Workshop
Two

Welcome Round:
Share something positive about yourself or your family member with a disability 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

The 5 Valued Experiences gives us a language to discuss a person's development and focuses our attention on the quality of a person's experiences. It results in a shared sense of direction and priority which guides the selection of personal and service objectives and activities, forms the essential link between plans and action and provides the means for regular follow-up and revision. It provides a way to get things done.

Those who make important decisions about another person's future need a useful vocabulary for discussing the effects of their decisions on the quality of that person's life experiences. The 5 valued experiences are helpful in describing a person's situation, identifying opportunities for improvement, and evaluating the merit of proposed activities.

Five related terms define this way to look at the quality of a person's life experiences. Each points to experiences that make sense for a person to seek more of; together they indicate a balance of experiences that make effort worthwhile. History shows that people with severe disabilities are likely to miss these ordinary positive experiences unless the people they rely on work hard to provide them. These valuable experiences come from cooperation between individuals and their allies. They bring out the quality of all people's lives because they are the result of personal investment, focused attention and learning through action; they cannot be manufactured through a mechanical process. (O'Brien 2002)

Everyone's world grows richer and more interesting when people have more opportunities for these valued experiences.

Belonging: Being a member of a group or an association or a congregation; being a friend; being a family member; being a partner. Having a variety of relationships and memberships including associations with both people with disabilities and people without disabilities, both paid, staff, volunteers and other citizens.

Being respected: Being seen and treated with dignity; being seen and treated as a whole person; being seen and treated in ways that honour the best in your culture; being seen and treated as a person with rights; being seen and treated in ways that fit your age.

Sharing ordinary places: Making the same use of community settings as any other citizen does, at the same times and for the same purposes as other citizens do: living, working, learning, and playing confidently in ordinary places.

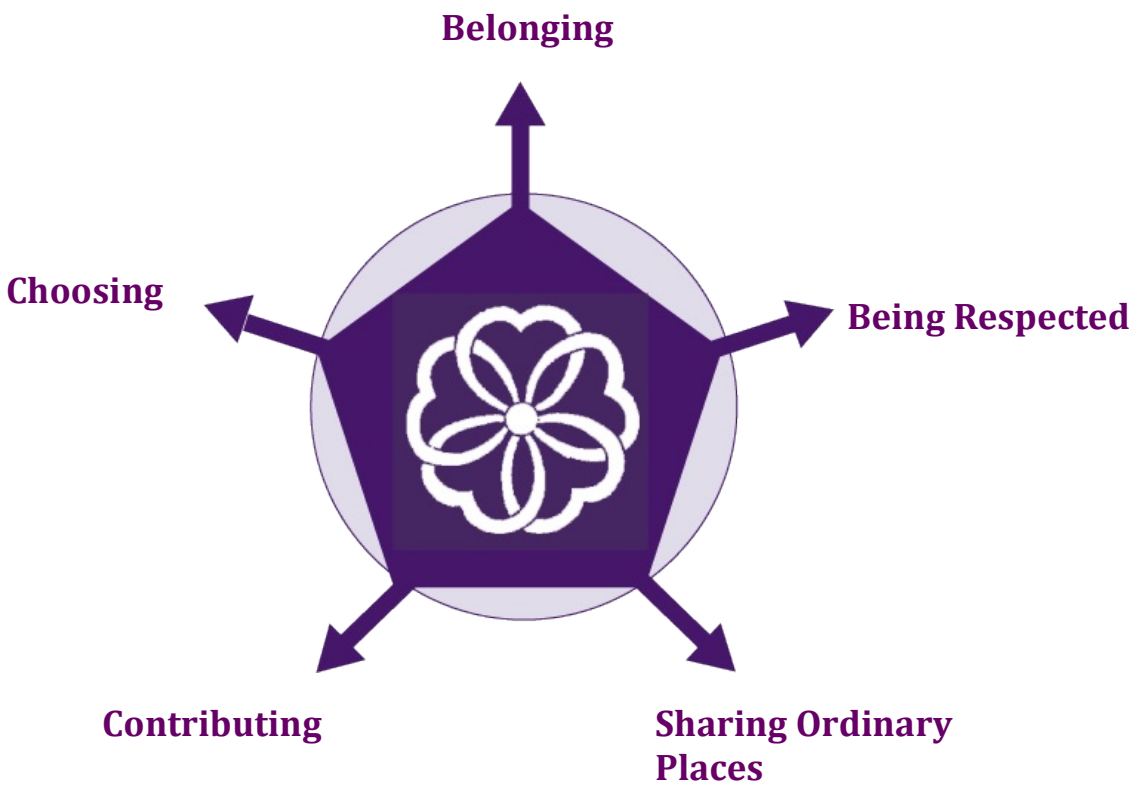
Contributing: Making a positive difference to other people, to community groups, and to the community at large by discovering, developing, and giving individual gifts and using personal

capacities. There are gifts of being and gifts of doing: contributions can include interested presence as well as capable performance; in some situations simply being present and involved makes a real difference. Contributions can be freely given or earn pay.

Choosing: Having the freedom and support and assistance to make the same sorts of choices as other people of your age and to learn to make wiser choices over time. As an adult, making big decisions (such as where and with whom to live and work) and smaller decisions (like what to eat and when to go to bed). At any age, being encouraged to use and strengthen your voice (in what ever way works for you to communicate), to clarify what really matters to you, to make thoughtful decisions, and to learn from experience.

O'Brien, J. & Lyle O'Brien, C. (2002, 3rd Printing). *A little book about Person Centred Planning* Inclusion Press

Activity: Identify ***where and how***, in your life or your son / daughter / family member with a disability, do these 5 Valued Experiences show up, right now.
Then identify where and how you would like them to show up in the future. Put a box or circle around the dreams for the future.



Think of one action, that you could do now, that would increase the opportunities for these Valued Experiences in your life or the life of your son / daughter.

Describe the goal –

What action needs to be taken	Who	When

Developing a vision & values statement

Why would we do this? Surely that sounds like something people do in business or in the organisations that support people with disabilities? While you would be absolutely correct in thinking this, family members & people with disabilities have sometimes found that this sort of approach can really help them within their daily lives.

A **vision** is a dream or hope of some future state that we may achieve. It is the 'big picture' & answers questions such as:

- What is our long term goal or aspiration?
- How do we see our situation in 2 years' time? 5 years' time?
- What is our ideal future state?

A **value** is a belief or conviction that affects the way we behave.

- Developing values statement helps to ensure clarity about what is important to the family and/or the person with disabilities. The truth is that not everyone has the same values, which means that if we don't identify these in the first, people can assume things that may not be correct or lead to other problems at a future time.

See page 24 – 26 for a way to work out what your values are right now.

When you have written down what your beliefs & values are, you should be able to say:
'This is what we are on about. This underpins everything we do. We can see this is reflected in all that we do.'
This is the sort of statement that everyone who supports you should be able to identify with as well. Over time, you will be able to review these statements to see if they are still current & reflect where you are up to in life now.

The following is an example of these statements:

VISION STATEMENT

Our vision is that Jenny is continually enabled, in every possible way, to live a lifestyle she chooses, is used to and entitled to.

OUR VALUES

Our values focus on Jennie with a particular emphasis on:

- Her right to make her own decisions in relation to her life and lifestyle
- The continual provision of support which enhances her quality of life
- Her right to experience risk, within an environment that ensures that her safety is also safeguarded
- Ensuring that her personal dignity is respected at all times
- Jenny is accorded the same respect as any other person of her age in her community
- Jenny has valued roles within her community and social networks
- Being able to respond to Jenny's changing needs, and plan for these changes where possible in advance
- Being able to continually encourage innovation and diligence amongst Jenny's supporters & to provide appropriate recognition of the important role of these people in Jenny's life

Reference:

Davis-Meehan, E. undated. *The Power of Positive Planning: A Strategic Planning Kit for Even Better Service Delivery,* Cooks Hill, NSW.

Activity: A Quick Look at Your Values
Russ Harris: The Happiness Trap (2010)

Values are your heart's deepest desires for how you want to behave as a human being.

Values are not about what you want to get or achieve; they are about how you want to behave or act on an ongoing basis.

There are literally hundreds of different values, but below you'll find a list of the most common ones. Probably, not all of them will be relevant to you. Keep in mind there are no such things as 'right values' or 'wrong values'. It's a bit like our taste in pizzas. If you prefer ham and pineapple but I prefer salami and olives, that doesn't mean that my taste in pizzas is *right* and yours is *wrong.* It just means we have different tastes. And similarly, we may have different values.

So read through the list below and write a letter next to each value: V = Very important, Q = Quite important, and N = Not so important; and make sure to score *at least ten* of them as Very important.

1. Acceptance: to be open to and accepting of myself, others, life etc
2. Adventure: to be adventurous; to actively seek, create, or explore novel or stimulating experiences
3. Assertiveness: to respectfully stand up for my rights and request what I want

4. Authenticity: to be authentic, genuine, real; to be true to myself
5. Beauty: to appreciate, create, nurture or cultivate beauty in myself, others, the environment etc
6. Caring: to be caring towards myself, others, the environment etc
7. Challenge: to keep challenging myself to grow, learn, improve
8. Compassion: to act with kindness towards those who are suffering
9. Connection: to engage fully in whatever I am doing, and be fully present with others
10. Contribution: to contribute, help, assist, or make a positive difference to myself or others
11. Conformity: to be respectful and obedient of rules and obligations
12. Cooperation: to be cooperative and collaborative with others
13. Courage: to be courageous or brave; to persist in the face of fear, threat, or difficulty
14. Creativity: to be creative or innovative
15. Curiosity: to be curious, open-minded and interested; to explore and discover
16. Encouragement: to encourage and reward behaviour that I value in myself or others
17. Equality: to treat others as equal to myself, and vice-versa
18. Excitement: to seek, create and engage in activities that are exciting, stimulating or thrilling
19. Fairness: to be fair to myself or others
20. Fitness: to maintain or improve my fitness; to look after my physical and mental health and wellbeing
21. Flexibility: to adjust and adapt readily to changing circumstances
22. Freedom: to live freely; to choose how I live and behave, or help others do likewise
23. Friendliness: to be friendly, companionable, or agreeable towards others
24. Forgiveness: to be forgiving towards myself or others
25. Fun: to be fun-loving; to seek, create, and engage in fun-filled activities
26. Generosity: to be generous, sharing and giving, to myself or others
27. Gratitude: to be grateful for and appreciative of the positive aspects of myself, others and life
28. Honesty: to be honest, truthful, and sincere with myself and others
29. Humour: to see and appreciate the humorous side of life
30. Humility: to be humble or modest; to let my achievements speak for themselves
31. Industry: to be industrious, hard-working, dedicated
32. Independence: to be self-supportive, and choose my own way of doing things
33. Intimacy: to open up, reveal, and share myself -- emotionally or physically – in my close personal relationships
34. Justice: to uphold justice and fairness
35. Kindness: to be kind, compassionate, considerate, nurturing or caring towards myself or others
36. Love: to act lovingly or affectionately towards myself or others
37. Mindfulness: to be conscious of, open to, and curious about my here-and-now experience
38. Order: to be orderly and organized
39. Open-mindedness: to think things through, see things from other's points of view, and weigh evidence fairly
40. Patience: to wait calmly for what I want
41. Persistence: to continue resolutely, despite problems or difficulties
42. Pleasure: to create and give pleasure to myself or others
43. Power: to strongly influence or wield authority over others, e.g. taking charge, leading, organizing
44. Reciprocity: to build relationships in which there is a fair balance of giving and taking
45. Respect: to be respectful towards myself or others; to be polite, considerate and show positive regard
46. Responsibility: to be responsible and accountable for my actions
47. Romance: to be romantic; to display and express love or strong affection

48. Safety: to secure, protect, or ensure safety of myself or others
49. Self-awareness: to be aware of my own thoughts, feelings and actions
50. Self-care: to look after my health and wellbeing, and get my needs met
51. Self-development: to keep growing, advancing or improving in knowledge, skills, character, or life experience
52. Self-control: to act in accordance with my own ideals
53. Sensuality: to create, explore and enjoy experiences that stimulate the five senses
54. Sexuality: to explore or express my sexuality
55. Spirituality: to connect with things bigger than myself
56. Skilfulness: to continually practice and improve my skills, and apply myself fully when using them
57. Supportiveness: to be supportive, helpful, encouraging, and available to myself or others
58. Trust: to be trustworthy; to be loyal, faithful, sincere, and reliable
59. Insert your own unlisted value here:
60. Insert your own unlisted value here:

Once you've marked each value as V, Q, N (Very, Quite, or Not so important), go through all the Vs, and select out the top six that are most important to you.

Mark each one with a 6, to show it's in your top six. Finally, write those six values out below, to remind yourself this is what you want to stand for as a human being.

Activity: Using the 5 Valued Experiences as a guide for your vision statement and the above values activity as a guide to your values statement. Develop your own / your son / daughter with a disabilities Vision and Values Statement.

Communication Expressive – What am I communicating to you?
ADHC, (2012). *Lifestyle Planning Policy* Version 1.1 Accommodation Support Directorate, Family & Community Services, ADHC - http://www.adhc.nsw.gov.au/publications/policies/policies_a-z/?result_237652_result_page=L

The 'What am I communicating to you?' chart helps us understand what the person with a disability is trying to tell us when their speech is unclear, or they don't use words to communicate so they communicate more clearly with their behaviour, or when what they say is not necessarily what they mean. The 'What am I Communicating to you?' chart should help any new person – in the person's life- to get off to a good start getting to know the person.

The chart is not just for people who don't use words to communicate, although they are certainly very powerful for these people. Many people who have been involved with services for a long time have learnt to say what they think people want to hear rather than what they really mean. Also, sometimes people say one thing, but mean something completely different – do you ever say 'I'm fine thanks', even when you're having a terrible day? When you do this other people in your life who know you well would pay attention to your non-verbal communication and understand that you are not okay.

Capturing how someone communicates and using this information also helps relieve the frustration felt by the person when they are not understood. It also makes it easier for new people in the person's life to get to know and understand them.
When the person has only a handful of ways of communicating to others, this may need to be recorded multiple times, using the first column to clarify how different situations or different times of day may change the meanings of the person's actions.

When people are struggling to understand how someone is communicating, referrals are often made to speech pathologists or behaviour clinicians. We can start to record what we know and act on it while waiting for the specialist support. This will ensure a wealth of information for the specialist to build on, and hopefully far less frustration for the person early on.

Tips:

- Start with what the person does, or what you think the person is trying to tell you, and then fill in the other columns.
- Pay attention to recording detail as this could have a big role in whether people provide consistent responses to the person.
- You could also use photos or video to capture this information, especially if what the person does is difficult to describe in words.

When this is happening (or just happened)	The person does this	We think it means	And we should
The music is on playing a happy song	Screams loudly	Jenny is happy and likes this song	Sing & dance with her, enjoy the music
Has been sitting on the floor for more than 40 minutes	Screams loudly	Jenny is in pain, her back is hurting	Help Jenny move to the lounge or her wheelchair where she has back support

You can also complete a communication chart for yourself and reflect on how you communicate when you are in different moods. For example, when you are happy, when you really like a person, when perhaps you don't like a person, when you are angry or frustrated, when you are sad, when you are stressed. How do your moods affect you in your day? Your self-awareness about your own communication patterns may provide insights that can help you be effective when interacting with other people.

Activity: Complete an expressive communication chart for yourself or your family member / friend with a disability

When this is happening (or just happened)	The person does this	We think it means	And we should

Communication Receptive – What are you communicating to me?
Receptive communication charts are for when we need to help the people understand something.

These communication charts are helpful when:

- A person finds it hard to understand information when it is just given in words.
- Particular words or ways of saying things, can be a trigger to make a person upset.

These communication charts help us to make sure a person is always told things in the way that helps them understand best.

Communication charts work best when they are kept somewhere easy for people to find and use, when people check them regularly, make necessary changes and add new things that they have learned.

When capturing how best to communicate with someone think about the following:-

- Do real objects, object symbols or pictures help the person's understanding?
- Do you need to give the person time to process what you are telling them? How long?

Are there phrases or words that you should avoid with the person? If so what other words or actions help communicate the same message? For example, using any negative language like no, stop or don't, doesn't work well for the person. Instead, people needed to find a phrase that communicated what they wanted the person to do. For example, "John, please move away from the water," rather than "John, don't get in the water!"

Tips:

- Start with what you need to let the person know and the detail of how to do this, i.e. words and actions, and then fill in the other columns.
- Pay attention to recording detail as this could have a big role in whether people provide consistent responses to the person.
- You could also use photos or video to capture this information, especially if how the communication happens is difficult to describe in words.

At this time	We need to let the person know	To do this	Helped or supported by
Immediately before going shopping	That we are going shopping	Show Jenny a Woolies bag (the one with the logo on it)	Give it to her to touch, when she smiles and laughs it means ready to go NOW! Don't make her wait.

Activity: Complete a receptive communication chart for yourself or your family member / friend with a disability.

At this time	We need to let the person know	To do this	Helped or supported by

Decision Making Profile:

ADHC, (2012). *Lifestyle Planning Policy* Version 1.1 Accommodation Support Directorate, Family & Community Services, ADHC - http://www.adhc.nsw.gov.au/publications/policies/policies_a-z/?result_237652_result_page=L

Decision Making Profiles and Decision Making Agreements look at what support someone needs to make decisions in their life, and ensures that they have as much power and control as possible in how these decisions are made. For most of us to make good decisions in our lives, we require support from others. This could be asking what family or friends have done in similar situations, or if they have information that may help us, it could be talking through the pros and cons, or hopes and fears. Very few people are 100% independent when making decisions, and very few people (if anyone) get all their decisions right all the time. For people to be their own unique selves, they must have the opportunity to exercise their rights and make choices about how they want to live. To begin with, we must learn how the person can best be supported to make their own choices.

Decision Making Profiles create a record of:

- How the person likes their information
- How to present choice
- How to help the person to understand
- The best times to make a decision
- When is not a good time to make a decision

How the person likes their information	How to present choice	How to help the person to understand	The best times to make a decision	When is not a good time to make a decision
Written down Pictures Objects	Take plenty of time Sit down with her in a quiet space and present just a 2 options at a time	Show me the pictures / object at the same time as telling me about it Give her time to process	When things are quiet When she is calm and rested	When she is hungry When she is over tired

Activity: Complete a Decision Making Profile for yourself or your family member / friend with a disability.

How the person likes their information	How to present choice	How to help the person to understand	The best times to make a decision	When is not a good time to make a decision

Important Decisions to be made:

For many people with disabilities, even small daily decisions may be made for them, so their experience of choosing may be very limited.

To begin to address this:
- List the important decisions in the person's life.
- Discuss and then record how the person must be involved.
- Discuss and record who makes the final decision.

Over time, the number and significance of decisions the person makes themselves should begin to increase. When people struggle to interpret the person's communication, as a minimum people should use communication charts to pay attention to what the person is 'saying' with their behaviour and what is working or not working about the situation or the decisions that are being made. A best guess of what's working or not working from different perspectives is a better way of involving the person than not involving them at all. (See working / not working framework on day 4) When people have a history of making decisions that challenge others or contradict what keeps them healthy, safe or valued, a lot of negotiation may be required if the person is to agree to others being listed as making the final decision. Remember there is no point recording things that the person does not agree with and will not follow through with. Most of us are particular about who we take or seek advice from, sometimes looking at who best supports the person to make decisions may be helpful.

Important decisions to be made	How the person must be involved	Who makes the final decision
What clothes to wear and food to eat for the day	Show Jenny a number of appropriate options E.g to suit weather, activity or time of day	Jenny
Medication levels	Discuss with Jenny in the room ask yes / no questions to get opinion	Doctors in consultation with Jenny
Who Jenny spends her time with	Show Jenny photos ask her simple yes / no questions or use photos she can point to	Jenny
Where Jenny lives and who with	Show Jenny options, must visit, look around and experience options. Then confirm with yes / no questions and photos she can point to.	Jenny in consultation with her parents

Activity: Complete an important decisions to be made chart for yourself or your family member / friend with a disability.

Important decisions to be made	How the person must be involved	Who makes the final decision

Things to think about and do until we meet again next month:

1. Share with the person with a disability and others that know and care about them, the 5 Valued Experiences, Vision & Values Statement, Communication and Decisions Making charts - get feedback and contribution.