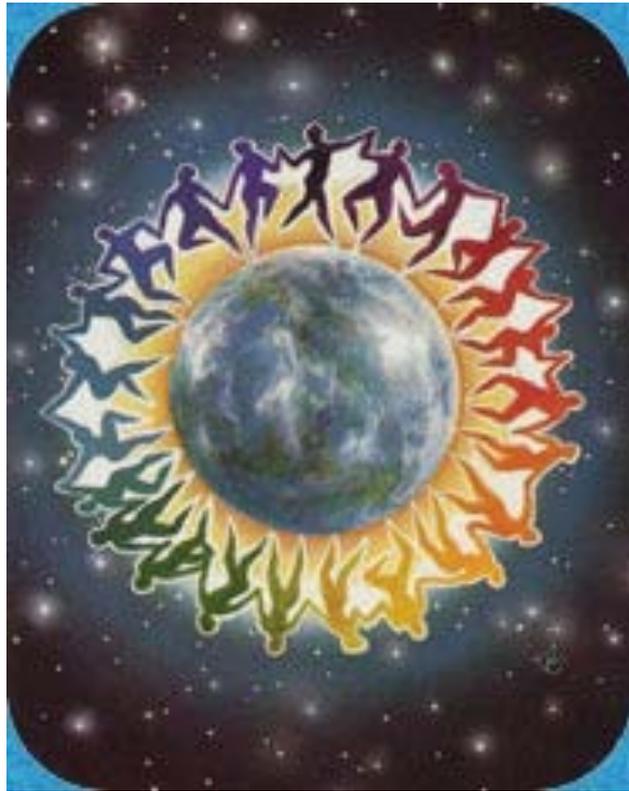


Workshop Six



Welcome Round:

Share how you are feeling today and something positive that has happened since we last met.

Review last session's work: Add any new information you learned from others that know and care about yourself or your family member with a disability

Writing the information into the Person Centred Lifestyle Plan template:

Now that you have thought about and made some notes on:

- What a good life looks like and have a positive vision for the future as well as a family culture statement
- Understand and can describe gifts and know where in the community these gifts can be received
- Who is in the person's life and who is important to be involved
- How the person communicates and makes decisions
- What's important to the person
- What good support looks like and what needs to be in place to ensure the person stays safe
- Characteristics of those that provide support
- A weekly timetable and budget
- What's working and what's not working
- Developed goals and an action plan of steps to achieving a good life

It's time to put it all into the plan. Hopefully you have started to do this along the way. You will have received the planning template, either via email, hard copy or downloaded from the Jeder Institute website; using the information gathered over the series of 6 workshops, decide what information is to be included in the plan.

The intention of the Person Centred Lifestyle Plan is for it to be the 'one' document or place (if you have done it via Power point, video or any other format) that all of the information about a person's lifestyle is held. You may have another space / folder that holds all medical information and another space / folder for financial matters.

From the Person Centred Lifestyle Plan a number of other pieces of information can be developed e.g. NDIS plan, One-page profiles for particular purposes, a public plan and a private plan.

We recommend that frameworks such as:

- Learning Logs, 4 + 1 Questions, Working / Not Working, Blue Sky Thinking, Good Day / Bad Day from ADHC, (2012). *Lifestyle Planning Policy* Version 1.1 Accommodation Support Directorate, Family & Community Services, ADHC - <http://www.adhc.nsw.gov.au>
- Solution Circles from www.inclusion.com
- Power of Ten from www.inclusionworks.org.au

Be used regularly to document learning, get creative with new ideas and work through issues. All learning from these practices need to be recorded in the Person Centred Lifestyle Plan; this can be done regularly i.e. monthly, or as life changes, as a minimum (especially for funding purposes) annually.

Self-Direction

The term 'self-direction' is being used a lot throughout the disability sector at the moment, but what does it really mean? We think it is also being confused with funding arrangements like self-managed and each state in Australia seems to have a slightly different interpretation, so the following definitions are an attempt to help to explain this a bit more:

- Direct payment:** Provision of a direct payment to a person with disability or his / her nominated person responsible, the person or the person responsible makes arrangement for support and is directly responsible to the funding body / government.
- Self-directed:** A person directing their own life free from external control and constraint. Directing the way they live their life, deciding on the journey, future goals, how and when to get there and when things change. Directing their own supports, how it is given and who is giving it. It has nothing to do with the way the funding.
- Self-managed funding:** The person with disabilities and/or nominated person responsible and significant other people manage all the aspects of the funding, and provide financial acquittals and reports directly to the funding body / government.
- Shared management:** This approach is based on an agreed sharing of supports / funding management responsibilities between the individual and/or their family and a Support Organisation.

State based Flexible funding programs, also referred to as direct payments, individual budgets, self-directed support, self-management, consumer-directed care, personal assistance, and individualized funding, have been promoted for a number of years throughout Australia, and reflect the continuation of international policy trends that have been operating in one form or another for at least the past fifty years. While these arrangements are not new, considerable interest has been placed over the years on specifying what self-management and flexible funding means to government, service structures and individuals.

We believe Self-directed support should be viewed as an option in which people with disabilities with the support of their families and their allies manage and direct their services and supports, with the opportunity also being provided for people to self-manage their funding package to design their own support requirements and purchase these in a way that suits them best.

The self managed approach under the NDIS provides the opportunity for people to have greater control over the recruitment, hiring and management of support staff & to use the funds flexibly to address other essential requirements. This approach recasts the person with disabilities from being a passive recipient of pre-purchased services, towards active citizenship where the person has the right to assert and exercise control over their supports and their own life. This has been seen as a progressive shift away from a 'professional gift model' towards a citizen-based approach, which is more in keeping with what is valued in most people's lives.

There are many examples of people self-managing their arrangements throughout Australia. The following diagram shows one example of the spectrum that self-management of funding covers: (Department of Communities, Child Safety & Disability Services 2013p9)

Spectrum of Self-Managed Support

A person can move across this spectrum depending on what they are comfortable doing, their previous experiences and current situation.

The person accepts full responsibility for the planning, budgeting and organising of their support. Funding is advanced to the persons bank account, usually on a monthly basis.

The person accepts most of the responsibilities for the planning and organising of their support. The remainder is purchased. Funding may be advanced, reimbursed or held by the service provider.

The person accepts some responsibility for the planning, budgeting and organising of their support. Additional support in these areas is purchased.

As a process, self-direction appears to have a number of common elements. These include specific budgets being attached to the individual, with these funds addressing support coordination, use of fiscal intermediaries, updating information technology, and adequate training being offered to ensure optimal benefits are experienced by the individual. The ability to use funds in flexible ways is critical in promoting true self-determination as well as achieving the impacts of effective implementation of self-directed services.

Adapted from References:

Department of Communities, Child Safety & Disability Services. 2013. *Your Life Your Choice: Self-Directed Support Framework*, [online]

<https://www.communities.qld.gov.au/resources/disability/key-projects/your-life-your-choice/ylyc-self-directed-support-framework.pdf>

Rees, K. 2012. "It's not just about the support: Exploring the ways in which family members and people with disabilities evaluate their self-directed / self-managed arrangements", commissioned by the Practical Design Fund, FaHCSIA, Canberra, ACT.

Succession planning

What needs to be done next? What happens when I am not around? These are questions that everyone asks from time to time. These questions also can lead to the beginnings of succession plans. However, thinking about what needs to be done when the primary carer is no longer around can be challenging to do. In some cases, people assume a family member will step in to provide support or management of supports. This process needs to be re-visited from time to time e.g. when family members change or acquire new partners, or as family members

themselves become ill or have to move interstate or overseas. Life changes – and we need to think about this within the succession planning processes.

As a family member of a person requiring extra support; one important element to consider is your will. You will need to find a solicitor who has a good appreciation for your situation & who is also mindful of the way you support the person with disabilities to live if you are not able to provide care & support, whether through your own ill-health or death. Finding a solicitor with this level of experience can make a great deal of difference in making sure yours will cover the requirements of the person with disabilities, as well as other beneficiaries you may have. This sort of solicitor may not be the solicitor you would usually go to e.g. when buying or selling your home, or for a very general will.

Another important person you will need to include in the succession process is your accountant. This person should also understand your financial wishes, as well as those of the person with disabilities. Some people can be supported to obtain a disability trust with the guidance of an accountant – and perhaps also the solicitor. Contacting an agency such as Pave the Way in Queensland, as well as local community services would be a good help.

You may also have to think about who will implement your instructions. This may or may not be people in your immediate family. They need to know where to find your will, what it contains (even roughly) & where to find the practical details associated with supporting the person with disabilities in their day-to-day life.

The following is an example of a succession plan & some of the components that had to be thought of to ensure the person with disabilities continues to enjoy a good life, regardless of whether the primary carer is around or not:

An example of a succession plan that I have in place covers what happens if I die before my daughter. I have had to think about this a lot, particularly when I realised that my assumption related to my adult children supporting the staff was proven to be way off track a few years ago. There were valid reasons for the way my other children think & believe – that is OK. However, I saw real problems for my daughter with disabilities if I simply assumed people would ‘do the right thing’ by her if something happens to me. To address this gap, I talked to some people who know me really well & also know my daughter really well. They agreed to be my administrators. This basically means that they would step in & make decisions about funding & keep my daughter’s life going in its usual calm way, regardless of whether I was there or not. They agreed to take on the foundation role, which is what I have been doing for many years – meaning that they are actively addressing issues in my daughter’s life but they are not going to be ‘in her face’ about it. My other children can make health decisions for me, if needed, but they don’t have to worry about their sister & what she needs over time. Doing this sort of back-up plan gave me time to think of all the safeguards that could be needed if I wasn’t around. This has now meant I can get on with my life, knowing that my daughter’s needs will be addressed the way that I would want – and not have her only option being an immediate move out of her home into a residential facility. I think that the time attending to the safeguards has been time well spent.

From The NDIS Grassroots Discussion Group on Facebook – written by Rose Quartz

When planning for the NDIS we need to bear in mind the wisdom of Rudyard Kipling when he wrote;

***“ I keep six honest serving men (They taught me all I knew);
Their names are What and Why and When and How and Where and Who.”***

**Question everything and while you are at it add these questions to keep planners from tangling
you in knots?**

“By whose authority?”

“Where is it written?”

“Compared to what?”

‘Who benefits?’

So when you are told, “No, that is not covered!”

Ask “By whose authority?” and “Where is that written?”

When you are told. “It is a great addition to the plan!”

Ask, “Compared to what?” and “Who benefits?”

Remember that the National Disability Insurance Scheme is about improving the lives of People with Disability and is about providing what is ‘necessary and reasonable.’ So if you ask for something and they say it is not reasonable, then ask “Compared to what?” And ask the planner for definitions. “Define reasonable?” “Define necessary?” Using some of these questions can be helpful to get a moment to gather your thoughts and to stop the pre-planned rote story that is being narrated by the planner. These questions will also give you pause for thought and consideration. Take you time and if you feel steam rolled at any point take a deep breath and use one of these questions to keep the planner from squishing you.

Self Care Activity (Daphne Hewson, 2011)

	Physically	Emotionally	Mentally	Spiritually
What currently energises me?				
What saps my energy?				
What would help to energise me more?				
What holds me back from doing the things that would help to energise me more?				
What values/principles do I want to live by?				

Some examples that you might enter into each column:

Physical energy: Eating; Drinking; Sleeping; Exercise; Breaks; Relaxation

Emotional energy: Relationships; Intimacy; Empathy; Processing Emotions; Balance; Safety; Down-time

Mental energy: Time management; Creativity; Thinking skills; Challenge; Mental preparation; Reflection

Spiritual energy: Commitment; enthusiasm; Values; A deeper purpose; Prayer/meditation; Giving to others; Nature; Stillness

Resilience:

Resilience - what an interesting term! Do we even think about our levels of resilience when exhausting situations are occurring on a daily basis or you feel you live in a continual blender of crisis & mayhem? Or when life is on track & things are going really well for our family member with a disability as well as for our family in general? Resilience is probably something we take for granted in many ways, but is something that is incredibly important in people's lives. Resilience includes those resources we can call on in challenging & stressful times, or when we are learning new skills or need to remain positive. Resilience has often been described as the ability to 'bounce back' when adversity strikes, or the ability to turn adversity into an advantage or new opportunity. We actually need resilience to manage everyday pressures as well as thrive in a positive & sustainable way.

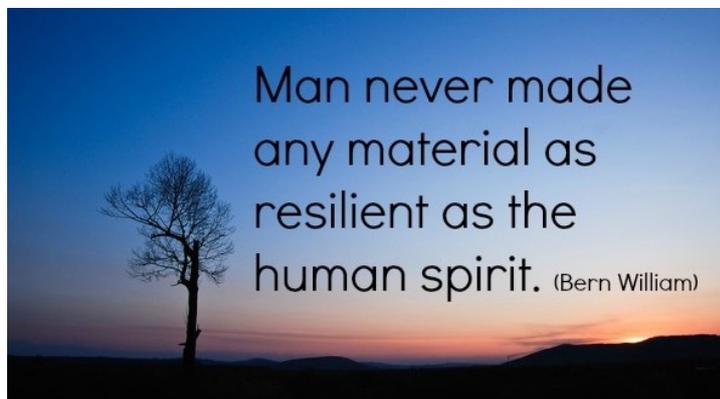
The following are some thoughts about enhancing your own personal resilience. No doubt there is many others, but here is a start:

- ❖ **Do things that you enjoy.** Find things that help you to be re-vitalised & to feel good about yourself – and then do them on a regular basis.
- ❖ **Develop your self-awareness.** Consider the role of reflection when you are learning, as this will help you to gain some new perspectives about things that you may not have considered before, or to think of new ways when you thought you knew all there was to know. Look back through memorable & challenging experiences (positive & negative) & look at what you have learned over time.
- ❖ **Get plenty of sleep.** Sounds obvious, doesn't it? But when you are stressed, it is very easy to neglect your own needs. When you lose your appetite, don't get out in nature or exercise very much, or don't get regular sleep, your ability to navigate through crisis can be compromised. By taking care of your own health & wellbeing needs, you can boost your own resilience levels & become more able to face life's challenges.
- ❖ **Embrace change.** Being flexible & adaptable to the changes that occur throughout life is an essential component of being resilient. Sometimes getting out of your comfort zone through doing things differently (even travelling to the same place via different roads every time) can help you to look at different & challenging situations as an opportunity to do some things differently.
- ❖ **Develop your own problem solving abilities.** Everyone has these abilities, but sometimes it is more about how we perceive problems & situations that can show how resilient we are – or not. Think about taking a step back, consider how you approach difficult issues, whether you are logical in the way you consider your responses or whether your judgement is continually clouded by emotional responses or irrational thinking. Perhaps there are other ways to look at the situation – if you did, what other possibilities might there be?
- ❖ **Find your own sense of purpose in life.** Often, resilient people find that having some structure, meaning & commitment in their life helps them to assess situations within a framework that includes the 'bigger picture'.
- ❖ **Become a dedicated 'lifelong learner'.** Learning new skills, gaining understanding in different ways, all help to build your resilience levels & help you to adapt through times of change. Sometimes you have to face the fact that the old ways you do things actually don't work the same way that they always did – so now might be a good idea to start learning & practicing some new skills.

- ❖ **Develop a strong network.** Whether you are a man or a woman, having supportive & caring people around you can really help when you are in crisis. These people must be individuals you can trust & can easily confide in. True, the crisis or trouble won't go away as if by magic, but by sharing your feelings, hearing yourself talk about the issue & getting feedback can help you to find possible solutions to your issues.
- ❖ **Build positive beliefs in your abilities.** Remind yourself of your strengths & accomplishments – these all help you to have a good self-esteem. If your self-esteem is sound, you will find that your ability to cope with stress & subsequently recovering from stressful events can be important components that build your resilience.
- ❖ **Be optimistic.** Yes, this can be difficult, especially when you are in the middle of a crisis or a difficult challenge, but maintaining a positive outlook is an important aspect of resiliency. One way to do this is to maintain a 'gratitude journal' where you record the things that you are grateful for every day. The reality is that difficult times are transient & ebb & flow through our lives, but remaining positive & grateful about today as well as the possibility of a brighter future is what helps our resilience as well.
- ❖ **Establish goals & take steps to solve problems.** Every crisis is daunting & you can feel overwhelmed about your ability to cope. When these times occur, resilient people find they can view these situations in a realistic way, then set some reasonable goals to deal with the problem before taking small steps towards solving the problem.

References:

Zolli, A. & Healy, A. 2012. *Resilience: Why things bounce back*, Headline Business Plus, London, UK.



What's next:

Share and discuss with the group what you have learned while developing a Person Centred Lifestyle Plan for your family member.

Discuss and decide the future of the group:-

- Are you interested in continuing to meet?
- What things would you like to do to support sharing and learning together?
- How often would you like to meet with others?
- Where would you like to meet?
- Who will coordinate the group?

Ten Principles to Live by in Fiercely Complex Times - Tony Schwartz

<http://blogs.hbr.org/2011/07/ten-principles-for-living-in-f/>

Here are ten that work for me:

- 1. Always challenge certainty, especially your own.** When you think you're undeniably right, ask yourself "What might I be missing here?" If we could truly figure it all out, what else would there be left to do?
- 2. Excellence is an unrelenting struggle, but it's also the surest route to enduring satisfaction.** Amy Chua, the over-the-top "[Tiger Mother](#)," was right that there's no shortcut to excellence. Getting there requires practicing deliberately, delaying gratification, and forever challenging your current comfort zone.
- 3. Emotions are contagious, so it pays to know what you're feeling.** Think of the best boss you ever had. How did he or she make you feel? That's the way you want to make others feel.
- 4. When in doubt, ask yourself, "How would I behave here at my best?"** We know instinctively what it means to do the right thing, even when we're inclined to do the opposite. If you find it impossible, in a challenging moment, to envision how you'd behave at your best, try imagining how someone you admire would respond.
- 5. If you do what you love, the money may or may not follow, but you'll love what you do.** It's magical thinking to assume you'll be rewarded with riches for following your heart. What it will give you is a richer life. If material riches don't follow, and you decide they're important, there's always time for Plan B.
- 6. You need less than you think you do.** All your life, you've been led to believe that more is better, and that whatever you have isn't enough. It's a prescription for disappointment. Instead ask yourself this: How much of what you already have truly adds value in your life? What could you do without?
- 7. Accept yourself exactly as you are but never stop trying to learn and grow.** One without the other just doesn't cut it. The first, by itself, leads to complacency, the second to self-flagellation. The paradoxical trick is to embrace these opposites, using self-acceptance as an antidote to fear and as a cushion in the face of setbacks.
- 8. Meaning isn't something you discover, it's something you create, one step at a time.** Meaning is derived from finding a way to express your unique skills and passion in the service of something larger than yourself. Figuring out how best to contribute is a lifelong challenge, reborn every day.
- 9. You can't change what you don't notice and not noticing won't make it go away.** Each of us has an infinite capacity for self-deception. To avoid pain, we rationalize, minimize, deny, and go numb. The antidote is the willingness to look at yourself with unsparing honesty, and to hold yourself accountable to the person you want to be.
- 10. When in doubt, take responsibility.** It's called being a true adult.

