



A 10-Year Plan for quality living for people with disabilities and their carers

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Accessible summary

- Planning allows people with disabilities and their carers to take steps to achieve their dreams and helps to ensure their security for the future.
- People with disabilities want to enjoy the same experiences that most other people enjoy, such as relationships, going to the movies with friends, having a job and going on holidays.

Abstract

Background: The concerns of older carers of an adult with disabilities have been well documented. The sudden incapacity or death of the carer can result in a crisis response rather than a planned transition to a chosen sustainable alternative care arrangement for the person with disability. Building on previous 'Futures Planning' projects, the aim of this project was to enrich the lives of people with disabilities and their carers whilst ensuring that their wishes for the future are documented to provide security.

Materials and Methods: This article reports on information sessions and workshops that were held for people with disabilities, their carers and staff, and the training sessions for staff for this project.

Results: The sessions underlined the fact that people with disabilities want to enjoy the same experiences that most other people enjoy. Drawing on the ideas and suggestions from participants, the 'Futures Planning' documents were modified to meet the aims of the Quality Living project, making them suitable for planning for quality living for the carer and the person with a disability for the next 10 years.

Conclusions: Findings supported the concept that planning allows people with disabilities and their carers to take steps to achieve their dreams.

Keywords *disabilities, dreams, future, planning, security*

Introduction

Services and the delivery of support for people with disabilities and their carers have changed over the past

decade. With the current focus on person-centredness and the introduction of the National Disability Insurance Scheme (NDIS), people with disabilities and their carers have greater choice about the services they receive, and

greater power in making decisions that affect them (Purcal *et al.*, 2014). Having such choices means that they can live more closely aligned to the life that they want.

This project was initiated by Mid Coast Communities, a not-for-profit organisation that provides professional development services for community organisations in New South Wales (NSW), Australia. The project was funded through the 'Stronger Together two' programme of the NSW Government, which aims to improve services for people with disabilities and their carers. In 2013, Mid Coast Communities contracted the ASLaRC Aged Services Unit of Southern Cross University to undertake the project. This group had previously conducted the Futures Planning for Older Carers of Adults with Disabilities project, in response to older carers who were asking 'who will care for them when I am not here?' (Cartwright *et al.*, 2008). Having plans in place for a time of future incapacity can relieve people's anxieties about their future and allow them to live well now (Parker & Cartwright, 2004).

The first three phases of that project assisted older carers to develop a 'Futures Plan' for a possible time when they could no longer provide care for the person with disability, thus giving them peace of mind and a measure of security. Issues covered in the Plan included: financial and legal matters (e.g. guardianship, wills and trusts); accommodation and daily living support; current health and medical requirements and contact details of providers; and leisure and recreation activities that the person with disability participates in or would like to be involved in. A 'Personal Portrait' of the person with disability was also developed, which provided information not only about the person's medical and other health situation but also outlined their food, music, clothing and recreation preferences, their friends, and other information that addressed the whole question of 'Who is this person?' The Futures Planning project worked with service providers and the families they support, and demonstrated that the project was viable within existing service delivery processes (Cartwright & Gale, 2010). A final phase of the project assisted a disability support organisation and their clients with disabilities to prepare for the current and future housing and support needs of the clients, in particular those who are ageing (Cartwright *et al.*, 2011).

The *Quality Living Project* builds upon the Futures Planning project by assisting people with disabilities and their carers to consider their dreams and put in place steps to achieve their goals now and in the next 10 years. The *Project* aimed to empower and resource carers and people with disability to proactively plan for how they can optimise their quality of life over the next 10 years. This article reports on information sessions and workshops that were held for people with disabilities, their carers and staff, and the training sessions for staff for this project. Those sessions underlined the fact that people with disabilities want to enjoy the same experiences that most other people enjoy.

Findings supported the concept that planning allows people with disabilities and their carers to take steps to achieve their dreams.

Background

The concerns of older carers who care for an adult with disabilities have been well documented (Bowey & McGlaughlin, 2007; Weeks *et al.*, 2009). In Australia during 2012, there were an estimated 668,100 people with an intellectual disability; 10% of those were 75 years of age and over (Australian Bureau of Statistics 2012). This figure is expected to grow in line with population growth and increased life expectancy (Australian Bureau of Statistics 2011). The 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; Bowey & McGlaughlin, 2007), who will speak for older people with intellectual disabilities when they do not have close family members to do so 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 (Bigby & Johnson, 1995). Older carers often feel anxious and uncertain about future support arrangements for the person for whom they care (Bowey & McGlaughlin, 2007). The sudden incapacity or death of the carer can result in a crisis response rather than a planned transition to a chosen sustainable alternative care arrangement for the person with disability (Bigby & Johnson, 1995).

Cummins *et al.* (2007) found that carers have the lowest wellbeing index score of any large group in Australia, reflecting the strain and challenge that carers face every day. The Australian Government's Discussion Paper on Succession Planning for Carers (2007) identified the following key barriers to planning which included:

- Families don't know where to start; who to go to; where to find information; or what to do.
- Future planning is a sensitive issue, challenging family assumptions and requiring people to face their own mortality and discuss personal issues and information.
- 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.

The Futures Planning Report (Cartwright *et al.*, 2011) recommended that families should be encouraged and supported to start the planning process whilst they are in good health and physically able to do so, and that the process should be ongoing throughout the life of the person

with disability. These recommendations were implemented in the Quality Living Project.

Methods

The project used Action Research methodology, which had proved suitable for the previous Futures Planning projects; this is a 'flexible spiral process which allows action (change improvement) and research (understanding, knowledge) to be achieved at the same time' (Costello, 2003). The processes employed here included information sessions, workshops and an intensive training programme. The participants were staff and clients of organisations associated with Mid Coast Communities. Invitations to participate were made by Mid Coast Communities through their email list and through newsletters. The only inclusion criteria was that the person cared for was at least 18 years of age and had a disability, as this was the focus of the research.

Information sessions

Two information sessions provided relevant information to people with (mostly intellectual) disabilities and their carers/families members and support staff; there were 25 participants. At each session, a brief overview was given of the work undertaken on the Futures Planning project and the aims of now developing a 10-Year Plan for people who have disability and their carers in order to enrich their lives by putting the steps in place to achieve their hopes and dreams.

Information was provided by professionals with the required expertise related to accommodation, financial and legal options and vocational and leisure activities, to assist participants to undertake the planning process and encourage quality living.

Workshops

Eight workshops, led by an experienced facilitator, were held across the NSW Mid North Coast. Separate workshops were held for people with disabilities, carers/family members and support staff who work with people with disabilities.

- People with disabilities ($n = 9$; 7 females, 2 males; 6 with an intellectual disability; age range 18–60). Workshops were held in three locations on the NSW Mid North Coast.
- Carer/family member ($n = 21$; 19 females, 2 males; 16 carers of a person with an intellectual disability; age range 30–70). Workshops were held in five locations on the NSW Mid North Coast. One session was held in an Aboriginal-specific organisation, and an additional informal session was held at a carers' respite retreat for Aboriginal Elders.
- Support Staff ($n = 19$; 16 females, 2 males). Workshops were held in two locations on the NSW Mid North Coast.

One session was held in an Aboriginal-specific organisation.

Participants were informed about the project in writing and verbally, including that: support was available during the workshops if required; information provided by individuals would be protected; and any reporting would be at a group level. Expedited ethics approval was obtained from Southern Cross University Ethics Committee.

At each workshop, participants were informed about the original Futures Planning project, given a copy of the 'Futures Plan' and 'Personal Portrait' documents and told that the project goal was to modify these tools to assist people with disabilities and their carers to set up a plan for the next 10 years, with a focus on quality living with security. They were given information about the aims, objectives and principles of the original project, guidelines for developing a new 10-Year vision and a Plan, and an explanation about issues to be considered, including the steps required to achieve participants' goals and dreams whilst ensuring that their wishes for the future are documented. In addition, four semi-structured questions were asked at each workshop, these were:

- Q1. What would you like (to do or experience) in the next 10 years and what would it take to do that? (Carers were asked to answer this in relation to themselves, not just for the person with disability).
- Q2. What do you think are the main issues in planning?
- Q3. What practical steps could be put in place to make it a reality?
- Q4. What support is needed to engage families in the planning process?

The questions were asked in a Focus Group format, with group discussion. For adults with intellectual disability, the facilitator used an informal conversational approach to ensure participants understood the questions and participated in the discussion.

With permission from participants, the sessions were digitally recorded and transcribed verbatim by a research assistant; two of the researchers read the transcripts, identified themes, compared their findings and reached consensus.

Drawing on the ideas and suggestions from participants, the 'Futures Planning' documents were modified to meet the aims of the Quality Living project, making them suitable for planning for quality living for the carer and the person with a disability for the next 10 years. (Note: Copies of the 'Futures Plan' and 'Personal Portrait', and the Quality Living Plan and amended Portrait are available at www.cartwrightconsultingaustralia.com.au, go to Resources.)

Training programme

Once the tools had been modified, the third phase of the project was a two-part Staff Training programme for those

who support people with disabilities and their carers across the Mid North Coast. Participants included were team leaders, case managers, coordinators, community support workers, programme coordinators and accommodation managers ($n = 28$).

The staff were given a brief overview of the previous Futures Planning projects and how the current *Quality Living* project builds on that work. Some of the main findings of the workshops were also presented to participants. Information was presented about why planning is important in a number of circumstances, including Advance Care Planning for end-of-life issues.

Guest speakers attended the first training session. Two were representatives from a service that assists people to strengthen and support personal relationships. They gave tips and strategies to help staff for when they are discussing sensitive issues with families. Another guest speaker was a 35-year-old woman who has cerebral palsy with quadriplegia. She told participants how she is achieving independence, her dreams and plans for her long-term security. Although she does not have an intellectual disability, her talk exemplified that it is possible for people with even severe disabilities to achieve their dreams, despite the challenges.

At the first session, participants worked through the Quality Living tools and suggested modifications, incorporating feedback from the Information Sessions and Workshops.

During the training, participants were given a copy of the Principles and Guidelines for Planning, developed for the previous Futures Planning projects (Cartwright & Gale, 2010; Cartwright *et al.*, 2008, 2011), to use when they are supporting families in developing their plans. The principles were both general (e.g., Emphasise people's own ability to bring about change; and Promote a positive attitude about the dignity, capacity and rights of all participants); and specific to carers (e.g., Focus on the strengths of the family, with recognition of the carer's experience and expertise); and the person with disability (e.g., Where appropriate, encourage and facilitate participation in the planning process by the person with disability).

Guidelines for Developing a Vision and a Plan were:

- 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 disability are to be included, as appropriate,
- The Plan should be realistic and achievable,
- Each Plan should be unique and reflect the needs and aspirations of the specific family (Ward, 2014).

Staff in the training were asked to complete a 10-Year Plan for themselves; they were asked to list the goals they would like to achieve in the next 2, 5 and 10 years. Participants next took part in an interactive session in pairs, role playing using the template of the modified Plan. One person took the role of the person with a disability and the

other took the role of the carer, then they reversed roles and finally gave feedback on the templates.

Participants were given 'their homework', to be completed in the 3 weeks between Training Session 1 and Training Session 2. They were asked to use the partially modified tools to commence working on a 10-Year Plan with a family that they knew well and with whom they had a good rapport to test how well the 'new' tools worked 'on the ground'. Participants were told that they would be asked to report on this process at the second training session.

Eighteen participants attended the second staff training session. Having now worked with the templates 'at the coalface', participants provided feedback on how well the template worked – or did not work – and recommended further modifications. When agreement was reached on these, they were incorporated into the final tools.

Outcomes

Summary of responses to the questions asked at the workshops and the ensuing discussion:

Key themes and priorities – people with disabilities

All the participants with a disability raised broadly similar issues. The participants spoke about people with disabilities wanting the same things as everybody else, such as friends, going to the movies, having a relationship. However, people with disability seem to miss out on relationships and physical touch and often feel lonely. The participants felt that the general attitude of society needs to change and that it needs to start at birth and continue in schools. To make friends, it was suggested joining community groups and activities as a way to meet people. Day programme activities can help a person with disability to gain confidence so they can talk to the people they meet.

I would like to make friends because I am naturally a shy person and don't tend to go up to people and say 'hello' randomly if I don't know them. I just feel uncomfortable about it.

It would be good to get into groups around town.

It is important to part of the local community beyond having mum or a support worker.

Many also said that they want to move into their own home.

Key themes and priorities – carers

When the carers of the people with disabilities were asked what they would like, many acknowledged that some of the things that stopped them from planning nice things for

themselves that would improve their quality of their life were: (i) that they are not used to thinking about themselves; and (ii) the challenging behaviours of those they care for, which makes it difficult for the carer to spend time on themselves.

We are not used to thinking about ourselves.

It is too hard. It is very important to think of both of us.

I've got think of my son; doing things for him. I want to put make-up on or get a haircut or go out to dinner with my husband; you can't because you have kids to think of first.

If you have someone to look after our kids, they muck up on them. My son would be ringing me every five minutes "when are you coming home, I don't like this person".

Some carers talked about how they would like to have a partner in their lives but how it is difficult for someone to come into their lives when a lot of their time is taken up caring. They feel other carers who are in the same situation would be more understanding.

It is hard when you are a carer to get a person in your life.

Who would want to come into a situation where you are virtually full time carers?

Others said that they would like to be able to travel, but they would need respite care and support from family and friends to be able to do that.

If you plan to go on a holiday overseas you have to have somebody that you know. There are respite care services, but they are only for several days, you don't go overseas for two or three days, you want at least a month or three weeks, so who looks after them; and there is nobody. I have often thought I would have liked to have been able to pay somebody to come to my home and live in my home and look after her for that time.

I have a niece in Sydney; her and my son grew up together and they are the same age. She takes him once, maybe twice a year if I want to go away. She is wonderful; they are more like brother and sister than niece and uncle.

Carer's dreams for those they care for: The dreams carers have for those they care for include the following: seeing them in their own home; not having to struggle; and to be part of the community.

I'd like to see my sons in their own accommodation and being able to have a decent sort of life without having to really struggle to survive; that is what I would really like.

That he gets his own place and is independent, and I don't worry about him.

They want to feel part of the community.

They have to find their own little niche.

Carers were also encouraged to 'be brave' where their dreams and goals for the person with disability were not the same as the person's own dreams and goals. They were advised of support services to assist them to deal with such issues.

Let's get away from keeping them in cottonwool and let's start letting them live life. That is an important part of planning too. It is not about getting your nose blown and your bum wiped; that is maintenance, that is not life.

Key themes and priorities – staff

Staff said that if they are supporting people with disabilities to achieve their hopes and dreams, there needs to be risk management strategies in place so that the person with disability (and/or their carer) understands the consequences of some activities.

If they choose to do a risky activity it is not fair that we say 'no you can't do that'. They need an understanding of what the difficulties would be if they did do that.

If they want to go bungy jumping, okay but if they did that it is going to affect this, this and this part of your health. This is why we discourage you from doing that. What else could we do that is different from bungy jumping that will give you the same sort of thrill?

(Other participant): They might love bungy jumping.

(First participant): But if it gives them high blood pressure or a heart attack they need to be aware that the reason we are stopping you from doing this is because if you did that it is going to affect this then you are going to be in hospital.

(Other participant): Or accept the risk and just do it, as we all do.

Staff acknowledged that many of their clients have lived with their disabilities all their lives, and they have adapted to it.

They know their own capabilities; we are only judging and guessing them.

Some staff reported that many families do not access services until they are ageing and realise they cannot continue to care for the person with disability.

They might have (recreational support service) or something like that. They are often not registered with (NSW Government Ageing, Disability and Home Care) and when they try to get registered they don't have all the evidence because the child is 50, they have grown up in the country, they have no evidence they have a disability. It is really difficult to get assistance for them.

This issue of 'unknown to the disability service system' was recognised in a submission to the Disability Care and Support Inquiry: Productivity Commission (Bigby, 2010).

Staff thought that the number of families without services will increase when the NDIS is implemented, especially if they are not happy with the current providers. The providers will start to outsource their services and the carers may choose to use family members or other people they know to assist them.

It is really difficult when people are out there who don't have services. I reckon there are more people out there without services than there are that have them.

Participants spoke of the value of the rapport that they have built with families and noted that it takes time to build a relationship that works well. They outlined the benefits of having planning meetings with all service providers at once.

It makes everyone work together and not be doing the same thing. It is going to make a difference. If you have five or six places in the one area doing exactly the same thing, I really don't think it is going to be productive.

Participants also suggested that counselling for carers would help them with transitioning and acceptance as the person they care for gains independence, as often the carer does not want to let go or is not ready to let go.

Another area discussed by staff was the value of utilising technology options and the availability of the internet. People with disabilities, as well as carers and staff, can use technology in numerous ways including, but not limited to, assisting with communication, mobility, monitoring health, recording client's information so that it can be accessed by all staff in different locations to improve the continuity of care, and for accessing unlimited knowledge and information. They noted that training needs to be provided for people with disabilities and their carers to be able to maximise the benefits of technology.

Recommendations for good practice

One carer said that people need to be proactive in finding information and services that can help. Family, friends and community members were recognised as being an important part of the future of the person with disability and would help to ensure that they do not have to rely solely on Government or other formal services. However, some participants said that they currently do not have a lot of support from family and friends and that they would need to take steps for that to happen.

I think the thing this has brought up is how important it is that our family, friends and community members are going to play such a big part in our children's futures, even if we don't have any support at the moment.

One family has formed a committee that includes siblings and cousins, to assist their daughter in decision-making. The family and their friends are identifying key people, whether it is a neighbour, another family member, family friend or siblings; they are meeting on a regular basis; it is not just the parents making decisions anymore, it is the person with the disability and their entire circle, so they are hearing a range of opinions before they make any decisions. Sanderson (2000) promotes this approach of including and involving family and friends as partners in planning. One carer noted:

Forward planning for when you are not there; who is going to help to make the decision and that is a hard one. . . . It is not just one of them saying 'I think you should do this' there will be four or five of them talking and getting a good outcome. They put their ideas together with her and talk it out with her and chose a course.

Staff commented that families need to have support so they can cope and have time to undertake the planning process. Carers also said that some days can be more challenging than others and they require understanding from service providers who are assisting them in the planning process if they cannot make an appointment or if they may not be in their best frame of mind on the day.

Other responses included the value of having trust and a good relationship with the staff and organisation and for the staff to inform the family of the purpose and process of planning; 'give them the heads up'.

Many families do not like to be asked the same questions over and over again. It was suggested that staff commence filling out the forms (e.g. the Quality Living Plan) from the information that they already have, then ask families to confirm that the answers are correct, for example details such as date of birth and address.

Carers agreed that a case worker can help them though the process but want a case worker who is consistent, who stays with the organisation and can work with the family for a length of time. They do not like it when staff change frequently. They acknowledged that each family situation can be messy, complex, unique and challenging.

Some staff approached families (to work on the Plan), but the family was not ready yet; however, they believed that they had 'planted the seed' which can be followed up at another time. Some families were at different stages in their lives and it was a priority for them (because of their age and poor health) to do the Futures Planning first and then the Quality Living 10-Year Plan at a later date.

Staff participating in the discussion agreed that good practice included identifying where each family is in relation to readiness for planning, and working at their pace, which may or may not result in the development of a Plan.

Conclusions

The evidence from this study suggests that people with intellectual disabilities and their carers, regardless of age, want to enjoy the same opportunities and experiences that many other people without disabilities get to enjoy, including relationships, to be able to work and to enjoy holidays. This was also reflected in comments from a participant who has a disability. She said that staff can help the person to achieve their dreams by having a positive attitude. Even if there are risks, as long as the person (or their carer) understands those risks and consents to go ahead anyway, then that is informed consent.

Don't say "you can't do it" because of the disability; say "you want to try it, give it a go and let's see what happens".

Robertson *et al.* (2007) note that having a person-centred plan can improve social networks, increase contact with family and friends, lead to increase in daily activities and greater community involvement and be a platform for making choices. These outcomes are more likely to be achievable with the commitment of a planning facilitator and the involvement of the person with a disability. The Quality Living 10-Year Plan can help people with disabilities and their carers to put Plans in place with steps and strategies to make their dreams an achievable reality.

Several authors have identified a range of person-centred planning styles and planning approaches, including for the person with a disability to have a planning support team (Coles & Short, 2008; Kilbane, 2004; Nicoll & Flood, 2005; Sanderson *et al.*, 2004). This approach had been adopted by one of the families in the current study, who had set up a committee of family members and friends to help the person with disability with decision-making. There can also be a flow-on effect from assisting a person with disability and their carer/family to undertake such planning, as they, in turn, may mentor and support other families in the process (Sanderson *et al.*, 2004).

This project has progressed the understanding of planning for people with disabilities and their carers and the Plan is now being used by more service providers as part of the Stronger Together two reform processes. However, more work/research needs to be done, including exploring what is needed to increase community awareness that each person, with or without disability, is a unique individual with their own unique characteristics, and not someone to be defined by their disability.

The final Plan covers many important practical aspects of life for people with intellectual and/or physical disability and their carers but also, their hopes and dreams. It outlines steps needed to achieve their goals, barriers they might need to overcome and who they could ask to assist them in the process. The Plan includes long-terms and short-term goals, with regular 'reporting stages' for both and instructions for

staff to help people with disabilities to think about the hopes and dreams they have described in relation to their abilities, strengths, preferences, limitations and challenges. It is particularly important that older people with an intellectual disability and their carers are informed and have considered their plans for current and future security.

As with the Futures Planning tools, the second part of the plan is a Personal Portrait of the person with disability. It is a written document that includes not just health and medical information but is designed to answer the question 'who is this person?' Topics covered include what the person likes to eat, to wear, what music they like, who their friends are and a range of other information 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. The Quality Living Portrait also includes information about mobility, communication, technology aids and religious/spiritual affiliation and practices. It is strongly recommended that the Plan and the Personal Portrait be reviewed regularly as circumstances and details about future needs and goals may change over time.

Whilst the Quality Living Plan is a useful tool, a written plan can only ever provide evidence of the person's wishes and dreams. It cannot, in and of itself, address the barriers people with disability face in achieving their dreams, but it provides carers and support staff with a tool to assist the person to take steps towards achieving their goals.

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