PEARLS OF WISDOM

Self-direction – the opportunity for a better life!

Powerpoint Presentation

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The Alliance for Self-Direction

The Alliance for Self-Direction consists of:

- Pearl Lifestyle Services
- Staffing OptionS
- Elements Lifestyle Support Association
- Mamre Association
- Pathways to Leadership

Self – Direction versus Self-Management

Self – Direction

Describes a person who routinely makes the vast majority of key decisions so that he/she considers him/herself to be fully in control of the support he/she receives

Self – Management

Describes a person who is responsible for the management and administration involved in funded support

Why self-direct?

- Personal autonomy and natural authority
- Gives people choice, control and flexibility
- It is a common sense approach - who should be making decisions in a person's life – the person themselves or those closest to them who know them best
- Opens up opportunities to take a normal pathway in life rather than the 'special' pathway that can lead to congregated, segregated and isolated lives.
- The person is central to every decision- the term "person centered" becomes irrelevant because it is **all** about achieving the best possible life for the person

Why self-manage?

- Empowerment - taking on responsibility shifts the power
- Cuts out the middle man
- Ease of communication with staff
- Flexibility
- Control
- Diminishes bureaucracy
- Ability to set up individualised arrangements

The elements of successful self-direction

- Expanding the boundaries of thinking beyond traditionally held views
- A clearly articulated vision
- Intentional planning around what the person wants in their life and then tailoring the supports they need to achieve their goals

- Putting plans into action with ongoing support (practical & financial)
- Supportive allies
- Information and knowledge
- Flexible & sustainable systems
- A belief that people with disability and their families can take responsibility for their own lives

What is the starting point?

A different question:

"What needs do you have and what programs/services would make life easier/better"

vs

"How do you want to live your life?"

Expanding the boundaries of thinking

- Answering this question involves expanding the boundaries of thinking around what is possible for people with a disability and how they can/should fit into their world.
- We need to challenge our views about what can be aspired to and achieved - we need to "imagine better"
- This involves dreaming big dreams and having hope rather than fitting peoples' lives into what is offered or available
- People often need to be supported and encouraged to expand their thinking and to take calculated risks.

NDIS – the role of the planner

"The planner will discuss with the participant their **needs**, **goals** and **aspirations**..... to enable **a good life**"

"Planning conversations (will be) conducted in a positive and constructive manner that allows freedom to explore choices for the participant and their family."

What is this good life?

People want to be healthy, happy and safe:

- **A home** of one's choice – what type, where, with whom
- **Relationships** – freely given/reciprocal
- **Doing something productive** – for most people this is work which often defines their identity
- **Helping others**/making a contribution
- **Leisure activities** of their choice that they enjoy
- Enough **financial resources** to live the life they choose

Why should these things be any different for people with a disability?

The role of planning

- People need to be clear and specific about **what they want** and just as importantly **what they don't want** in your life before they can work out the steps to achieve what they want.
- Start with **the person** – their interests, skills, passions, beliefs, culture
- An ongoing process

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Focus of planning

Maybe the focus for the NDIS planning should be:

Aspirations → Goals → Needs

The role of funding

- Having a vision and planning to make this a reality is not about funding – having funding doesn't in itself equate to having a good life because as Michael Kendrick says "Money doesn't think!"
- The important thing is how the funding is used.
- Once people know what they want to achieve, then they need to think about using funding in the best possible way to achieve their vision and goals.
- Often this happens the other way around – people start with the service/support that is offered and then try to make this fit their lives.

What is involved in planning?

- The role of **dreaming** to expand horizons
- **HOPE** – **H**elping **O**ther **P**ossibilities **E**merge
- The power of having high expectations
- Taking calculated **risks**
- Listen to inspiring stories & talk to positive people
- People need help to think more broadly of what is possible before they start thinking of the $ required
- Plan around life's stages as we all do
- Be creative and innovative

Thinking differently about supports and services

- As consumers, people will have the ability to choose what they purchase and from where.
- People need to be really clear what support they require and start thinking more broadly about how to achieve this.
- They will have the opportunity to think outside the traditional disability support systems & 'programs' – they can decide what support they need to live a typical life in community

Support for what?

Eg.

- Developing skills
- Building knowledge
- Domestic support
- Support for daily living tasks –developing a person's capacity to do things for themselves rather than doing things for them

- Support for leisure activities– fitting with the person's interests/age/gender? Where do these things happen in community?
- Support to work/volunteer/run a business
- Communication
- Personal care
- Specialist support – e.g. therapy
- Developing interests/hobbies
- Building relationships
- Becoming involved in community life
- Developing a social life

A typical life

- We have been planning for our son to live an independent, fulfilling adult life for the past 10 years.
- Our vision for him is based on looking at what other young men of his age are doing:

e.g. Study
Work
Friends
Social activities
Community involvement
Relationships

- We now look for the **ordinary** when deciding what support is needed. We are constantly working towards an **inclusive** rather than a segregated, congregated or 'special' life.

What it takes

However, as someone once said, to make the 'ordinary' happen requires extra-ordinary effort.

- For our family, this means:
- Ongoing commitment
- Continually looking for ways to improve things
- Being willing to take calculated risks
- Letting go
- Thinking outside the square
- Learning from others
- Being prepared for the set backs & getting up again
- Seeking out and accepting informal support

However, the effort is well worth it!
We are now being proactive rather than reactive.

The Power of Expectations

We realised that if we allowed ourselves to narrow the boundaries of what was possible – these would be the limits of what our son would achieve.
So …. we set about lifting the bar much higher !! And …. he has surpassed our expectations!

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Living a valued life in community

- Contributing
- Being respected
- Sharing ordinary places
- Choosing
- Belonging
- Having a valued role

Developing a valued role

- Family member
- Businessman
- Volunteer
- Provider of service
- Student
- Friend
- Home maker
- Neighbour
- Host
- Community member
- Helper/contributor
- Sportsman
- Customer

Who provides the support?

- We **manage the support** ourselves - we recruit, choose, train, remunerate and supervise all the staff – more work but so worthwhile.
- We choose support people according to what is needed by our son e.g. – Auslan communication; running his business; community involvement; supporting his learning; personal care; running his household; socialising etc
- We are more concerned about workers' beliefs, attitudes, willingness to learn and listen and their demonstrated level of commitment than their qualifications and experience
- We clearly outline our requirements of the role they are undertaking and share our vision with them - we work together as a team to fulfil this vision and improve our son's life.
- We adopt a collaborative approach – workers are able to take ownership of their ideas.
- We also adopt a professional approach – have signed contracts; fortnightly payroll; regular meetings; worker training; individual supervision

What is different for our son and our family under self-direction:

- Offers **flexibility** , **consistency** & **reliability**
- Provides far greater opportunity to **set goals** and then carry them to fruition.
- Open lines of **communication** & **greater collaboration**
- Workers like their work and are excited by seeing Robbie improve – great **job satisfaction**. They also want to stay in his life.
- **Empowerment** for everyone – our son, family, workers
- Our son's world has expanded and he is a completely different person
- It has become a "normal" life rather than a service driven life for our son and for us.

What we need:

- Information and knowledge
- Practical & financial support
- Mentoring
- Belief in ourselves and our ability
- People who trust in our ability & judgement
- People who believe in our son and give him opportunities
- People who will accept our son into their lives
- Flexible and user friendly systems
- Limited bureaucracy
- Common sense approach

What we don't need:

- Negative people around us
- People making assumptions
- People who don't listen
- Sympathy or pity
- Inflexible systems/bureaucracy
- Rules & regulations for their own sake
- Patronising professionals
- Lack of choice
- Exclusion

How difficult is it to self-direct and what supports do you need?

We have heard it said that people won't want to self-direct or manage their own supports because it is too hard. Although there is work involved, the experience of the members of the Alliance has been that if people have the support they need, they find the work they do is worth it because it is proactive and they like being in control of the support they receive. Some actually find it easier!

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Building informal networks

- Relationships are so important to bridge the isolation that many people with disability experience
- and it is true that it is "people who keep people safe"
- People who are paid to be in people's lives come and go – an important part of their paid role may well be to facilitate the person with disability to develop friendships and freely given relationships.

Sustainability/Succession Planning

- Share the vision
- Involve other people
- Embed people in their communities
- Intentional planning for sustainability around finances, legal issues , health, living arrangements, future support

The elements of successful self-direction to achieve a good life

- Expanding the boundaries of thinking
- Having the belief that person with disability should live a typical' life in community
- Intentional planning for the sort of life the person wants to lead today and in the future before planning the support they require rather than the other way around
- Putting these plans into action with support – both formal and informal
- Reviewing and re-thinking for continuous improvement