



National Disability Services
Innovative Workforce Fund

Seven steps to self-direction

Building right relationship
between people with disability, families & committed friends
and support-workers

Workbook

February 2018



Contact: Margaret Ward

Griffith University

margaret.ward@griffith.edu.au

mobile +61 409 898498

Acknowledgements

This workbook was developed by Griffith University as a project funded by the National Disability Services Innovative Workforce Fund. The authors thank the people with disability, their families and support-workers who generously shared their experience and wisdom gained from self-directed arrangements. The following organisations also contributed as critical friends:

- Community Living Project (SA)
- Community Resource Unit
- Resourcing Inclusive Communities (NSW)
- Sharon Bourke, Professional Development and Training Consultant
- UnitingCare Queensland
- University of NSW and Southern Cross University
- Workability Queensland

Terms

Family and committed friends	are the people who have committed to be in the life of the person with disability in the long-term and give freely-given support.
Self-direction	is when the person with disability (or their nominee) directs the type and quality of support they receive (This might include choosing, training, and directing the support-workers).
Self-management	is when the person with disability (or their nominee) manages all aspects of their support, including receiving NDIS funding directly.
Support-worker	is paid to carry out specific support tasks for a person with disability, or the family of a child with disability. Other terms are sometimes used; for example, lifestyle assistant, or for a particular task, personal trainer, community connector.
Support-team	are the people who are paid to support the person with disability.
Person with disability	is, in this workbook, the person receiving the support. The person may direct the support themselves or they might have a nominee.
Right-relationship	is an ethic of providing supports or assistance “with” the people with disability rather than “on” or “to” or even “down to” them ¹ .

Disclaimer

This workbook is supported by a grant offered under the Innovative Workforce Fund, administered by National Disability Services (NDS) with funding from the Australian Government. However, the information and views contained in this material are not intended to reflect government or NDS views.

¹ Kendrick, M., *Some Initial Thoughts On Establishing “Right Relationship” Between Staff, Professionals, Service Organisations and the People They Assist*, in *Queensland Advocacy Incorporated Newsletter*. 2000: Brisbane.

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Introduction

A person with disability may have a range of people supporting them to have a good life; including family members, committed friends and paid support-workers.

This workbook is a guide to developing supports that work respectfully and constructively together—sometimes this is called right relationship. It is for anyone involved in a self-directed arrangement and wants it to work as well as possible. This workbook can be used by a group, or on your own.

There are seven-steps—you can start at the beginning, or at any step along the way.

Good teamwork happens when each person knows their role, takes responsibility for themselves and their communication with others, is respectful of others, and does their job as well as they can. There are things that the person with disability can do, the family and committed friends can do, and the support-workers can do to build a trusting relationship and resilience.

People with disability who have directed their support for some time say, “Take the chance, learn as you go, and you get better at it over time!”

What is a good life?

Each of us is unique, yet we can agree on what essentials make a good life. Most people want to love and be loved, to be safe, to belong to be part of something bigger than themselves, and to have opportunities to reach their potential. People also want to belong, to have a place they can call home, to determine the direction of their life, and to contribute.

Many people with disability can benefit from some intentional thinking and planning about how to achieve a good life. Real participation and inclusion in community and family life, and the opportunities that follow, come from much more than a life full of activity.

Using this book does not guarantee a good life; yet, believing that a good life is achievable is an excellent place to start. There are many stories, ideas, opportunities and tools available to help people with disability, with their families and committed friends, to envision and plan for a good life for themselves.

See Helpful Resources at the back of the workbook.

What is self-direction?

Some people with disability or their nominees may choose to direct their own support, and many involve their families and committed friends. Self-direction has been found to give greater choice and control, and more effective and flexible use of their available formal and freely-given support.

“The secret of getting ahead is getting started.”

Mark Twain

My humanity is bound up in yours, for we can only be human together.

Desmond Tutu

The current options for funding are to receive a direct payment, use a financial intermediary, or engage a service provider. Some people with disability or their nominees take responsibility for all aspects of the employment of the support-workers (this is self-management). Other people with disability or their nominees delegate some of these tasks. Through service agreements, they can take the desired level of responsibility for planning, recruitment, training and support, and payment of staff. This can change as the situation changes. Self-direction is a work in progress.

Good support means working well together

When self-directing, people with disability often use both paid and freely-given support. Good support requires the right people to provide the right level of support at the right time. Providing good support means knowing what to do, having the trust of the person with disability and working well with others. Knowing the person with disability well allows for problems to be solved quickly, locally and creatively. Good support does not happen overnight, but it can and does happen.

If you want to go fast,
go alone. If you want
to go far, go together

African Proverb

Setting up for success

There are some preconditions that make good support in self-directed arrangements more likely to happen. The first is that everyone is willing to work respectfully and constructively with each other towards the person with disability having a good life.

These are when the **person with disability** or nominee:

- has a vision and plan for a good life
- is willing and able to self-direct, and solve problems as they arise
- makes available the time and resources to train the support-team well
- is willing to overcome hurt and lack of trust in the past
- has provided ethical and safe working conditions.

These are when **family and committed friends**:

- share the vision for the person with disability to have a good life

These are when the **support-team**:

- is chosen by the person with disability or nominee
- shares the vision for the person with disability to have a good life
- is willing to work in right-relationship, that is, in a respectful manner, and to build trust over time
- can adapt and change to the person's circumstances and lifestyle
- has the knowledge, authority and discernment to solve problems as they arise.

Who provides support?

Support-workers

Support-workers are employed specifically to provide support. Although they often come as strangers, they can bring skills, ideas, perspectives, connections and interests, which contribute to the life of the person with disability.

Professionals

There are other people who have particular expertise, such as, nurses and therapists, who come into the person's life from time to time. Although their tasks may be quite specific, they can choose also to work in right relationship.

Family and committed friends

Most people with disability have family-members and some committed friends, who give their time freely and are there in good times and in bad. They have a lot of knowledge and understanding about the person and are a valuable resource for paid support-workers.

Housemates, neighbours and community members

Some people with disability share their home with housemates who might also provide some support, say, by sharing daily tasks and living expenses or by providing company over night.

Neighbours and community members may offer to assist in small, helpful ways. Everyone is important. They all can work well together.

Seven steps to self-direction

This workbook is a simple guide working in right relationship in self-directed arrangements.

It has seven steps. Feel free to start at the first step, or at any step along the way.

The seven-steps are:

1. Start with the person
2. Develop the vision and plan
3. Make a good match
4. Learn to support the person well
5. Build a relationship of trust
6. Solve problems quickly and locally
7. Check for resilience.



Each step has an exercise and suggests what the person with disability (or the nominee), the family and committed friends and support-workers can do to make that step work well. There is also a story to illustrate each step.

Step 1. Start with the person

A good place to start is to ask, “Who is the person with disability, who is in their life, what is their story and what is important to and for them, what brings joy, what brings fear, what are their dreams for the future?” There is so much to know.

Today you are you! That is truer than true!
There is no one alive who is you-er than you!

Dr. Seuss

Exercise

With the person with disability present, ask the group: “What do we know about the person with disability?”

Expand the question with:

- What is their story?
- What are they good at?
- What are their passions?
- What causes sadness, distress or fear?
- What is typical, ordinary and valued for a person of their age, gender and culture?
- Who is in their life that they care about and who cares for them?

Ask each person to reflect on their knowledge of the person. Then ask the group:

- Where are the gaps in the knowledge?
- How could you learn more about the person?

What can the person do?

As difficult as it may be, you will need to:

- Share who you are, what has happened to you, and what support you need.
- Name the sort of life you want to lead, what is important to you, what you love, like, dislike and fear.
- Be explicit about what you expect from your support-workers, what is negotiable and what is not.

This is a lot of work—it is better to have too much information than not enough.

What can the family and committed friends do?

The person belongs to a family and a community – you can help the person to:

- Collate information (over time) and write it down
- Ensure the story is told in a positive and creative way
- If the person communicates in different ways, help them to express who they are
- Include family customs, beliefs, history, rituals, favourite food, events, anniversaries and celebrations that are important to the person.

Step 1 Start with the person

What can support-workers do?

It is important to:

- Leave your habits and customs at home, and assumptions at the door
- Listen for and learn about the unique life and customs of the person you are supporting
- Find out who are the family members and committed friends and how they relate
- Learn how the person prefers the support-work to be done
- Take note of the information which is shared with you – it will be your greatest resource
- Ask when you need to know something
- Apologise when you make a mistake or an error of judgement
- Adapt your usual way of doing things so that you become “part of the scene”. This can include how you dress, speak and act.

Some things to think about...

- Treat personal information about a person with disability and their family as private and confidential. It is their information, not yours. Sharing personal information outside of the support-team is a breach of trust, and trust lost is hard to regain
- People with disability and their families may not wish to share some information with the support-team. Similarly, support-workers have a private life
- From the start, present positively in how you behave, dress and speak. Poor impressions are hard to undo, and directly impact on the person with disability and others in the team.

Story

Jane, Freda and Sandra knew each other since they went to the local school together. Their families had a plan that the three women would live together when they grew up. The local service had sent the families an invitation to see their newly constructed residential facility. There were three spaces available. Jane’s parents were very keen for Jane to consider this option.

Jane had other plans. She wanted her own home. Besides, she had grown apart from her old school friends, and now had a boyfriend.

It sometimes takes courage to start with the person. Ready-made solutions can be seductive; they can make the future seem secure and predictable. Life can be very empty, living a life decided by others.

Reflective question: What are the “pros” and “cons” of both solutions for the person with disability?

Step 2. Develop a vision and plan

A vision and plan for a good life may be modest to start, or it may be grand. What is important is that the person with disability has a vision and a plan and shares them with the support-team. There are many ways to do this, including words, photos, drawings and stories.

Tell me,
what is it you plan to do
with your one wild
and precious life?

Mary Oliver-poet

Exercise

Ask each team-member to list, in three minutes, nine things that are essential for them to have a good life. Share these on a whiteboard.

Ask each member to cross out four of these “essentials”. Explain that “they are currently not possible”. Ask each team-member to reflect on the following questions:

- How does it feel to give up four “essentials”?
- If these “essentials” are so important to you, why are people with disability often denied them?

Share the person’s vision and plan for a good life and ask each team-member how they might contribute to them. If the vision and plan are not clear, ask, “What can we do to help the person to strengthen the vision and plan?”

What can the person with disability do?

It helps if you:

- Think big because no dream is too big
- Start small if small steps work better for you
- Find some people who have gone ahead of you. Ask them how they made it happen, what did it take, where did they start
- Ask others to help you plan the first steps. Bring your family and friends along—they might need some help too
- Involve support-workers who know you well. They can help with imagination, practical steps and different perspectives
- Keep sharing your vision and plan with everyone.

What can the family and committed friends do?

It helps to:

- Be supportive; encourage the person to imagine their good life, even if you don’t know how it will happen. You can then help them plan the first (doable) steps to help build the person’s confidence
- Be careful; it is the person’s vision and plan, not yours
- Be brave; build strategies for the person’s safety, but remember we learn from our mistakes.

What can support-workers do?

It is useful to:

- Find out about the person's vision and plan for a good life. You can assist the person and their family (if you know them well) to develop one
- Encourage the person to expand their vision and plan
- Be discerning. The person and their family might have good reasons for caution. Respect their wisdom and experience
- Support the person's vision for a good life. If you do not, this is not the job for you.

Some things to think about...

- People's vision and plans change over time. Make times to discuss them regularly with everyone, so no-one is left behind
- Revisiting the vision and plan is a good way to see progress and learn from the past.

Story

Tom wanted to leave home—it was time to have his own place. His mother supported this idea but could not imagine how it would work.

His support-worker, Jesse, offered to support him in a serviced unit for two weeks. Jesse had worked for Tom for a couple of years and they got on well. Jesse wanted him to fulfil his dream of having his own home.

Together, they identified what support Tom needed each day. Tom's mother was cautious but was willing to go with the plan. A year later, Tom is in his own home and has learnt to manage with even less support than they thought.

In the same way that young people "practise" living away from home, people with disability can be supported to experience similar "practice" opportunities, to clarify what they want in the future, and how to get there.

Reflective question: What might be a "safe" opportunity for learning? List what might it take. What other experiences would a young man of Tom's age expect to have? How can he be supported to have those life experiences?

Step 3. Make a good match

It is important to consider what sort of support-worker is needed, what they are to do, and why. Support-workers come from many different backgrounds.

They can be found through your networks, word of mouth, or through formal advertising. To attract the right person, it helps to advertise the job positively and realistically, and in the right places. Each support-worker comes with new ideas, interests and skills. A new support-worker can both enrich the person's life and add to the support-team.

Most important is the support-worker's attitude. There are things that cannot be taught, such as honesty, reliability, personal integrity and common-sense. Most support-workers will learn how to do the job if they come with the right attitude and enjoy working for the person.

There are many resources to help people who are self-directing to find, train and employ support-workers. (See Helpful Resources at the end of the workbook.)

We recruit for attitude and train for skill.
Atul Gawande MD

Exercise

Before looking for a new support-worker, ask the group:

- What part of the vision and plan could a new support-worker contribute to?
- What attitudes and values would a new support-worker need? What sort of support-worker would fit well into the team?
- What is the task to be done? Are there different tasks?
- What skills, talents and abilities would the support-worker need to do the task well? What is essential, desirable and negotiable?
- What characteristics does the support-worker need to do the tasks?
- Where might you find such a person?

You can use this table to sort your ideas.

Attitudes & Values	Task	Skills, talents & abilities	Characteristics	Where to look
<i>Reliability and honesty</i>	<i>To teach the person to swim and to get fit</i>	<i>Good communicator. Can swim and teach swimming</i>	<i>Young male, 30-ish, physically fit, well presented.</i>	<i>Local pool, gym.</i>

Then as a group, write a job description that would attract that sort of person.

What can be done to find the right support-worker?

You can find good support-workers beyond specialist disability services; for example:

- through your networks
- word of mouth through other support-workers

Step 3 Make a good match

- through formal advertising, such as, employment and house-mate websites
- through connections at local clubs, swimming pool, library.

It helps to:

- advertise the job positively and realistically
- find the right places (where people with the right skills and attitudes hang out)
- research cheap and reliable methods, e.g. Gumtree, Seek
- match the method to the role.

What can the person with disability do?

It is important to follow a formal process for employment, which means:

- Do a structured interview with prepared questions
- Take the time from the beginning to explain who you are and what the job entails
- Do police checks, and interview personal referees
- Do a thorough induction
- Have a probation period and follow up reviews
- Have regular (yearly) appraisals.

What can the family and committed friends do?

You can:

- Offer to assist; your insights or observations can be helpful
- Ensure the person is engaged in the process, including the interview, and induction and training stages. Trust the person's instincts
- Explain to the support-worker your relationship with the person and how you are involved.

What can the support-worker do?

It is important to:

- Read information about the person
- Be open and willing to learn, and, when you need more information, ask questions
- Be clear about your flexibility and limitations—when you can and cannot work
- Keep a healthy, connected life outside your support role
- Identify as soon as possible if the job is not a good fit.

Some things to think about...

There is a balance here between employing “interesting” people and ensuring that they are trustworthy, reliable and ethical. Support-workers are “rented strangers” with varying histories, working styles and experience. Choosing support-workers takes time and effort. Hasty decisions lead to poor outcomes.

Trust in God but tie
up your camel.

Mohammed

Step 3 Make a good match

Remember:

- Employment arrangements should be clear, ethical and legal. Seek advice if you are unsure. (See Helpful Resources at the end of the workbook)
- Be open—some support-workers who present well can disappoint later, and support-workers who are tentative to start, with the right support, may blossom in the job
- Be clear about the difference between paid and freely-given support. Paying a friend or family-member to provide support can lead to the loss of a freely-given relationship (It is difficult to sack a family member or friend for poor performance and not cause harm). Similarly, a friendly support-worker does not make them a friend
- Conflicts of interest may arise when people are paid to give support. Recognise their potential harm. Ask yourself, “What is the harm in the action for the person with disability if this continues?”

Story

John was asked by a friend if he was interested in applying for the position of support-worker for Theo. He was unsure because he has no experience in supporting a person with Down Syndrome. He then discovered that not only was Theo a talented musician, but so were all his family. They had a band, and a large part of his work would be to support Theo to practice his music and prepare for gigs. This job was perfect for him! John had been in a band in the past, and he understood the discipline required to be a reliable, performing artist.

The support-team had identified the skills for the support that was required and then searched in the right places for the right person. This gave a much greater chance to make a good match.

Reflective Question: What are the strengths and difficulties in having support-workers without prior experience in working for people with disability?

Notes

Step 4. Learn to support the person well

When self-directing, the person with disability, or their nominee, guides the support-team on a day-to-day basis.

Taking time to recruit and train support-workers is an investment in the person's future. This is the foundation for the person with disability and their support-workers to work well together and to build trust.

Choose a job you love,
and you will never have
to work a day in your life.

Confucius

A support-worker has a lot to learn, including:

- How to contribute to the person's vision and plan
- How to support the person with disability well; including, what is important *to* the person and what is important *for* the person
- How to support the person's relationships, including family and friends, and community connections
- How to work well with other support-workers, professionals, and people who provide freely-given support.

Exercise

As a group, list some things that are important to a person to have a good life, and that are important for a person have a good life. See the example below.

What is important <i>to</i> the person?	What is important <i>for</i> the person?
<ul style="list-style-type: none"> ▪ Listen to jazz before I go to sleep 	<ul style="list-style-type: none"> ▪ Have my evening medication
<ul style="list-style-type: none"> ▪ See my friends at the pub on Fridays 	<ul style="list-style-type: none"> ▪ Have only two drinks so that I can get home safely on the train
<ul style="list-style-type: none"> ▪ Sleep in on the weekend 	<ul style="list-style-type: none"> ▪ Avoid getting pressure sores

Ask the group:

- What are the complexities and where might there be tensions?
- What can be done to support the person to find a balance?

What can the person with disability do?

You can:

- Acknowledge that learning how to support you takes time and effort, and people have different learning styles
- Develop a Code of Conduct to set the culture of personal behaviour you expect
- Give as much basic support information as you can. Outline what is critical and important, and describe specific tasks; such as, how you want the telephone answered, how you want the bathroom left after it is used, or what items should be in the pantry
- Use different formats—photos, lists, verbal demonstrations
- Keep it up to date—this is easy with a computer.

Step 4 Learn to support the person well

What can the family and committed friends do?

You can:

- Ask how you can assist in the training of staff. If the person communicates in different ways or needs assistance, you might help with the communication
- Be available to assist the relationship between the person and new support-worker for as long as is needed. Getting to know the support-worker well in the first few months will lay a valuable foundation for the future.

What can support-workers do?

It is important to:

- Be aware how you best learn
- Avoid making any suggestions or changes until you know how to support the person well
- Listen to the person, the family and others on the support-team. Read the information carefully, ask for guidance and learn from situation.
- Be open and honest about issues and challenges as they arise
- Ask for extra training if it might improve work practices or support.

A good rule is “Never assume. Be open to learn.”

Some things to think about...

Supporting a person with disability well means supporting their relationships and community connections. These relationships are sometimes messy, changeable and complicated. They are also valuable. Good support-workers know these relationships were there long before they started work and will continue long after their employment has ended.

Support-workers stay longer when the work is positive, respectful and where there are values that match their own.

Story

Tracey’s support-worker was confused. She had taken Tracey to the movies many times and thought she would enjoy this latest film about sailing. As soon as the film started, Tracey panicked and had to leave the cinema. The support-worker called Tracey’s mother for advice. She discovered that Tracey nearly drowned when she was a teenager and had been frightened of boats ever since.

Tracey’s mother thought she had briefed the support-workers well. She reviewed her information and realised that she had omitted this part of Tracey’s story and now understood the importance of sharing it.

It is a challenge to learn everything that might be important to support a person well. There are no shortcuts; however, it is good to have someone knowledgeable on hand to help when needed.

Reflective question: What information about the person or the family might be unnecessary, difficult or unwise to share with the support-team?

Step 5. Build a relationship of trust

Trusting relationships can develop once the previous two steps are in place.

Once trust is built, greater risks can be taken, and a person's life opens to greater possibilities. The person, the family and the support-team can work together towards the vision and plan for a good life.

When people with disability and their families have had their trust in services violated in the past, it may take time for them to trust again. Building trust is a work in progress that cannot be rushed.

Trust is best built when everyone is trustworthy.

A good support-team values this trusting relationship and understands what might damage or break this trust. Gaining and maintaining the trust of the person and their family is a particularly satisfying experience for everyone.

“Coming together is a beginning;
keeping together is progress;
working together is success.”

Henry Ford

Exercise

Ask the group to think about some people in their life that they trust. Ask them to reflect on:

- How long have they known them?
- Why do they trust them?
- What would it take to break that trust?

Allow each participant some personal reflection time. Then ask the group to think of a support-worker in the past that everyone trusted.

- What were their personal qualities? Why were they trustworthy?

What can the person with disability do?

You are the focus for these trusting relationships, so it is important to:

- Be an ethical and fair employer
- Meet with the support-team regularly
- Acknowledge when support-workers have done well; counsel when they have not. Never discipline one support-worker in front of the others
- Give ongoing directions and strategies as needed
- Manage conflicts as they arise
- Ask for help when you need it.

What can the family and committed friends do?

It helps to:

- Get to know the support-workers well and attend the support-team meetings, when invited
- Take spontaneous opportunities to see how they work
- Be available by sharing your contact details.

What can support-workers do?

Trust is more likely to be built when you:

- Comply with the agreed Code of Conduct always, including maintaining strict confidentiality
- Understand that building trust takes time, and can be easily lost
- Own up to your mistakes—it is better to be honest than perfect.

Regular meetings

Regular meetings with everyone are a good way to:

- Share information and experiences
- Revisit the vision and plan. Review what has occurred in the past
- Solve problems together
- Review emergency strategies and safeguards
- Get to know each other and welcome new team-members
- Celebrate achievements.

Meetings work best with some structure and formality. Set a regular time and pay support-workers to attend. Have an agenda, take notes, delegate tasks, and check that the tasks have been done. This formality can be made more enjoyable with some refreshments! You might sometimes invite others, like flatmates or helpful neighbours, who need to be informed on what is going on.

Some things to think about...

- Support-workers eventually leave – this is a part of life. It is less upsetting and disruptive for everyone if the support-workers are thoughtful about their departure. They can explain why they are leaving and help identify and train a suitable replacement. A positive experience of change will help the person become more resilient to change
- Some support-workers become faithful friends and allies after they leave the paid role. Most do not—they have their own lives to lead. It is important not to make promises of ongoing contact that might not be kept.

Story

Bill had worked for Jay for some years. He got on well with Bill's mother, who trusted his discernment about Jay's support. One day, Jay fell out of the shower chair and hit his head. Bill had neglected to fasten the belt around his waist. Bill sought medical help immediately. He then called his mother. He apologised and went through the incident with her. On reflection, he knew he had made the error because he was tired. Jay's mother thanked him for getting medical help immediately, and acknowledged that, perhaps it was time to get a sturdier shower-chair. Bill said that he would not work so many hours in the future.

Trustworthiness is not about avoiding any incident. It is about what you do when an incident occurs.

Reflective question:

What are some situations that would make it very difficult for the person with disability, the family, or the support-worker to rebuild trust?

Step 6. Solve problems quickly, creatively and locally

Life is messy and, despite the best efforts of everyone, problems arise. Acting quickly, creatively and locally can avoid problems escalating or reoccurring.

Sometimes, there is not a simple solution. Some problems for people with disability are complex and difficult. A good question to ask is “What will it take to....?” The answer will identify to the next positive step that can be taken within this complexity.

Problem-solving is a skill that improves over time. Support-workers who have learnt to support the person well and have built a relationship of trust use their discernment, confront difficult matters thoughtfully, and seek opportunities to continue their learning.

Also, a problem shared is a problem halved, and a chance for everyone to learn. A good practice after each problem is to review how it was handled, identify what needs to change and act on it. Then everyone learns to do better next time.

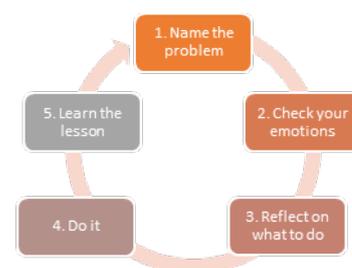
“A stitch in time saves nine.”

Proverb

Exercise

Share this simple problem-solving cycle with the team (See diagram).

- **Name the problem:** Don't avoid the issue or pretend it didn't happen
- **Check your emotions:** If you are angry, get angry where no-one can hear you
- **Reflect on what to do:** Give yourself some time to think calmly
- **Do it:** Any thoughtful action, however small, will change the situation for the better
- **Learn the lesson:** Never miss an opportunity to learn from a mistake.



Invite each team-member to identify a personal issue or problem and ask them to reflect privately on how they would work through the problem-solving cycle.

What can the person with disability do?

It is important to:

- Speak up when things are not right
- Invite your support-workers to do the same
- Build strategies for safety; for example, know how to contact trusted people quickly
- Have clear processes to follow when a problem is solved, to learn the lesson
- Keep open communication.

What can the family and committed friends do?

When something goes wrong, it is easy to act emotionally and in haste. It is worth asking:

- Is anyone at risk?

Step 6 Solve problems quickly, creatively and locally

- Is it my place to intervene?
- What more information do I need to help find a solution?

It helps to clarify with the person for the next time:

- When and how is it best to resolve a problem?
- What is the best course of action for you to be helpful, and when do you intervene?
- What safeguards might be needed?

What can support-workers do?

It is good practice to:

- Handle problems and issues in a calm, timely and considered way
- Offer a possible solution with any problem
- Strive to be better at what you do, and to model this practice to other support-workers
- Look hopefully to the future. Ask what to do next time, what changes can be made
- Work collaboratively, then more creative solutions are possible.

Some things to think about...

If problems are not addressed, they will grow. Relationship damage is likely. What is hidden becomes loudest. If you are asked to cover up, collude or act unethically, seek clarification and guidance from a trusted and knowledgeable person.

Unlawful is unlawful. You are required by law to act. Again, seek appropriate guidance before you report an incident to the police. See the Helpful Resources at the back of the workbook.

It is everyone's responsibility to ensure that there is a regular review of:

- The Code of Conduct
- Employment contracts
- Any policies or manuals that guide the support-workers
- Current communication and meeting processes.

Story

Tessa was employed to support Kate on a beach holiday with her family. She excitedly packed her favourite beachwear. Kate's Dad and brother felt a little uncomfortable on the first day, when they saw Tessa's ample cleavage, as she bent down to assist Kate. Kate's mother suggested to Tessa to wear something less revealing. Tessa apologised and quickly went to Kmart to buy some tops of a more modest design.

Because the family and the support-worker had a trusting relationship, they were able to solve this delicate "family culture" problem quickly, locally and creatively without anguish. Although the support-worker may not have agreed personally that she had dressed inappropriately, she understood her role within this family setting and the importance of minimising any dilemmas.

When everyone understands the purpose of the support, what role they play and are communicating well, problems can be more easily solved

Reflective question: Can you think of other personal or family "culture" dilemmas that might arise?

Step 7. Check for resilience

When people with disability are supported by people they trust, and problems are solved when they arise, they become more resilient in managing the ordinary ups and downs of life. The support-team also becomes more resilient.

Everyone takes responsibility for their behaviour and communication.

The family, committed friends and the support-team plans for inevitable changes in the future as the person with disability grows older.

Sometimes progress is slow, and support-workers cannot see the changes that have occurred. It is important for everyone to “stop and smell the roses” and celebrate even the smallest of achievements.

If the person is becoming less resilient, it is time to review which step in the process is not working well. Someone external to the support-team can sometimes help by identifying a problem that is eluding those close to the situation.

There is nothing permanent except change.

Heraclitus c. 500 BC

Exercise

Ask the group:

- What are the signs of developing resilience?
- What are the signs that might indicate that things need review?
- Which step could work better? What are some possible actions you could take?

Seven-steps as a Ready Reckoner

The seven-steps can be used as a Ready Reckoner to identify a problem, and what can be done about it.

For example, if the person is finding it difficult to build a trusting relationship with a support-worker (Step 5), they could ask, “Does the support-worker know well enough how to support me?” (Step 4) or “Is the support-worker the right match for me?” (Step 3) or “Did I make my vision and plan clear?” (Step 2). Then, the next step is to ask, “What will it take to...?”

(See the diagram below.)



Step 7 Check for Resilience

Considered action where it is needed is always better than hasty and emotional reaction. This workbook can assist you to make a step work better for one person or for the team as a whole.

(See the diagram below.)



Story

Joshua had been anxious all his life. He needed support to do most daily activities. He and his mother had worked diligently to ensure he had his own home, a good life and compatible support-workers. Over time, Joshua's brothers and sisters became involved.

Joshua was middle-aged when his mother died. His brothers and sisters noted that he grieved deeply for their mother; however, he was able to continue much as before. He looked after his home, met up with his friends and went to work each day.

Grieving the loss of a loved one is part of a good life; having one's life fall apart because of it is not. By working well together, Joshua's family and support-team contributed to Joshua's resilience, including managing major life events.

Reflective question: What are some major life events that are likely to occur in the near future? What would enable the person with disability, the family and support-workers to manage these life events?

Helpful Resources

Envisioning and planning a good life

Bringing the Good Life to Life: <http://thegoodlife.cru.org.au> (Queensland)

is a resource for the person with disability and their supporters to envision and plan a good life, to understand the blocks and barriers, and to develop good practices and strategies?

Resourcing Inclusive Communities: <http://www.ric.org.au> (New South Wales)

gives a range of information on developing a vision, building networks of support, and creating community connections. It also offers advice on self-direction using NDIS funding.

Belonging Matters: <http://www.belongingmatters.org> (Victoria)

aims to inspire the person with a disability, their families and allies to enable the person with a disability to have opportunities and pathways typical of other citizens in the community.

Opening Homes: <https://www.openinghomes.org.au> (South Australia)

offers a diverse range of lived-in inspiring accessible housing. The person who live in these homes share how they use technology and design to create a home that not only suits their access needs, but also matches their lifestyles and interests.

Imagine More: <http://imaginemore.org.au> (Australian Capital Territory)

provides resources for families to assist their family-members with disability to hold socially valued roles, to have strong relationships and to explore what is possible.

Valued Lives: <http://valuedlives.org.au> (Western Australia)

provides information for the person, particularly in Western Australia, to develop a vision, explore possibilities and new ideas, set goals and assist you to prepare for self-direction.

Imagine Better: <http://www.imaginebetter.co.nz> (New Zealand)

offers information, advice, planning support, mentoring and events for people with disability, families and organisations.

Canadian Association for Community Living: <http://www.cacl.ca> (Canada)

shares information about inclusive lives for people with intellectual disability, fosters leadership for inclusion, engages community leaders and policy makers, seeds innovation and supports research.

Diversity Matters: <http://www.diversity-matters.co.uk/> (United Kingdom)

works for a more inclusive society, developing capacity, skills and strengthening networks. Its aim is for communities that work for everyone.

Employing and directing support-workers

National Disability Insurance Scheme: NDIS (*Directly engaging my own staff*):

<https://www.ndis.gov.au/html/sites/default/files/Directly-engaging-my-own-staff.pdf>

This booklet provides general information about some of the considerations that may be relevant in employing support-workers directly.

Pearls of Wisdom: <http://pearl.staffingoptions.com.au>

offers practical advice on self-direction, including planning, engaging support-workers, and purchasing other supports.

Bespoke Lifestyles: <http://www.bespokelifestyles.org.au>

mentors and skills people to self-direct and self-manage their funded supports

Hireup: <https://hireup.com.au>

is an example of an online capacity for people who are self-directing to find a good match in a support-worker for a particular task.

Fair Work Australia: <https://www.fairwork.gov.au>

provides information and advice about Australia's workplace rights and rules.

First Aid Training: (National)

- Red Cross Australia: <https://www.redcross.org.au/first-aid>
- St Johns Ambulance Australia: <http://stjohn.org.au/first-aid-training>