.

*Participation is entirely voluntary*

If you choose not to participate you will not be asked for an explanation, nor will there be any negative consequences for you from the Research Team or your employer.

*Possible Discomforts and Risks*

There is the potential that as you undertake this Futures Planning work with your families, you may experience some distress. The challenges of this work will be discussed at the training session and at that time you will be provided with a list of counselling and support services which you can use if you become distressed. In addition, at the feedback & support meetings you will have an opportunity to debrief and will be reminded of the external counselling support available. There will also be opportunities for you, between feedback meetings, to receive phone support from the Project Coordinator, who will have experience working with and counselling people and also from the Principal Researcher, who is a qualified social worker.

This research has been approved by the Southern Cross University Human Research Ethics Committee. The approval number is: ECN 08-145. If you have any concerns about the ethical conduct of the research, please contact:

Ethics Complaints Officer<sup>3</sup>  
HREC  
Southern Cross University  
PO Box 157  
Lismore NSW 2480  
Tel: (02) 6626 9139  
Email: [sue.kelly@scu.edu.au](mailto:sue.kelly@scu.edu.au)

All information is confidential and will be handled as soon as possible.

Should you wish to discuss further this Project, please do not hesitate to contact me or the DADHC Project Manager (see contact details below).

Yours sincerely



Professor Colleen Cartwright  
Director, ASLaRC

**Chief Investigator**

Professor Colleen Cartwright  
Director  
ASLaRC  
Southern Cross University  
Ph: 02 6659 3197  
Email: [colleen.cartwright@scu.edu.au](mailto:colleen.cartwright@scu.edu.au)

**DADHC Project Manager**

Ms Jane Roser  
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Improvement  
Dept Ageing Disability & Home Care  
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<sup>3</sup> All complaints, in the first instance, should be in writing to the above address. All complaints are investigated fully and according to due process under the National Statement on Ethical Conduct in Research Involving Humans and this University. Any complaint you make will be treated in confidence and you will be informed of the outcome.



## APPENDIX 5 – FAMILY FUTURES PLAN Template



**Aged Services Learning and Research Centre**

### **Futures Planning for older Carers of Adults with Disabilities Project**

**Futures Plan**

.....**Family**

**July 2009**

**Aim: The person with a disability is able to remain living with the same level of security that they currently experience in the care of their carer/s.**

**Plan for:**

## Plan development Record

### 1. Accommodation

**a) Where do you expect (name ) to live when you are no longer able to care for him/her?**

**b) Who will be the manager or owner of the housing arrangement?**

**c) If relevant, what arrangements have been made for the ongoing management of the maintenance of the dwelling, both inside and outside?**

**d) Has \_\_\_\_\_ been placed on the DADHC Accommodation Register?**

**Yes**

**No**

**e) Has \_\_\_\_\_ been placed on the Department of Housing waiting list?**

**Yes**

**No**

**2. Personal Support: (For each of the following activities, please place a tick in the box. If you wish you may also write something in the relevant box )**

**a) Level of independence**

<b>Activity</b>	<b>Independent</b>	<b>Requires Prompting</b>	<b>Requires some carer assistance</b>	<b>Requires full assistance</b>
<b>Personal Hygiene</b>				
<b>Meals preparation</b>				
<b>Medication Management</b>				
<b>Dental and health Appointments</b>				
<b>Household cleaning, including washing etc</b>				
<b>Transport</b>				
<b>Household budgeting and financial management</b>				
<b>Shopping</b>				
<b>Social and community Interaction</b>				
<b>Recreation</b>				

<b>b) What has been put in place for future lifestyle support relating to each of the above.</b>	
<b>Personal Hygiene</b>	
<b>Meals preparation</b>	
<b>Medication Management</b>	
<b>Dental and health Appointments</b>	
<b>Household cleaning, including washing etc</b>	
<b>Transport</b>	
<b>Household budgeting and financial management</b>	
<b>Shopping</b>	
<b>Social and community Interaction</b>	
<b>Recreation</b>	

<b>3. Legal or Guardianship Issues</b>			
<b>3.1 Wills</b>			
<b>Is there a family solicitor?</b>		<b>Yes</b>	<b>No</b>
<b>Solicitor Name</b>			
<b>Address</b>			
<b>Contact Numbers</b>	<b>Phone</b>		
	<b>Fax</b>		
	<b>Mobile</b>		
	<b>Email</b>		
<b>If no, do you need assistance finding a local solicitor?</b>		<b>Yes</b>	<b>No</b>
<b>Do you (parent/ carer) have a Will?</b>			
<b>Carer 1</b>		<b>Yes</b>	<b>No</b>
<b>Carer 2</b>		<b>Yes</b>	<b>No</b>
<b>If yes does it need updating?</b>		<b>Yes</b>	<b>No</b>
<b>If yes where are copies held?</b>		<b>Yes</b>	<b>No</b>
<b>Does (PWD) have a Will?</b>		<b>Yes</b>	<b>No</b>
<b>Is it intended that she/he have a Will?</b>		<b>Yes</b>	<b>No</b>

<b>Enduring Guardianship</b>		
<b>Have you (parent / carer) each appointed an Enduring Guardian for yourself?</b>	<b>Yes</b>	<b>No</b>
<b>If yes, please provide details:</b>		
<b>Carer 1</b>	<b>Name of Guardian</b>	
<b>Carer 2</b>	<b>Name of Guardian</b>	
<b>If yes where are the documents held?</b>		
<b>If PWD has proven capacity has she/he appointed an Enduring Guardian for him/herself?</b>	<b>Yes</b>	<b>No</b>
<b>If yes, Name of Guardian</b>		
<b>Where are the documents held?</b>		
<b>If no, does she/he intend to?</b>	<b>Yes</b>	<b>No</b>
<b>Appointed Guardian</b>		
<b>Does (PWD) have a person (family or friend) who can act as his/her informal guardian?</b>	<b>Yes</b>	<b>No</b>
<b>Informal Guardian's Name</b>		
<b>Informal Guardian's Address</b>		
<b>Informal Guardian's phone numbers</b>	<b>Home</b>	
	<b>Work</b>	
	<b>Mobile</b>	
	<b>Email</b>	
<b>Has a Guardian been appointed for (PWD) by the NSW Guardianship Tribunal to make lifestyle and/or healthcare decisions for (PWD)?</b>	<b>Yes</b>	<b>No</b>

<b>If yes:</b>		
<b>Who is it</b>		
<b>Contact telephone number</b>		
<b>Office of Public Guardian number</b>		
<b>Timeframe</b>		
<b>If no, is there a need (now) to have a formal Guardian appointed?</b>	<b>Yes</b>	<b>No</b>
<b>If there is a need now, would it be for lifestyle or healthcare matters, or both? (please tick one answer)</b> (a) Lifestyle matters (b) Health matters (c) Both		
<b>If this should become necessary in the future, would it be for lifestyle or healthcare matters, or both? (please tick one answer)</b> (a) Lifestyle matters (b) Health matters (c) Both		

<b>4. Financial Security</b>		
<b>4.1 Trusts</b>		
<b>Has a trust been established for (PWD)?</b>	<b>Yes</b>	<b>No</b>
<b>If yes what type of trust?</b>		
<b>4.2 Assets and Savings</b>		
<b>Does (PWD) currently have any assets or savings?</b>	<b>Yes</b>	<b>No</b>
<b>Is it anticipated that (PWD) will inherit any assets or money?</b>	<b>Yes</b>	<b>No</b>
<b>If yes, and the assets or money are not within a Trust, will this affect the Centrelink benefits currently received?</b>	<b>Yes</b>	<b>No</b>
<b>Do you need to contact a Centrelink Financial Information Service to clarify the effect on benefits?</b>	<b>Yes</b>	<b>No</b>

<b>4.3 Financial Management</b>		
<b>Is (PWD) able to manage his/her own finances</b>	<b>Yes</b>	<b>No</b>
	<b>Yes</b>	<b>No</b>
<b>If yes, please provide details</b>		
<b>Name</b>		
<b>Address</b>		
<b>Contact Numbers</b>	<b>Home</b>	
	<b>Work</b>	
	<b>Mobile</b>	
	<b>Email</b>	
<b>Does this person have knowledge of this informal arrangement?</b>	<b>Yes</b>	<b>No</b>
<b>Have you confirmed that this person agrees to undertake this informal arrangement?</b>	<b>Yes</b>	<b>No</b>
<b>Are you aware that the Guardianship Tribunal can appoint a private manager to manage (PWDs) finances, if an informal manager is not available or cannot be agreed upon?</b>	<b>Yes</b>	<b>No</b>

<b>Does the family have a financial advisor?</b>	<b>Yes</b>	<b>No</b>
<b>If yes, please provide details</b>		
<b>Name</b>		
<b>Address</b>		
<b>Contact Numbers</b>	<b>Work</b>	
	<b>Fax</b>	
	<b>Mobile</b>	
	<b>Email</b>	
<b>If you do have a financial advisor, do you think your financial plans need reviewing?</b>	<b>Yes</b>	<b>No</b>

Do you need to discuss your superannuation or future planning for your superannuation, annuity pension etc?	Yes	No
If you do not have a financial advisor, do you need help to contact one?	Yes	No
<b>4.4 Enduring Power of Attorney</b>		
Have you (parent/carer) each appointed an Enduring Power of Attorney?	Yes	No
If yes, please provide details		
Carer 1	Name of person appointed	
Carer 2	Name of person appointed	
If PWD has proven capacity has she/he appointed an Enduring Power of Attorney for him/herself?	Yes	No
If yes, name of person appointed:		
Where are the documents held?		
If no, does she/he intend to?	Yes	No

<b>5. Needs and Concerns in relation to the care of (PWD)</b>	
Needs and concerns identified by the carer/s	
<b>Area</b>	<b>Concerns</b>
Accommodation	
Support	

<b>Legal and Guardianship</b>	
<b>Financial Security</b>	

<b>Needs and concerns identified by PWD</b>	
<b>Area</b>	<b>Concern</b>
<b>Accommodation</b>	
<b>Support</b>	
<b>Legal and Guardianship</b>	
<b>Financial Security</b>	

<b>What has been achieved since the start of the Futures Planning Project?</b>

### **Disability – Family Services**

If the need arises in the future for any of the following, contact Interrelate Family Centre on 1300 736 966, who are funded to provide free counseling and mediation for families where their son or daughter has a disability:-

- Someone to talk to or personal counseling about - family members, practical issues such as housing for a person with a disability, financial difficulties, worry etc, or
- Help for families to communicate with each other or family counseling about – the future, implications of decisions, planning, understanding, or
- Family counseling or help families identify – services, strengths in the family, community activities, support needed to deal with stress, family goals, or
- Family dispute resolution where – there is hostility, blame, conflict between carers/parents, legal action and courts.

<b>Suggested Plans for the Future</b>		<b>July 2009</b>
<b>Activities and Actions</b>	<b>Timeframe</b>	
<b>Accommodation</b>		
<b>Physical Housing</b>		
<b>Accommodation Support</b>		
<b>Personal Portrait</b>		
<b>Legal and Guardianship aspects</b>		
<b>Wills</b>		
<b>Enduring Guardian for carer 1</b>		
<b>Enduring Guardian for carer 2</b>		
<b>Enduring Guardian for PWD</b>		
<b>Enduring Power of Attorney for carer 1</b>		
<b>Enduring Power of Attorney for carer 2</b>		
<b>Enduring Power of Attorney for PWD</b>		
<b>Financial Aspects</b>		
<b>Trusts</b>		
<b>Centrelink</b>		

<b>Futures Plan Review</b>		
It is strongly recommended that this document be reviewed regularly as details about future needs may change over time. It is suggested that this Futures Plan be reviewed at least once every year.		
<b>Review 1</b>		
Date of Review		
Were any changes made?	Yes	No
Name of reviewer		
Relationship of reviewer		
Signature		
<b>Review 2</b>		
Date of Review		
Were any changes made?	Yes	No

Name of reviewer		
Relationship of reviewer		
Signature		
<b>Review 3</b>		
Date of Review		
Were any changes made?	Yes	No
Name of reviewer		
Relationship of reviewer		
Signature		



**APPENDIX 6 – PERSONAL PORTRAIT Template**

PERSONAL PORTRAIT  
OF

.....

Attach photo here

This document is designed to provide important and relevant information about  
..... in case of a future crisis or emergency.

This Portrait was created on.....

<b>1. Personal Details</b>		
Name		
Date of Birth		
Address		
Telephone		
<b>2. Cultural Information</b>		
Country of Birth		
Language spoken at home	Interpreter required Yes / No	
Aboriginal or Torres Strait Islander origin and/or descent?		
Religion		
Other information relating to culture:		
<b>3. Carer Details</b>		
Carer Name	1.	2.
Relationship to PWD	1.	2.
Address	1.	2.
Contact Numbers		
Home	1.	2.
Work	1.	2.
Mobile	1.	2.
Email	1.	2.

**4. Emergency Contacts ( in addition to Carers)**

Name		
Relationship		
Address		
Telephone Numbers	Home	
	Work	
	Mobile	

**5. Emergency Contacts**  
**6.**

Name		
Relationship		
Address		
Telephone Numbers	Home	
	Work	
	Mobile	

**7. Emergency Contacts**  
**8.**

Name		
Relationship		
Address		
Telephone Numbers	Home	
	Work	
	Mobile	

**6. Medical / Dental Practitioners**  
**7.**

Name	
Telephone	
Address	
Specialist	

<b>Medical Practitioners</b>	
Name	
Telephone	
Address	
Specialist	
<b>Medical Practitioners</b>	
Name	
Telephone	
Address	
Specialist	

<b>8. Medical Details</b>	
Medicare Number	
Health Care Number	
Private Medical/ Hospital Insurance Number	
Ambulance Membership Number	
Allergies	
Location of Medication Prescriptions	
Location of Medication	

## 9. Things I like

Food	
Activities	
TV programs	
Music	
Friends	
Personal items / Special Possessions	
Other	

**10. Things I don't like or that upset me**

Food	
Activities	
Noise	
Other	

**11. Things to remember when supporting me**


**12. Support I need to do things**

Activity	Level of support required			
	Can do by myself	Can do with prompts	Can do with some help	Need carer to do
Communication				
Meal preparation				
Eating				
Drinking				
Showering / bathing				
Toileting				
Dressing/ putting on my shoes				
Cleaning my teeth				

Brushing my hair				
Cleaning my room				
Washing my clothes				
Doing the dishes				
Traveling				
Managing my money				

### 11. Emergency Plan

Have any specific alternative arrangements been made in the case of an emergency?

Please provide details

Have you made a Will	No	Yes	If yes, where is the Will kept?	
Have your carers made a Will?	Carer 1 Name			
	No	Yes	If yes, where is the Will kept?	
	Carer 2 Name			
	No	Yes	If yes, where is the Will kept?	
Have financial arrangements been made in the case of an emergency?			Yes	No

If yes, what are they?	
If yes, who is the contact?	

**13. Personal Portrait Review**

It is strongly recommended that this Personal Portrait be reviewed regularly as the likes, dislikes, medication and personal circumstances may change over time. It is suggested that this Personal Portrait be reviewed at least once every year.

**Review 1**

Date of Review		
Were any changes made?	Yes	No
Name of reviewer		
Relationship of reviewer		
Signature		

**Review 2**

Date of Review		
Were any changes made?	Yes	No
Name of reviewer		
Relationship of reviewer		
Signature		

**Review 3**

Date of Review	
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Were any changes made?	Yes	No
Name of reviewer		
Relationship of reviewer		
Signature		

## APPENDIX 7 – TRAINING MANUAL – key pages



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### Futures Planning for Older Carers of an Adult with a Disability

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#### Futures Planning - Phase Two

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#### Training Manual

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Aged Services Learning and Research Centre

Department of Ageing, Disability & Home Care

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- 14. Appendix 8: Consent Form – Carer**  
**Consent Form – Person cared for**

**Electronic copies of:**

- Interview guide template;
- Consent Forms;
- Research Report Templates;
- Futures Plan template; and
- Personal Portrait template.

## Project Team

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<b>Service Providers</b> <b>DADHC Access Team</b>	

## Training Objectives

**Upon completion of the training participants will have:**

1. A clear understanding of Phase 1 of the Futures Planning Project (FPP);
2. A clear understanding of the aims and objectives of Phase 2 of the Futures Planning Project;
3. A clear understanding of the requirements and constraints of the Futures Planning Project;
4. A clear understanding of how to complete the research documentation;
5. A clear understanding of how to conduct interviews with the families involved in the Project with consistency and reliability; and
6. The knowledge to develop consistent Futures Plans and Personal Portraits with families.

## **Overview of training program**

*10.00am to 4.00pm – morning tea and lunch provided*

- 10. 00 am**    **Introductions and Overview**
- Understanding the Futures Planning Project
  - Review of Phase 1 of the Project
    - the aims
    - what worked
    - what didn't work and
    - what could have improved the process for each stage of the project
  - The aims and objectives of Phase 2 of the Project
- 10.15 am**    **Working with Families**
- Identifying and making initial contact with potential families
  - Group discussion on potential challenges and good practice
  - What's involved in the 3 interviews
  - The purpose and timing of the Information Session for carers and the person with a disability (PWD)
  - How and what service providers need to report
  - Understanding the Research Documentation
  - How the Coordinator can assist you
- 11. 30 am**    *Morning Tea*
- 12. 00 pm**    **Review and group discussion about the First Interview**
- What's included in the first interview
  - Futures Plan
  - Personal Portrait
- Review of the Information Session**
- 1.00 pm**    *Lunch*
- 1.45 pm**    **Review and group discussion about the Second Interview**
- 2. 45 pm**    **Review and group discussion about the Third Interview**
- 3. 30 pm**    **Summarise and evaluate**

## **Interview 1 – Interview Guide**

**The questions in the interviews are designed to guide the interview, not to be prescriptive and, depending on each situation, not all will be asked. As the interviewer you can use your own words and adapt your style and language to suit the communication needs of the family.**

### **Interview 1: Approximately 1.5 - 2.0 hours**

- Ascertain that the family has no objection to the conversation being recorded;
- Check that the family is aware that the recorder can be switched off at any time if the family so wishes;
- Explain that the subject matter of the interview is of a very sensitive nature, which may possibly cause some discomfort or distress. Ask the family to let you know if they feel in any way disturbed or uncomfortable or if they wish to stop at any time;
- Let the family know that counseling can be arranged if they require it; and
- Emphasise the importance of including the person with a disability's input through the process, if possible, and discuss ways to encourage and support that person to participate.

### **Part 1 of Interview 1**

#### **1. Clearly outline the project**

Research indicates that many carers find it difficult to plan for the future. There are many reasons for this. This Future Planning Project aims to assist carers to plan for a future time when they may not be able to care for their loved one. No two families are exactly the same and your picture of the future will be unique, reflecting your individual values and needs. My role is to assist you as you progress through telling your story, your wishes for the future and develop planning towards it.

#### **2. Questions relating to Informed consent**

- a) Have you read the information sheet or had it explained to you?
- b) Is there anything on the information sheet you would like to discuss?
- c) Do you have any other questions?
- d) Are you aware that some issues we discuss will be of a personal and sensitive nature and could be distressing?
- e) Do you feel comfortable to tell me when you would like to take a break if you find the discussion too upsetting?

- f) Are you clear about who to contact if you have a complaint either about the project or with a family member or close friend, about an issue that relates to the project?;
- g) Have you read the consent form and is there anything relating to consenting to this project that you would like to discuss?

### **3. Clearly outline the limitations of the project**

The project does not aim to solve your problems, rather it aims to support you to find your own solutions;

### **4. Check understanding**

Do you understand the purpose of the Futures Planning Project in respect to financial arrangements, accommodation and legal issues?

### **5. Explain time commitment**

There will be three interviews each lasting approximately 1.5 hours including this one as well as an Information session where professionals such as Accountants and Solicitors will talk with you about possible options.

**If the family agrees to participate, ask them to read and sign the consent form(s).**

## **Part 2 of Interview 1**

- Explain that:
  - This part of the first interview begins the process of developing a background picture of your family, your hopes and dreams and what planning you have done so far, if any;
  - The second interview will continue the development of the Futures Plan; and
  - The third and final interview will provide an opportunity for you to check the Futures Plan and Personal Portrait for accuracy and relevance.
- Encourage the family to tell their story, their dreams and visions as well as their fears and concerns; and
- Check what planning they have done to date, for example made a Will, appointed an Enduring Power of Attorney, informal arrangements and family agreements; and
- Provide a Personal Portrait template and explain its purpose and that it becomes a part of their FP

### Questions relating to the Futures Plan

- 1) What type of planning have you already done for the future?
- 2) Can you list the areas of planning for the future that concern you the most?
- 3) Concerns for the Future:
  - What are your hopes and dreams for the future, for you and for (name of person cared for)?
  - Do you have any concerns about the future for yourself and for (name)?
  - If yes, what are they?
  - What future support and services do you think (name) will need if you are not able to care for them?
  - Have you discussed any of the following with (name):
    - a. What kind of home would (name) like to live in?
    - b. Would (name) like to live on his/her own or with other people?
    - c. Who would (name) like to help them live in their own home and do you think that is possible?
    - d. What help would (name) need to live in his/her home?
    - e. Where does (name) want to live?
  - Have you thought about who might be the primary carer for (name) if you are no longer able to care for him/her?
  - Have you discussed it with (potential primary carer)?
  - If yes, was he/she happy about that role?
  - If yes, was (name - PWD) happy about that?
- 4) Personal Support:
  - a) How independent is (name) relating to issues such as:
    - Personal Hygiene?
    - Meals preparation?
    - Medication management?
    - Dental and health appointments?
    - Household cleaning, including washing and ironing etc?
    - Transport?
    - Household budgeting and financial management?
    - Shopping?
    - Social and community interaction?
    - Recreation?
  - b) What has been put in place for future lifestyle support for (name) relating to the above points?

- Explain that the information gathered today will form the basis for the Futures Plan which will be further developed at the next interview.
- Ask if there is anything else the family would like to talk about in relation to Interview 1?
- Explain that there will be an Information Session for families (28 May in Coffs Harbour and 26 May in Lismore) to provide information and strategies that may assist them with the development of their Future Plans.

## **Information Session**

In Phase 1 the families who attended the Information Sessions commented afterwards that they had gained important and relevant knowledge from the various speakers and that this would assist them to make decisions relating to the future of the person they cared for.

We encourage all families and service providers to attend these sessions.

- It is recommended that you make contact with the family/ies at least 2 weeks prior to the sessions to remind them of the Information Session and to check if they will be attending.

## **Interview 2 – Interview Guide**

The questions in all interviews are designed to guide the interview, not to be prescriptive and, depending on each situation, not all will be asked.

The questions asked in Interview 2 will guide the formalising of the Futures Plan. Some of the answers to these questions may have already been provided during Interview 1.

### **Interview 2: Approximately 1.5 - 2.0 hours**

Briefly recap what was discussed during the last visit.

Ascertain:

- That the family has no objection to the conversation being recorded;
- Check that the family is aware that the recorder can be switched off at any time if the family so wishes;
- Explain that the subject matter of the interview is of a very sensitive nature, which may possibly cause some discomfort or distress. Ask the family to let you know if they feel in any way disturbed or uncomfortable; and
- Emphasise the importance of including PWD's input throughout the FP, if possible and discuss ways to encourage and support that person to have input.

### **Introduce the interview and outline what will be discussed:**

To continue the process of formalising the Futures Plan can you tell me about the following aspects of planning:

#### **1. Feedback regarding the Information Session**

- Did the family attend the Information Session?
- Did the family find the Session helpful?
- Did the family learn anything they did not already know?

#### **2. Asking about Plans Currently in Place**

##### **2.1. Accommodation**

- Where do you expect (name) to live when you are no longer able to care for him/her?
- Who will be the Manager and/or Owner of the Housing arrangement?
- If relevant, what arrangements have been made for the ongoing management of the maintenance of the dwelling both inside and outside?
- Has (name)'s name been placed on the DADHC Accommodation Support Need Register (phone 1300 364 563)?
- Has (name)'s name been placed on the Department of Housing waiting list

## **2.2. Legal and Guardianship issues**

### **2.2.1 Wills**

- Is there a family solicitor?
  - If yes, what is the solicitor's name and contact details?
  - If no, do you need assistance finding a local solicitor?
  
- Do you (carers) have a Will?
  - If yes, does it need updating?
  - Do you need help with accessing a Solicitor?
  - Do you need respite for (name) to enable you to meet with a Solicitor?
  - If there is a Will, where are copies held?
  - Does (name) have a Will?
  - Is it intended that she/he will have a Will?
  
- Now that you have attended the Information Session, are you still happy with your Will or would you like to make some changes to it?
  - If you are going to make a Will or make changes to your existing Will, is it likely that any other family member (or other person) will be upset about those changes?
  - If Yes, would you like us to arrange for some counseling or mediation before you make the Will or make changes to your existing Will?

### **2.2.2 Enduring Guardianship**

- Have you (carer/s) appointed an Enduring Guardian for yourself?
  - If yes, who has been appointed?
  - If yes, where are the documents held?
  - If (name) has proven capacity, has she/he appointed an Enduring Guardian for him/herself?
  - If yes, who has been appointed?
  - If yes, where are the documents held?
  - If no, do you think he/she would like the opportunity to do so?

### **2.2.3 Appointed Guardian**

- Has the Office of the Public Guardian appointed a Guardian?
  - If yes, who is this person and what are their contact details?
  - If yes, for what period of time does the Guardianship appointment apply?
  - If no, does (name) have a person (family or friend) who can act as his/her informal guardian?
  - If yes, who is this person and what are their contact details?
  - Is there a need to have a Guardian appointed by the Office of Public Guardian?
  - If this should become necessary, would it be for lifestyle considerations or financial considerations or both?

## **2.3 Financial Security**

### **2.3.1 Trusts**

- Has a trust been established for (name)?
  - If yes, what type of trust?
  - If yes, where are the documents held?

### **2.3.2 Assets and Savings**

- Does (name) currently have any assets or savings?
  - Is it anticipated that (name) will inherit any assets or money?
  - If assets/money are not within a trust, will this affect the Centrelink benefits currently received?
  - Do you need to contact Centrelink Financial Information Service to clarify the affect on benefits?

### **2.3.3 Financial Management**

- Is (name) able to manage his/her own finances?
  - If not, has a person been nominated for the future who is willing and capable to manage (name) finances?
  - If yes, who is this person and what are their contact details?
  - If yes, do they have knowledge of this informal arrangement and have you confirmed this arrangement with that person?
- Are you aware that the Office of Public Guardian can appoint a formal Guardian to manage finances, if an informal guardian is not available or cannot be agreed upon?
- Does the family have a Financial Advisor?
  - If yes, what is the Financial Advisor's name and contact details?
  - If you do have a Financial Advisor, do you think your financial plans need reviewing?
  - Do you need to discuss your superannuation or future planning for your superannuation, annuity pension etc?

### **2.3.4 Enduring Power of Attorney**

- Have you (carer/s) appointed an Enduring Power of Attorney for yourself?
  - If yes, what are the details of the person you appointed?
  - If yes, where are the documents held?
  - If (name) has proven capacity has he/she appointed an Enduring Power of Attorney?
  - If yes, what are the details of the person appointed?
  - If yes, where are the documents held?
  - If no, do you think he/she would like the opportunity to do so?

Make sure the carer realises that Enduring Power of Attorney is not the same as a Will. She/he can authorise the person holding the EPA to continue to pay for such things as accommodation, personal care, leisure or anything else that the carer decides she/he wants the person with the disability to have – within the bounds of available funds – and could even instruct the person holding the EPA to sell the family home and apply the money for the benefit of the person with the disability - but if the carer dies, the EPA ceases to have any effect, and everything would then be dealt with under the Will. This is so even if the person holding EPA is also the Executor of the Will.

Also make sure that the carer/s knows that the person holding the EPA only has authority to make decisions about money and property and cannot make decisions relating to health, personal care or medical treatment.

### **Ending interview 2**

Explain that you (SP) will return for the third interview with a draft copy of the FP and PP for the family to check for accuracy and relevance prior to the final plans being prepared.

## **Interview 3 – Interview Guide**

### **Interview 3: Approximately 1.5 - 2.0 hours**

**The questions in all interviews are designed to guide the interview, not be prescriptive and, depending on each situation, not all will be asked.**

Briefly recap the previous interviews:

- Ascertain that the family has no objection to the conversation being recorded;
- Check that the family is aware that the recorder can be switched off at any time if the family so wishes;
- Emphasise the importance of including PWD input throughout the FP and discuss ways to encourage and support that person to have input.

#### **Introduce the interview and outline what will be discussed;**

Explain that the purpose of this interview is to provide an opportunity for the family to check the FP and the PP for accuracy and relevancy prior to the FP and PP being prepared for printing and being presented back to the family as a finished document and in electronic format. Ask the following questions:

- Have you thought of anything else that needs to be included in your Futures Plan?
- Have you thought of anything else that needs to be included in the Personal Portrait?
- Is there anything that needs to be changed or corrected in the FP or the PP?
- Have your thoughts about Futures Planning changed throughout this project?
- How have you found the process of this project?
- Is there anything else you would like to add?

# Futures Planning Project

