

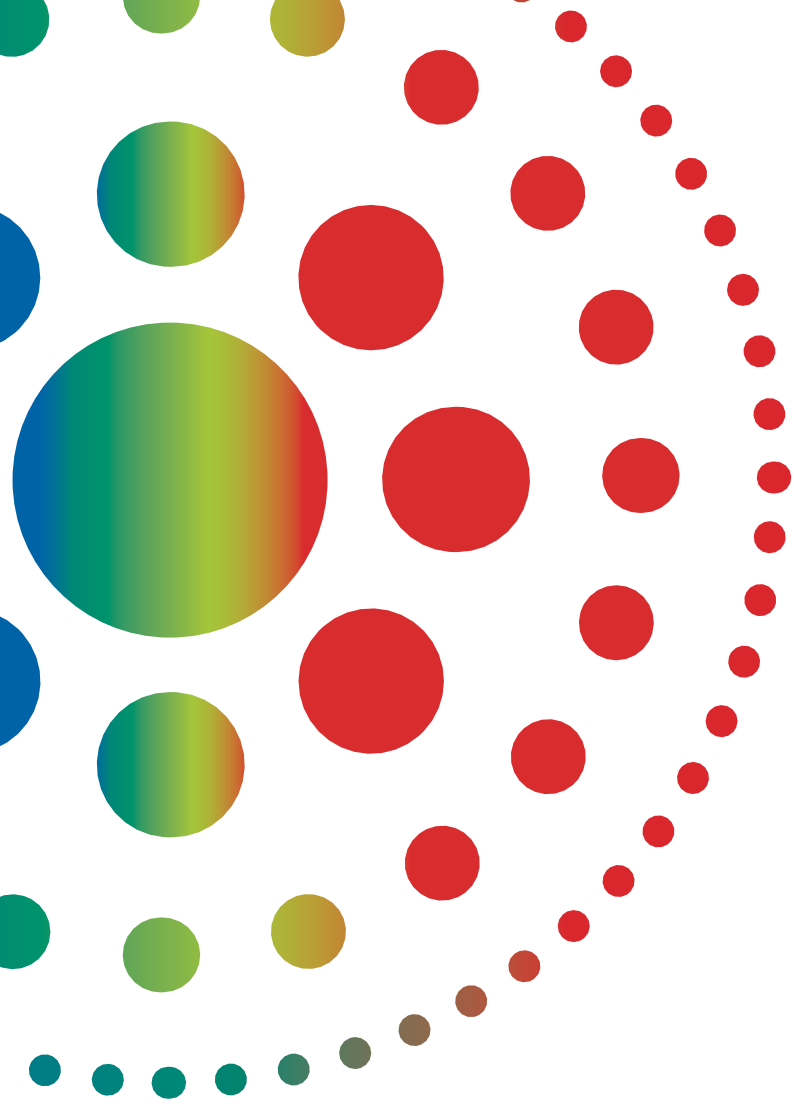


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SEVEN...STEPS TO SELF...DIRECTION

Building right relationship between people with disability, their families, friends and support workers



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RIGHT RELATIONSHIP

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

Desmond Tutu

A person with disability may have a number of people supporting them to have a good life, including family members, friends and paid support workers. Right relationship occurs when these people work respectfully and constructively together towards the person’s vision and plan for their life.

Right relationship is not something that happens by accident. It is built over time and through a number of steps which are explored in this workbook. People in self-directed arrangements are well placed to use these steps to achieve a good life for a person with disability.

— Terms used

Person with disability	is, in this workbook, the person receiving the support. The person may direct the support themselves or they might have assistance to do this from family and friends.
Family and 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, sometimes with their family and friends, directs the type and quality of support they receive. This might include choosing, training and directing the support workers.
Support worker	is the person paid to carry out specific support tasks for a person with disability, or the family of a child with disability.
Support network	are all those supporting the person with disability, in both paid and freely-given ways.
Right relationship	is an ethic of providing supports or assistance, paid or freely-given, 'with' the person with disability rather than 'on' or 'to' or even 'down to' them (Kendrick, 2000).



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

African Proverb

What



is the 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 and to have a place to call home. They may wish to be part of something bigger than themselves, to contribute, to have opportunities to reach their potential and to determine the direction of their lives.

People with disability benefit from intentional thinking and planning about how to achieve a good life. Real participation and inclusion in family and community comes from a deep understanding about what is meaningful in the life of the person being supported and strategic planning to make it happen.

Using this workbook does not guarantee a good life but believing a good life is achievable is an excellent place to start. There are many stories, ideas and tools available to help people with disability and their support networks to envision and plan a good life. See a list of contacts at the back of this workbook.



SEVEN STEPS TO SELF- DIRECTION

**This workbook is a simple guide
for working in right relationship in
self-directed support arrangements
through a seven step process.**



Step 1: Start with the person



Step 2: Develop the vision and plan



Step 3: Make a good match



Step 4: Learn to support the person well



Step 5: Build a relationship of trust



Step 6: Solve problems quickly,
locally and creatively



Step 7: Check for resilience







STEP 1.

Start with the person

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

Dr. Seuss



Step 1: Start with the person

A good place to start is to ask; “*who is the person with disability?*”

There is so much to know and there may be things you have never considered before.

Exercise

Ask the support network; “*what do we know about the person with disability?*” Include the person with disability in this exploration as much as possible.

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 do they care about, and who cares about them?
-  what are their hopes and dreams for the future?
-  where are the gaps in your knowledge about the person?
-  how could you learn more about the person?



What can the person with disability do?

-  Share who you are, your relevant life experiences and what support you need?
-  Name the sort of life you want. What is important to you? What do you love, like, dislike and fear?
-  Be clear about what you expect from your support workers.

What can family and friends do?

-  Ensure the person's story is told in a positive and creative way.
-  If the person communicates differently, help them to express who they are.
-  Share information about family customs, beliefs, history, rituals, favourite things, events, anniversaries and celebrations that are important to the person.
-  Write this information down and keep it up to date so that it is available to others.

What can support workers do?

-  Set your own habits and customs aside and any assumptions you have about the person with disability.
-  Actively learn about the unique life and customs of the person with disability and their family.
-  Respect the information which is shared with you, as it will be a great resource.
-  Find out who are the family members and friends and how they relate.
-  Ask when you need to know something.

Things to think about...



Allow the person with disability to change and grow. Never assume you know everything about them, even if you have known them a long time. Let them surprise you and explore the unexpected.



Personal information should be respected by everyone. Check what information should be kept private and confidential.



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 tempting and may make the future seem secure and predictable. Life can be very empty, however, living a life decided by others.

Reflective question:

What assumptions are often made about a person with disability that deny him or her the opportunity to be who they really are and could be?



STEP 2.

Develop the vision and plan

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

Mary Oliver-poet



Step 2: Develop a vision and plan

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

Exercise

Ask each person in the support network to list nine things that are essential for them personally to have a good life.

Ask each person to cross out four of their own essentials. Explain that these are currently not possible. Then discuss:

-  how does it feel to give up four essentials?
-  if these essentials are important to you, why is a person with disability often denied them?

Share the person's vision and plan for a good life and ask each person how they might contribute to it. If the vision and plan are not clear, ask; *"what can we do to help the person clarify their vision and plan?"*



What can the person with disability do?

- ☼ 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 it took and where they got started?
- ☼ Ask others to help you plan the first steps. Bring your family and friends along, as they might need some help too.
- ☼ Involve any support workers who know you well. They can help with creative ideas, practical steps and offer different perspectives.
- ☼ Persist. Keep sharing your vision and plan with those who can assist you.

What can family and friends do?

- ☼ Encourage the person to imagine a good life, even if you don't know how it will happen. You can then help them plan the first doable steps to build their confidence.
- ☼ Remember it is the person's vision and plan and not yours.
- ☼ Understand we all learn from our mistakes. At the same time, develop strategies for the person's personal safety.

What can support workers do?

- ☼ Support the person's vision for a good life. If you can't, then this not the right job for you.
- ☼ Respect the wisdom and experience of the person, their family and friends and follow their lead.

Things to think about...



The vision and plan will change over time, as people's lives change. It is important to share 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.



If it is hard to develop a vision and plan, look at what other people of the same age and background are doing with their lives.



Story

Tom had left school a few years ago and wanted to leave home. It was time to have his own place. His mother supported this idea but could not imagine how it could happen.

His support worker, Jesse, offered to support him to live in a serviced apartment 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 willing to go with the plan. A year later, Tom is in his own home and is learning to manage with even less support than they thought.

In the same way that young people can experiment living away from home before they finally leave, people with disability can be supported to experience similar opportunities. This helps to clarify what they want in the future and how to get there.

Reflective question:

What other life experiences would a young person of Tom's age expect to have? How can he be supported to have those opportunities?



STEP 3.

Make a good match

*"We recruit for attitude
and train for skill."*

Atul Gawande MD



Step 3: Make a good match

Support workers can come from many different backgrounds. They bring new ideas, interests and skills. They can both enrich the person's life and add to the support network.

It is important to consider what sort of support worker is needed, what they are to do and why?

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 support the person's vision and plan.

There are many resources to help people who are self-directing supports to find, train and employ support workers. The list of contacts at the back of this workbook is a good place to start.

Exercise

Before looking for a new support worker, ask the existing support network some key questions.

-  What part of the vision and plan could a new support worker contribute to?
-  What are the tasks to be done?
-  What skills, talents and abilities would the support worker need to do the tasks well? What is essential, desirable and negotiable?



-  What character traits would the support worker need to do this job well?
-  What attitudes and values would a new support worker need?
-  Where do you look to find such a person?
-  Finally, what sort of support worker would fit well into the support network?

You can use this table to sort your ideas.

Task <i>To teach the person to swim and to get fit</i>	Skills, talents & abilities <i>Good communicator, can swim and teach swimming</i>	Character traits <i>Physically fit, well-presented, willing to spend lots of time in the water, patient</i>
Attitudes & Values <i>Reliable and honest</i>	Where to look <i>Local pool, gym</i>	Needs of support network <i>Able to come to regular network meetings</i>

Together, write a job description that would attract the right person to this particular job.

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
-  by word of mouth through other support workers
-  through job or community websites
-  through connections at local clubs, libraries and community centres.

What can the person with disability do?

-  Undergo a formal employment process to find the right person.
-  Advertise the job positively and realistically.
-  Prepare a clear job description and employment contract.
-  Do a formal interview with prepared questions.
-  Take the time from the beginning to explain who you are and what the job entails.
-  Do police and working with vulnerable people checks.
-  Speak personally to any referees.
-  Have a thorough orientation and training schedule.
-  Have a probation period and give clear feedback.
-  Have regular, ongoing appraisals.



What can family and friends do?

-  Offer to assist. Your insights or observations can be helpful.
-  Explain to the support worker your relationship with the person and how you are involved.
-  Ensure the person to be supported is engaged in the process, including the interview, orientation and training stages.
-  Trust the person's instincts and observe closely how they respond to the person being interviewed.

What can support workers do?

-  Read carefully the information provided about the person.
-  Be open and willing to learn.
-  Ask questions when you need more information.
-  Be clear about your flexibility and limitations, when you can and cannot work.
-  Identify, as soon as possible, if the job is not a good fit and you want to leave it.

*Trust in God but tie up
your camel.*

Old Muslim proverb

Things to think about...



Some support workers who present well initially may not suit, and support workers who are tentative to start may blossom in the job.



A rushed decision is often a bad decision. Try to avoid being pressured or feeling anxious during this step. Believe there is always someone who will be a good match.



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 also difficult to sack a family member or friend for poor performance and not cause harm to the relationship. Similarly, a friendly support worker does not necessarily make them a friend, as they are in a paid role and their connection may not continue after their employment.



Be sure that the interests of the person with disability take priority over other interests. Learn to identify conflicts of interests.



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 had 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 network had identified the skills the support worker 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 advantages and potential conflicts of interest do you think there are in recruiting a support worker who matches the interests, experiences and skills that an individual specifically wants to explore?



STEP 4.

Learn to support the person well

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

Confucius



Step 4: Learn to support the person well

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

Exercise

List some things that are important **to** the person with disability to have a good life and those that are important **for** the person with disability to have a good life. See an example below:

What is important <i>TO</i> the person?	What is important <i>FOR</i> the person?
• Listen to jazz before I go to sleep	• Have my evening medication
• See my friends at the pub on Fridays	• Have only two drinks so that I can get home safely on the train
• Sleep in on the weekend	• Avoid getting pressure sores

Ask:

-  where might there be tensions between the two?
-  what can be done to support the person to manage any tensions?



What can the person with disability do?

-  Give as much basic support information as you can and outline what is critical and important to you. 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.
-  Acknowledge that learning how to support you well takes time and effort and people have different learning styles. Use different formats to teach and remind people; such as, photos, lists and verbal demonstrations.
-  Be clear about your expectations of the role, duties and conduct of support workers in written job descriptions and contracts.
-  Keep relevant information up to date. It is surprising how quickly life changes.

What can family and friends do?

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

What can support workers do?

-  Be aware of how you learn best.
-  Avoid making any suggestions or changes until you have learned to support the person well.
-  Be open and honest about issues and challenges as they arise.
-  Ask for extra training, if needed.

Things to think about...



Good support is not a generic 'one way suits all' process. It requires good listening, honesty, openness and respect within the whole support network to shape support unique to the person's wishes and best interest.



Supporting a person well means supporting their relationships and community connections. These relationships are sometimes messy, changeable and complicated. They are also valuable and should be respected.



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 and provided enough information during orientation. She now realised that she had omitted this part of Tracey's story and understood the importance of sharing it.

It takes time to learn everything that might be important to support a person well and it is good to have someone knowledgeable on hand to help when needed.

Reflective question:

What information about the person or the family would be important to share with support workers? What information should the support worker share with the person?



STEP 5.

Build a relationship of trust

"Coming together is a beginning; Keeping together is progress; working together is success."

Henry Ford



Step 5: Build a relationship of trust

Building trust takes time, after the previous steps are in place.

Once trust is built, more positive risks can be taken. This opens a person's life to many more possibilities and enables everyone to work optimally towards the vision and plan.

Trust can be lost easily and takes much longer to rebuild, so aim to maintain it at all costs.

Exercise

Think about some people in your life that you trust. Then reflect on:

-  how long have you known them?
-  why do you trust them?
-  what qualities does a trustworthy person have?
-  what would it take to break that trust?



What can the person with disability do?

-  Keep communicating and meet with the support network regularly.
-  Be an ethical and fair employer.
-  Acknowledge when support workers have done well and counsel privately when they have not.
-  Manage problems as they arise.
-  Ask for help when you need it.

What can family and friends do?

-  Get to know the support workers well and attend the support network meetings when invited.
-  Drop in on the person with their support worker to see how things are going.
-  Be available to talk through any issues.

What can support workers do?

-  Comply with the expectations, duties and conduct set within your role.
-  Maintain strict confidentiality.
-  Mistakes and accidents happen, so share what happened quickly and agree to help fix the issue.



Regular meetings with the support network 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 people
-  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 of what is going on.

Things to think about...



Regardless of your role, apologise when you make a mistake or an error of judgement and commit to do better in the future.



Support workers eventually leave; this is a part of life. It is important to fully prepare people in good time. A positive experience of change will help the person become more resilient to it in the future.



Some support workers become good friends and allies after they leave the paid role. Many do not, as 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 Jay'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 and then called Jay's 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, their family, friends and support workers to rebuild trust?

A white silhouette of a human head in profile, facing right. Inside the head, there are three interlocking gears of different sizes. To the right of the head, there are three blue circles of increasing size, resembling bubbles or a trail.

STEP 6.

Solve problems quickly,
locally and creatively

"A stitch in time saves nine."

Proverb



Step 6: Solve problems quickly, locally and creatively

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 the next positive step that can be taken within this complexity.

Problem solving is a skill that improves over time. Support networks 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.

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. That way everyone learns to do better next time.



Exercise

Share this simple problem-solving cycle with the support network.

01 Name the problem

Face the issue—no matter how difficult it may be.

02 Check your emotions

If you are angry or frustrated, vent your emotions where no-one can hear you.

03 Reflect on what to do

Give yourself some time to think calmly about what to do.

04 Do it

Any thoughtful action, however small, will change the situation for the better.

05 Learn the lesson

Never miss an opportunity to get better at what you do.

Invite each person to identify a problem and ask them to reflect on how they would work through the problem-solving cycle.



What can the person with disability do?

-  Speak up when things are not right. This might take some courage.
-  Invite your support network to do the same.
-  Have clear processes for everyone to follow when there is a problem.
-  Keep communication open, even when times are tough.
-  Build strategies for your personal safety; for example, know how to contact trusted people quickly.

What can family and friends do?

When something goes wrong, it is easy to act emotionally or in haste. Instead:

-  check first if anyone is at risk
-  ask yourself if it is your place to intervene
-  determine what information you need to help find a solution
-  work out when and how is it best to resolve a problem
-  share best courses of action with others
-  determine what further safeguards might work in the future.

What can support workers do?

-  Handle problems and issues in a calm, timely and considered way.
-  Offer a possible solution with any problem.
-  Listen and take advice if suggestions are made to improve your work practice.
-  Work collaboratively, so that more creative solutions are possible.

Things to think about...



If problems are not addressed, they will grow and relationship damage is likely. Sometimes what is hidden becomes loudest.



Abuse and unlawful behaviour are not acceptable at any time. Seek guidance from a trusted colleague, a state ombudsman or the NDIS Quality and Safeguarding Commission.



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 Tessa's beachwear didn't cover her, as she bent down to assist Kate. Kate's mother suggested to Tessa to wear something less revealing. Tessa apologised and quickly went to buy some tops that were more suitable.

Although Tessa may not have agreed personally that she had dressed inappropriately, she understood her role within this family setting and the importance of this family holiday.

When problems are solved quickly, locally and creatively there is more time and energy for having a good life.

Reflective question:

How do you presently solve problems? Can you suggest improvements to the process that may benefit everyone?



STEP 7.

Check for Resilience

*"There is nothing permanent
except change."*

Heraclitus c. 500 BC



Step 7: Check for Resilience

When a person with disability has hope for their future, is 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. There is also stability within the support network even with the inevitable changes of people leaving their paid role, parents ageing and new friends being made.

Sometimes progress is slow and it is hard to see changes. 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 network can sometimes help by identifying a problem that is eluding those close to the situation.

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?



The Seven Steps as a Tool for Review

The seven steps can be used to identify a problem and determine what can be done about it. Considered action is always better than a hasty and emotional reaction. A review can assist you to make a step work better for everyone. It may also improve the effectiveness of the other steps and the overall outcomes for the person.

For example, if the person is finding it difficult to build a trusting relationship with a support worker (step 5) ask;

-  does the support worker know me well enough and how I want to be supported? (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 you can ask; “what would it take to build a trusting relationship?”
Be sure to follow up with a clear action to make the necessary change.

The Seven Steps as a Tool for Review



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?



Hube

To Fas

Reference

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

For more information, contact:

Belonging Matters (Victoria) www.belongingmatters.org

Community Resource Unit (Queensland) www.cru.org.au

Imagine More (Australian Capital Territory) www.imagemore.org.au

JFA Purple Orange (South Australia) www.purpleorange.org.au

Resourcing Inclusive Communities (New South Wales) www.ric.org.au

Valued Lives (Western Australia) www.valuedlives.org.au

Notes



resourcing inclusive communities

Resourcing Inclusive Communities is a capacity building initiative of Family Advocacy.

Please contact us if you want more information about any of the ideas in this booklet, to join our mailing list and to be informed about our events.

Resourcing Inclusive Communities provides fee for service training for community groups, organisations and professionals. Please contact us for more information.

info@ric.org.au or call 1800 774 764

Take a look at our website for more ideas and resources.

www.ric.org.au



Family Advocacy is an independent, impartial advocacy organisation that supports families across New South Wales to promote and defend the rights and interests of people with developmental disability*. Our aim is to achieve positive social roles for people with disability through the development of advocacy by families and by strengthening the knowledge, role and influence of the family.

*Developmental disability includes but is not limited to: autism, intellectual disability, cerebral palsy, spina bifida and multiple disability.

www.family-advocacy.com



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Building right relationship between people with
disability, their families, friends and support workers

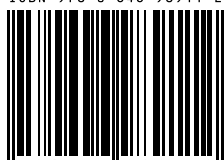


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