

# Learning to Lead

A guide to planning supports for  
your child with a disability and family

**1st edition 2012**



 Association for  
Children with a Disability

## **Association for Children with a Disability**

**We provide information, support and advocacy to families who have a child or young adult with any type of disability or developmental delay across Victoria.**

**Our Association is run by parents and siblings so we know what it means to have a family member with a disability. We understand issues from a family perspective. Our services include free telephone information and advocacy support for families.**

**Our member magazine, NoticeBoard, includes family stories that are a great source of strength and inspiration for other families and professionals who work with families.**

**Association for Children  
with a Disability  
Suite 2, 98 Morang Road,  
Hawthorn VIC 3122**

**Phone 03 9818 2000 or  
1800 654 013 (rural callers)  
Fax 03 9818 2300  
Email [mail@acd.org.au](mailto:mail@acd.org.au)  
Web [www.acd.org.au](http://www.acd.org.au)**

+

### **Language interpreters**

**If you need a language interpreter to access our service, call the Translating and Interpreting Service on 13 14 50. Tell the operator your preferred language and that you want to speak to the Association for Children with a Disability on 03 9818 2000. This is a free service.**

# Learning to Lead

A parent guide to planning supports for  
your child with a disability and family

1st edition 2012



## **Acknowledgements**

Funded by the Department of Human Services Victoria

Produced by the Association for Children with a Disability

In association with Fertile Films, VICSEG New Futures and Interchange Outer East

Thanks to the families who contributed to this resource:

Mun Chin, Ei Leen Lee, Daniel Chin, Amelia Chin

Thuy Dong, An Tong

Gabs, Maram, Maryam & Khaled El-Ali

Liz Kelly, Stephen, Connor & Claire Bailey

Thanks also to:

Chrissy Lauritz, Anne Muir, Tom Pagonis, Liz Newland,

Michelle Harmer, Lucy De Petro, Ann Sayer, James Slater,

Jane Pan, Tuyen Luong. Alison Romeril, Elizabeth McGarry,

Diane McCarthy, (other ACD staff and those who had

significant input)

## **Acknowledgements**

Learning to Lead: A parent guide to planning supports for your child with a disability and family

© Association for Children with a Disability 2012

Learning to Lead is available free of charge to families thanks to the generous financial assistance provided by the Department of Human Services

ISBN 978-0-9804065-9-7

This document may be reproduced and distributed in full or part as long as appropriate acknowledgement is given

# Contents

Introduction	3
Getting ready to lead	6
Building your support network	9
Identifying the supports you need	11
Parent story: Making it possible	12
Learning to lead - planning cycle	14
Leading the planning conversation	15
Ten Tips on leading the planning process	18
Teaching your child to lead	19
Documenting your plan	20
Now I have a plan – what comes next?	21
Glossary	23
Resources	24
Parent feedback	25

## Your feedback

We welcome your feedback on this booklet and any other aspect of our service.

Send to: Association for Children with a Disability, Suite 2, 98 Morang Rd, Hawthorn VIC 3122

Phone: **03 9818 2000** or **1800 654 013 (rural callers)** Fax: **03 9818 2300**

Email: **mail@acd.org.au** Web: **www.acd.org.au**

### **Changing times**

Only a few decades ago it was common for many people with a disability, including children, to live away from their families in large institutions. The residents of those institutions had very little control over how they lived their lives. They had to obey the rules of the institution about when they ate their meals, when they went to bed and what they did during the day.

In the 1970s and 80s, some people living in these institutions and their families began to speak out and demand more control over their lives. Over time, the large institutions were closed down and the residents moved out to live alongside other members of society.

People with a disability now have the same rights as others to live in and participate as valued members of the community.

In Victoria today, the government aims to support children and young people with a disability to live with their family and as part of the community, and to have equal access to opportunities that help them reach their full potential at all stages of their life.

Because of changes to the way disability supports are provided, your child and family now have a greater say in how you want your lives to be.

To achieve this goal, services and supports should focus on the needs of your child and family. This way you have the opportunity to think about what would be helpful for you and your child and what supports you would need to achieve any goals you set.

More details about how planning works and your involvement in leading the process is explained in the following chapters.

## Introduction

This booklet and DVD are designed to help you and your family learn to lead the planning process for accessing services and supports for your child and family.

Taking the lead means feeling confident to say what your child and family want and need rather than waiting for others to tell you what to do or how your supports should be organised.

This booklet offers helpful tips such as how to set goals and become a confident communicator and negotiator. The booklet also shares ideas about assisting your child to gradually build decision making and problem solving skills. There are several specific terms used in the booklet that appear in **'bold'** and their meanings are explained in the Glossary on page 23. You will also find on page 24 a list of other resources that can help you learn more about planning and available supports. The DVD complements the booklet and includes four families who share their experiences of planning their supports. You can watch the DVD by choosing the English, Arabic, Chinese or Vietnamese language version.

Children are a key part of family life and as they get older they usually grow more independent of their parents. Some children leave home when they are teenagers while others stay at home when they are adults. Some people may think that having a child with a disability makes family life very different, but most aspects of life are the same for all families. While having a child with a disability often means that your family needs more support, you still have the same rights as other families to make choices about how your family lives.

As a parent, you are the primary influence on your child and family and you automatically make plans. For example, you make decisions about which school your child will attend and what activities they are involved in. Many of these decisions you make together, taking into consideration the needs of all family members.



**“There is actually a lot of support out there, just waiting for you to go and get it, because it won’t come to you. You have to go out and seek it, and grab it with both hands, and don’t let go. I mean that, don’t let go of it.  
Parent**



**“Families who haven’t had any support, they may not have ever been really asked, what is it that you want, for yourself, what do you want for your family, what do you want for your child?” Worker**

Plan for your child with a disability as you would for any child. While they will have additional needs because of their disability, they also have needs and wants that all children have. All children need support to learn new things, make friends and to strive for independence. As a parent, planning with disability in mind involves thinking and making decisions about specific requirements, as well as things that you already organise regularly.

### **Planning strategies**

If family life feels like a day-to-day struggle, the idea of planning may seem too time consuming. Making the decision to do some planning can help life feel more organised. It can allow you to stop and think about what your child and family need and want and the future can feel less chaotic.

Planning for the future can be:

- Short term - the next few weeks or months
- Medium term - the next six months to two years, or
- Long term- the next two years and beyond

### **Becoming a confident leader**

Remember that you know your child and family better than anyone else. In supporting your child, you already know what can be helpful. Think about what your child and family want and the support you need to make it happen.

You may already have family or friends or other supports that assist you to do what is needed to care for your child and family. Or you may want to set up a group of people to help you with planning. This may include people with skills that would help you achieve what you need or maybe professionals who support your family. This is sometimes called a **circle of support**. More details about this support option are explained on page 9.

The Department of Human Services provides information on what disability funded support you might be able to access, as well as the disability funded service providers in your local area. Phone 1800 737 783 Web [www.dhs.vic.gov.au](http://www.dhs.vic.gov.au)



If you have a disability service provider to help with planning, don't be shy to say what you want even if you don't know how to get it. Don't be afraid to seek support for your child and family. If you don't speak up, others may not understand what you need.

Useful resources to assist with thinking about what supports you need may include some of our Association's resources – Through the Maze: an overview of services and support for parents of children with a disability in Victoria; Growing Together; Helping You And Your Family; Kindergarten Inclusion Tip Sheets; Positive Education Planning; Transition to Secondary School. These resources are available on our website **www.acd.org.au** or phone the Association office on **9818 2000** or **1800 654 013 (rural callers)** for a print copy. Helping You and Your Family, Kindergarten Inclusion Tip Sheets and Through the Maze is available in English, Arabic, Chinese and Vietnamese.

The Department of Human Services' website also has information on Planning in English, Arabic, Vietnamese and Chinese – Disability Services – Self-Directed Planning Information Sheet. [www.dhs.vic.gov.au](http://www.dhs.vic.gov.au)



**"I went from, 'what am I doing?' to 'what am I thinking?'  
But now it's a lot easier because what I'm thinking I can actually put on paper. This is what I want, this is what I'd like to happen, and this is where I'd like to be."  
Parent**

## Getting ready to lead



Before you start planning, allow some time to think about the things, people and experiences that are important to your child and family now and going into the future.

Think about what a good life for your child would look like. Listen, observe and understand what is important to your child. Think about why you believe your ideas for your child's life are important. This belief becomes your vision for your child and family's life.

There are different ways to do this and there is no set way that you have to follow, you just need to choose what works for your child and family. It could mean talking to different people in your child's life, writing a list of ideas, drawing pictures or diagrams that identify what would be helpful in achieving your vision. The important thing is to take the time to think about these things and to include your child in the process.

Talk about your ideas with a trusted family member or friend to fine-tune and consolidate your vision. Your commitment to making this vision a reality is what will help your child and family achieve a good life. Without that commitment, you run the risk of settling for less than what is possible.

### Setting goals

Your child has unique characteristics, interests, skills and aspirations and they have their own personality, likes and dislikes. Every child and family is different. When thinking about planning it's important to think about what goals you want to see your child achieve over the coming months and years.

Your child and family may be aiming to achieve a physical or social goal. Think about what would help you to move towards achieving that goal. It may be a form of therapy or it could be an activity such as dancing or swimming, where your child gains skills and social experiences.

**"I know what my child likes and I also know that he has skills and interests that other people may not pick up on. I want him to have friends and activities that he enjoys because that's what most children have."  
Parent**

Observe what activities your child enjoys doing and try to understand why they enjoy doing these things. This will assist you to find activities where your child could meet others with similar interests and broaden their friendship circle. Think about new activities they might like to try. There may also be activities that the whole family can participate in that may help your child to be more involved in your community.

### **Including your child in planning**

Children with a disability have the same rights as other children. They should have enough information and support so that they can participate actively in the decisions that affect their lives so they can reach their full potential. All children can be included in the planning process even if they have limited communication. By including them early, they gain experience and learn to be involved in the process. They are encouraged to communicate what they like, what they want to achieve, and the friendships they want to develop. As parents we are always trying to find ways for our children to learn and develop, stay fit and enjoy life. Once your child and family have identified what you want to achieve you are well on the way to taking the lead in planning.

### **Think possibility not disability**

In the beginning, your focus should be on what your child and family want to achieve rather than how you're going to achieve it. The 'how' comes a little later. An explanation of how this can be achieved is explained in the chapter, 'Documenting your plan' on page 20.

As you think about the goals that your child and family want to achieve, try not to let disability alone determine what is possible. Where possible, encourage your child to tell you what they want to do.



**"My child has very limited communication but we can see on his face when he's doing something he loves. He also lets us know very clearly when things are not to his liking. As he gets older we hope he'll be more involved in the planning process but for now we just make sure we tune in to his responses to different activities and situations."  
Parent**



**"No one else understands my child the way I do. If I don't stand up and say what she needs no one else will do it." Parent**

You could write a list and work through some questions like these, with your child:

- What is my child interested in?
- What makes them happy?
- What would make their life more enjoyable or fulfilling?
- What do they want to achieve?
- Is there a new skill that they would like to learn or would help their development?
- What things would our whole family like to do together but do not seem possible because of disability?

Your child might be interested in learning to paint, draw, dance, do karate, join a basketball or soccer team or learn to play board or computer games. These activities are available to many children but you may not have considered them if there are obstacles that make it more difficult for your child to do these types of activities. Think about what would need to happen to overcome any limitations and what additional support could help achieve your goal. Think possibility not disability.

Obstacles could include:

- The lack of specific equipment to participate in the activity.
- The teacher or activity leader may need encouragement or specific training to include your child in the activity.
- Your child may need some additional support to participate fully in the activity.

These types of obstacles can often be overcome by thinking about how they can be solved. For example, you might have ideas about:

- What equipment or adjustments your child needs to access the activity.
- Other ways that extra support would enable your child to participate in the activity.
- What type of information or training an activity leader would need to include your child in their program.

Not all solutions will require **disability funding** but may just need you to share some knowledge that will give others the skills they need to assist your child. It would be helpful to write down what skills would be required to:

- Undertake favourite activities
- Set up new activities

## Building your support network

Planning isn't something you have to do on your own, and it can be helpful to ask other people to be involved.

Bringing together family and friends to contribute ideas can assist to develop goals or work out ways to do the things your child might like to do. Often this process is called a **circle of support**.

### **Circles of support**

Forming a circle of support is an informal way of involving others interested in supporting and planning your child's future. If you decide to form a circle of support you could approach several people who are a part of your child's life or who you think would like to be.

A circle of support is one way to bring people together to form meaningful connections with your child and to form longer term friendships with your family. They can add a fresh dimension to how you might reach your child's goals. Your circle can begin with one person supporting you and may expand and change over time, as new people join and others leave.

### **Inviting people to join a circle of support**

When bringing people together, think about what skills each member of the circle can contribute from their personal interests or professional life.

When you ask someone to be involved, be clear and confident about what you think that person has to offer. If you don't feel comfortable asking them, you can ask someone else you trust to ask them for you. Giving people some information about the commitment involved in being part of the circle of support can help them to understand what would be expected of them.

Don't assume that family and friends will automatically want to be part of your circle of support, or know what to do or how to contribute. It might be challenging for some people if they have a different understanding of disability or expectations of what your child can achieve. It could be helpful to share stories about your child that highlight their strengths, interests and achievements.

You may need to explain to them in detail what you are trying to do. Providing an explanation about how the circle works will help people decide what level of involvement they could have. Others who use this method to support their child have found that the level of participation of circle members increased over time, as their confidence and interest increased.



**"I was brought up with the idea of the Greek village where everyone pitches in and supports a family and a child with a disability. It's not left up to the family to cope alone."  
Circle of support member**



Be prepared for some people to say no, but keep asking others until you have a group of people who want to be involved and who have the time and energy to actively contribute to the group and support your child and family.

Think about the vision you have for your child and family and share your ideas with members of the circle. This can include thinking about your child's strengths and interests, the roles that different people play in your child and family's life, and common experiences of other children of similar age who don't have a disability. As the planning progresses, you can refer back to this and check that what you are talking about and doing matches up with the goals you want to achieve. Sometimes you might be surprised by the ideas that come from planning with others. Sharing different ideas often leads to exciting opportunities for your child. Remember from sharing little ideas big possibilities can grow.

### **Circle of support get-togethers**

Generally people in the circle of support will meet regularly and it can be quite a relaxed and fun event. The frequency of meeting will depend on how much there is to discuss and what needs to be organised. It would be a good idea to prepare a list of issues that need to be discussed. Allow everyone to contribute ideas and to assist in the 'how', 'who' and 'what' it will take to achieve a goal. It's important to delegate tasks and to follow-up actions. As a parent you may feel more comfortable if someone you trust could work with you to organise your circle of support. Over time they may eventually become the circle leader, although it will always be important to work closing together, to ensure that circle decisions and activities are heading in the right direction.

There may be some obstacles to overcome along the way but the important thing is to keep going and to have people around you who can support your child and family through the ups and downs and to keep striving to achieve your vision. Remember to celebrate your successes, both big and small!

You might find the 'Resourcing Families' website helpful in explaining in English and other community languages, more about circles of support.

[www.resourcingfamilies.org.au/index.php/building-support-networks.html](http://www.resourcingfamilies.org.au/index.php/building-support-networks.html)

## Identifying the supports you need

The government's intention is that disability services are provided in a way that suits your child and family's needs.

Part of the process of applying for **disability funding** is making a plan. As we have mentioned, it is important that the planning process is led by you, your child and family.

The purpose of making a plan is to document what goals you want your child and family to achieve. Don't forget that this is the starting point. How goals will be achieved can be a combination of what help you can find from family, friends and others who know your child (often called **informal support**), activities in your local area that are available to all children, local volunteers and disability funded supports.

Sometimes disability funding (**formal support**) can complement the other help you can find. Not every family wants respite or paid carers to assist their child, so it is important to think about other ways funding might help you achieve your goals.

Here are 3 examples –

### **Disability funding (formal support)**

The family and worker found a solution that allowed Angela to attend swimming activities. They looked for a pool that better met Angela's needs and applied for funds so that a carer could go along and help with Angela's personal care needs at the pool.

### **Disability funding and help from others (formal and informal support)**

Thuc loves soccer. Thuc's dad has a workmate (Boris) who is a coach at the local soccer club. Thuc is able to join the soccer club because his family sourced disability funding for respite and have used it to organise for a carer to accompany Thuc to soccer matches. Boris offers to take Thuc to training sessions during the week and supports Thuc to socialise with the other young soccer players.

### **No Disability funding (informal support)**

Maria a family friend shares a love of music with Andrew. Maria often invites Andrew over to her home to watch music DVDs. Andrew wants to go to a concert because his favourite band is touring, but he is unable to go by himself. Maria offers to accompany Andrew to the concert.

In the end it won't matter what combination of supports you choose to pursue your goals, as long as the steps to achieve them are realistic.



**"Prior to meeting the family I like to encourage them to think about what they want. What quality support means to their child. To start thinking about the activities that their child is involved in, what their child enjoys."**

**Worker**

## **Making it possible**

Stephen and I met when we were working a ski season in Austria. We share a love of skiing and the mountains and have regularly embarked on ski trips throughout our life. We appreciate that skiing is not everyone's idea of a fantastic holiday, due to the dislike of the cold and the cost!! Once we had children we didn't know whether a ski holiday was still going to be an option for us, but we have had some fabulous times with other families. With other families we could share cost, care and manage some adult time.

Our daughter Claire first got on skis when she was five, so when Connor was 5 we thought we would love to give him a turn. As you could imagine, after being in the disability system, we thought this is going to be incredibly difficult. A boy with severe and profound disabilities going skiing... what were we thinking? We went down to the ski school at Hotham and it seemed too easy to book him in for a ski. We went away thinking he is booked in for an hour, in this time, he might, if we are lucky, get a little push about at the bottom of the summit. We arrived the next day and within 5 minutes Connor was whisked away by a big burly lad called Dean, put in a sit ski and was on the chair lift. The next thing I saw Connor zooming down the mountain with Dean behind him and Stephen close alongside. I looked on stunned and emotional as a man behind me commented "that is amazing" I said "that is my son"!! (thank God for goggles)

After Connor's first run I asked him how it was and asked if he wanted to go again and it was pretty clear from his response that he loved it... must be genetic!! Moving along a couple of years we were planning our annual ski trip to Hotham. One of the major concerns for us was that Connor was now a much bigger boy and we had to think of ways of getting him around at the snow... the skiing proved easy, but transferring from A to B was going to be much more difficult.

We discussed this concern at our Circle of Support meeting. We debated various alternatives and one of the members mentioned TADVIC. TADVIC's volunteers make custom equipment for people with a disability throughout Victoria. The service helps people with disabilities, for whom no commercially available solution meets their needs. Stephen contacted TADVIC and between him and Doug from TADVIC they came up with a very practical design that Connor's wheel chair would fit on and he could be pushed around the snow.

To have Connor participate in something with us that we all love, is fantastic. One of my fondest memories of my many snow trips will always be Connor's friends Nick and Mia whooping and yelling as they skied the summit with Connor. Sometimes things that may seem insurmountable can actually be solved by asking questions, making inquiries and thinking outside the mainstream.

Liz Kelly





## Learning to Lead - Planning Cycle



Planning is a valuable and continuous process that we do every day. It focuses on thinking about what can be done or needs to be done, then working out ways of doing it. If the right results aren't being achieved, then we start the planning process again.

## Leading the planning conversation

Taking the lead doesn't mean that you have to do all the work, but you can begin to clarify what your child and family needs.

You can request that a **worker** employed by a disability service provider meet with you at your home, or somewhere else, to help develop your ideas into a plan.

### Planning with a worker

The worker will want to understand your family situation and to identify appropriate opportunities and supports but you need to take an active role in leading the discussion. You know your child well, including what they like and what motivates them. Be confident in your own skills and knowledge and don't be shy to express them in a positive way. Talk about any supports you have organised in the past or any disability services you have used.

When leading the planning conversation, explain your vision and ideas and why they are important. This will help the worker to better understand and respect your point of view and the decisions you make. Wherever possible include your child in planning discussions. As they grow older they will be more able to contribute their own ideas about what they would like to achieve. Also remember that you may need to explain your ideas more than once. Some workers might be new to their work while others may have a long history of supporting families, so the ability your worker has to step back and allow you to lead the process will vary.

You will achieve better outcomes by speaking up about what your child and family want and by taking the lead in making decisions about supports. Don't wait to be asked for your opinion as this could be misinterpreted as you not having any of your own ideas and could lead to an assumption that you want to hand responsibility over to others to plan and direct what they think would be helpful for your child and family.



**"The actual process of making the plan was managed by the worker over a few sessions at our home. All we really had to do was come up with ideas and participate in the discussions about how it all might happen. It was actually a really interesting process and I felt really inspired afterwards."**  
Parent



**“So it’s okay to take the lead because you will be creating greater opportunities for your child and family.” Parent**

It is completely acceptable to say what you want and to expect that the worker will look for options and ideas to match what your child and family needs. Some workers are still learning **“self-directed planning”** as a way of supporting you to plan. If you find the worker is controlling the conversation, you can respectfully remind them of your role in determining what you believe is best. You can use comments like “Maybe the best way we can work together is for me to explain what we are wanting to achieve and for us to think about ways to make it happen.”

Or, you could say, “It’s important to us that we talk about our ideas first and then we can listen to how you think you can help us achieve the goals we want,” or “We’re very happy that you will be assisting us to find a way to make our ideas work.” You may also wish to invite others to help you plan with the worker. Family, friends and others often have ideas and ways of doing things that you may not have considered.

If you feel that the worker is not really understanding your needs or goals, speak up and let them know how you feel. You could try the following:

- “My child would really like to do..... (insert activity or goal) and I don’t understand how your suggestions will work.”
- “I’m not sure about this. Can we try something different?”
- “Is there another way we can get support so that my child can..... (insert activity)?”

If you feel that the discussion is not including some of your ideas, you can direct the conversation by saying “Now I would like to talk about my particular idea .... (name activity) and how we could achieve it.”

If you are not getting what you need from the planning process and you speak up, the worker should understand that they need to listen and try again to make a support plan that works for your child and family. If you don't speak up, the worker won't know that the support plan is not right and you will not get what you need.

Speaking up about goals that are important to you, should lead to a good discussion where different ways of getting an outcome can be explored. Some goals can be easily achieved while others are more complicated and may take time to finalise.

If the planning conversation still isn't heading in the right direction or if the worker's ideas about what should be included in your plan are not what you believe would be helpful, you can stop the discussion and explain why. You can use comments like, "I understand that what you are suggesting sounds like a good idea but I know my child would not enjoy it because ....(give reason)". Or the worker may say, "No that won't be funded." You could ask, "Why won't it be funded? How is my situation exactly the same as the one you mentioned?" You could also suggest, "How can you write down my idea in a different way so that it is more likely to be approved and funded?"

If you are still not happy about the way the support plan is being developed, you have a right to express your opinion. The first step would be to talk to the worker's manager about the problem. If you feel that they do not understand your concerns you could speak to one of the Parent Support Workers at the Association for Children with a Disability or seek advice from the **Disability Services Commissioner**, see page 24.

The Association for Children with a Disability website **[www.acd.org.au](http://www.acd.org.au)** lists some useful tips about how to advocate for the outcomes you want.

## **Ibrahim**

Ibrahim wants to join the local football team. Ibrahim's disability means that he needs someone to stay with him to help with his anxiety and the risk of him running away. Ibrahim's Individual Support Package does not pay for the team membership fees for the football club or for Ibrahim's team uniform but it does pay for a support worker to travel with Ibrahim from home to training, to games on the weekends, and to bring him home afterwards.

## Ten tips on leading the planning process

- Sometimes thinking about your child and talking to others about their needs might make you feel sad or angry about the challenges your child and family face. This is a common experience for many families and talking about your feelings to someone you trust, can be helpful. Even though you could feel the planning process is difficult because of the emotions that might emerge, remember what is motivating you – to make a better life for your child and family.
- You may have thought about people you already know who might be willing to share their interests or relevant skills to help your child achieve their goals. It is important to include these ideas in your planning discussions because they may provide a solution other than sourcing disability funding. For example, someone you know may enjoy spending time with your child because they both share an interest in music, sport, gardening, pets or computer games, so be clear what you are asking of people. It would be helpful to clarify whether they will volunteer their skills or if funding will be required.
- Your planning discussions will be more successful if you prepare beforehand, by thinking about what you and your family want to achieve.
- Identify any obstacles that prevent your child from participating in activities. Could some extra support, help to overcome those barriers?
- Find out about services and supports in your local area. The worker may be able to advise you about this or you may wish to contact your local council, neighbourhood house or other local community groups and ask what programs or activities are operating in your local area.
- If you need a language interpreter phone the Translating and Interpreting Service on **13 14 50**.
- Have a clear idea about the outcome you are seeking and together with the worker prioritise your ideas and goals in case it isn't possible to achieve them all at once.
- You can ask for written information in your preferred language.
- If you feel that you want to stop at any time during the planning conversation, don't be shy to say so. Concentration uses a lot of energy and taking a break can help you to re-focus your mind.
- Find out about the disability system by reading 'Through the Maze: An overview of services and supports for parents of children with a disability in Victoria' and think about what might be helpful for your child and family.

## Teaching your child to lead

Many children will grow into fully independent decision-makers while some will need ongoing support to actively participate in planning.

Including your child in the planning process from the start means that they can learn from you to take the lead as they get older and become more independent. This will also help others who are involved in the planning process to respect and encourage your child's active role in planning.

You can encourage a partnership approach to decision-making with your child as they build their capacity to make decisions. Rather than making all the decisions, as parents do for younger children, your role becomes one of guiding and supporting their decision-making as they grow to adulthood.

Some examples could include:

- Whenever possible, have your child present and involved in conversations that concern them.
- Use your child's preferred communication methods to gauge their interest in particular suggestions.
- Use different methods to gain an insight into their preferences – pictures, drawings and observing their body language.
- Communicate directly with your child and encourage the worker to do the same.
- Determine if your child likes the suggestions being discussed.

One of the biggest challenges for parents is adapting when their child becomes a young adult, with adolescence and the emergence of independence. While this time can be challenging, by teaching your child to develop skills that build independence you can increase their self-esteem and confidence in their own abilities.



**"Respectful listening, good communication and realistic goal setting are keys to successful planning"**  
ACD parent support worker

## Documenting your plan



Your plan is a document that includes the goals you want to achieve for your child and your family. It should also identify what supports will be required to ensure that each goal can be achieved, whether or not disability funding will be needed and who will provide support.

You do not have to engage a worker to help you develop and write up your plan but it is important to ask for assistance if you feel you need it. Contact the Department of Human Services' Intake and Response Team (see page 24) and request assistance with planning the support needs for your child and family.

**"Ultimately my goal is to support people to get out of planning what they need. So part of that is helping them to learn how to lead the planning and how to direct where the planning goes and take it in the direction they want and need to go. I'm merely there to help facilitate that, that's how I see things."  
Worker**

Your Plan will describe key action areas such as:

- Your goals (objectives)
- Why your goals are important (rationale)
- What you hope your goals will achieve (outcomes)
- What is needed to achieve your goals (supports/activities/equipment/therapy etc.)
- Who will provide the support to achieve your goals (human resources)
- How much the supports to achieve your goals will cost (budget)
- When your goals will be achieved (timeline)
- How to determine that your goals have been achieved (evaluation)

Documenting your plan is extremely valuable because it draws the key elements of planning together -

- 1 Thinking
- 2 Identifying
- 3 Deciding
- 4 Doing
- 5 Reviewing

After the discussions are completed and the plan has been written up by the worker, check to see that it contains all the information you want to be included. If you require formal support say that you want to see the final plan before it is submitted for approval and keep a copy.



## Now I have a plan - what comes next?

Not all goals require funding, but if you need to access formal supports through the Department of Human Services, there are a few steps you need to take.

Usually families with significant needs are able to access funding, however each request for ongoing disability support is individually assessed. There are specific guidelines that need to be followed before a final outcome is reached. It is important to discuss the application process with the worker. It can be complicated so we encourage you to ask as many questions as needed, to make sure you understand what is entailed in applying for your formal support needs through the Department of Human Services.

Information about how to make a plan and accessing ongoing disability funding is available on the Department of Human Services' website and is available in English, Arabic, Vietnamese and Chinese. See page 24.

Also other short term funding or support may be available for you to access, so ask the worker to explain all the support options relevant to your child and your family's needs.



**"We're trying to look at a few things, such as what the service system or the government can provide for him."  
Parent**

### **Amina**

Amina has speech difficulties and finds it hard to make friends. Amina loves going out and seeing movies so Amina's mum has found a student, Kate, who gets on really well with her and has learned to understand her. Once a month they go out on a Saturday afternoon to see a movie and have afternoon tea. Amina really looks forward to going out with Kate and Amina's mum has a bit of time to herself while knowing that her daughter is having a good time. Amina's Individual Support Package pays for Kate to spend time with Amina while Amina's mum pays for Amina's movie ticket and afternoon tea.



Sometimes thinking about your child and talking to others about their needs might make you feel sad or angry about the challenges your child and family face. This is a common experience for many families and talking about your feelings to someone you trust, can be helpful. Even though you could feel the planning process is difficult because of the emotions that might emerge, remember what is motivating you -

**to make a better life for your child and family**

## Glossary

**Circle of Support**

A group of family, friends and others who meet together and volunteer their time, skills and ideas to plan and support a person with a disability to achieve their personal goals.

**Disability Services Commission**

Is a body independent of government and service providers. Provides a free confidential resolution process for complaints about disability service providers.

**Disability Services**

A division of the Department of Human Services that provides and funds a range of services for people with intellectual, physical, sensory and neurological disabilities.

**Disability service provider**

A person (worker) or body (for example a community service organisation) who provides disability services under the Disability Act 2006 and are registered on the register of disability service providers.

**Disability funding**

Funds provided by the Department of Human Services to support a person with a disability to access services that are not readily available in the community.

**Disability support**

Supports that specifically meet the needs and goals of a person with a disability.

**Disability worker**

A person employed by a disability service provider or the Department of Human Services to assist with helping people with a disability and their families to identify the supports they need.

**Individual support package**

The amount of money the Department of Human Services allocates to a person that is used to purchase a range of ongoing supports as set out in an approved funding plan.

**Formal support**

Funding provided by the Department of Human Services to meet the cost of disability specific support.

**Informal support**

Naturally occurring support or assistance available through families and friends, neighbours and members of the community.

**Self-directed planning**

A process whereby a person decides how their needs, goals and aspirations should be met. Principles for self-directed planning are outlined in the Disability Act 2006.

## Resources

### **Action on Disability in Ethnic Communities (ADEC)**

Phone: 9480 1666 or  
1800 626 078  
Email: [info@adec.org.au](mailto:info@adec.org.au)  
[www.adec.org.au](http://www.adec.org.au)

### **Disability Intake and Response**

Department of Human Services  
Phone: 1800 783 783  
TTY 1800 008 149  
[www.dhs.vic.gov.au](http://www.dhs.vic.gov.au)

### **Disability Services Access Policy**

Department of Human Services (DHS)  
Phone: 1800 783 783  
TTY 13 36 77 and ask for  
1300 650 172  
[www.dhs.vic.gov.au/disability/publications-library/access\\_policy](http://www.dhs.vic.gov.au/disability/publications-library/access_policy)

### **Disability Services Commissioner**

Phone: 1800 677 342 (free call)  
or 1300 728 187 (local call)  
or TTY 1300 726 563  
Email: [complaints@odsc.vic.gov.au](mailto:complaints@odsc.vic.gov.au)  
[www.odsc.vic.gov.au](http://www.odsc.vic.gov.au)

### **Disability Services Individual Support Package**

Information Sheet and Handbook  
available in community languages  
Phone: 9096 0000  
[www.dhs.vic.gov.au](http://www.dhs.vic.gov.au)

### **Helen Sanderson Australia**

[www.helensandersonassociates.co.uk/about-us/hsa-australia.aspx](http://www.helensandersonassociates.co.uk/about-us/hsa-australia.aspx)

### **Inclusive Solutions—Making Inclusion Happen**

[www.inclusive-solutions.com](http://www.inclusive-solutions.com)

### **Information and support**

Association for Children  
with a Disability  
Phone: 9818 2000 or  
1800 654 013 (rural callers)  
Email: [mail@acd.org.au](mailto:mail@acd.org.au)  
[www.acd.org.au](http://www.acd.org.au)

### **Resource Families 'Building Support Networks'**

Information available in  
community languages  
[www.resourceingfamilies.org.au](http://www.resourceingfamilies.org.au)

### **Through the Maze: An overview of services and supports for parents of children with a disability in Victoria booklet**

Available in English, Arabic,  
Chinese and Vietnamese  
Phone: 9818 2000 or  
1800 654 013 (rural callers)  
Email: [mail@acd.org.au](mailto:mail@acd.org.au)  
[www.acd.org.au](http://www.acd.org.au)

### **Translating and Interpreting Service**

Phone: 13 14 50

### **Youth Disability Advocacy Service (YDAS)**

Phone: 9267 3755 (Manager)  
9267 3733 (Advocate)  
TTY is via the National Relay Service  
133 677  
SMS: on 0412 814 851  
1300 727 176  
(from outside of Melbourne)  
[www.ydas.org.au](http://www.ydas.org.au)

## Parent feedback

Your feedback will help us provide information that is relevant and of interest to families of children with a disability. After completing the survey please tear off this page and post to **Association for Children with a Disability, Reply Paid 84584, Hawthorn VIC 3122**. You can also email feedback to **mail@acd.org.au** or fax it to **03 9818 2300**.

Did the **Learning to Lead** booklet and DVD provide you with the information you were looking for?

**Yes**      **No**

What other information would you like to see included?

---

---

---

---

Was the information easy to find?

**Yes**      **No**

Could the layout or design be improved to make it easier to read?

**Yes**      **No**

If yes, how?

---

---

---

---

Is the size of this booklet right for this type of information?

**Yes**      **No**

Does the booklet have the right balance of pictures and text?

**Yes**      **No**

How did you receive this booklet?

---

Do you use the internet to find information?

**Yes**      **No**

Are you a member of the Association for Children with a Disability?

**Yes**      **No**

Any other comments?

---

---

---

## Parent feedback

Any other comments?

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

**Your name:**

---

**Address:**

---

**Phone:**

---

**Thank-you:**

---

## Membership

If you're not already a member of our Association you might like to consider joining.

Membership is **FREE** for families for the first 12 months.

Benefits of membership include our member magazine, NoticeBoard, which includes family stories, news and information about services and changes to government policy.

We encourage families to join our Association as well as other disability self-help groups. Our aim is to work together on issues that reach across all disabilities.

Service providers, organisations, interested persons and other community supporters are also encouraged to join our Association.

In addition to membership, we also welcome donations. All donations over \$2 are tax deductible.

For more information contact the Association office on 03 9818 2000 or 1800 654 013 (rural callers), by email [mail@acd.org.au](mailto:mail@acd.org.au) or visit [www.acd.org.au](http://www.acd.org.au)





 **Association for Children with a Disability**  
**Suite 2, 98 Morang Road, Hawthorn VIC 3122**  
**Phone 03 9818 2000 or 1800 654 013 (rural callers)**  
**Fax 03 9818 2300 Email [mail@acd.org.au](mailto:mail@acd.org.au)**  
**Web [www.acd.org.au](http://www.acd.org.au)**