



resourcing  
inclusive  
communities



# HARNESS THE POSSIBILITIES

Planning a positive future for a child with disability



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inclusive  
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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.

**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**

# Foreword

This booklet is based on the shared stories and experiences of families in NSW and is intended to help families develop a positive vision for their child with disability. It is hoped that it provides some ideas and strategies for building meaningful and fulfilling lives. It does not cover every aspect of a child's life, but aims to present a big picture view of how your child with disability can be supported to live an inclusive life in the community.

## Thank you

To all families who have generously shared their stories, photos and reflections.





# Introduction

**Having a child changes our lives forever. Children are a source of great joy and provide parents with unexpected opportunities to learn more about themselves and what it is that's really important in life. Parenting opens us up to a deeper love and gives us the capacity to care about someone else in a way many of us never previously imagined. Children bring us many gifts and this is part of the delight and wonder of parenting.**

Every child is unique - each with their own personality, qualities, abilities, characteristics and challenges. The birth of a child should be a time of celebration. Unfortunately, many families have said that when they gave birth to a child with disability, the feedback was largely negative and mostly about the difficulties that lay ahead. Although there may be challenges, there are also wonderful opportunities that exist for your child.



# A life beyond diagnosis

from Marianne Brazier

Gerard is a happy, sociable boy who loves music, school, watching movies and the Parramatta Eels football team. He was also diagnosed at birth with profound multiple physical and intellectual disabilities. The early years were full of surgery, hospital stays and early intervention therapies. While this was necessary, and in fact essential for our son, one of the unintended consequences was that our family became bogged down by this negativity. As a result, we could have lost sight of our son as a unique individual.

It would have been liberating at the time to have been encouraged to think about a positive future, to dream for Gerard in the same way I did for my other kids. **What if Gerard could have a real life instead of just an existence? Real friends instead of only paid workers? Wouldn't it be worth checking out? The answer was yes.**







# What does a

If asked what a good life is, people from around the world and from all different backgrounds are likely to come up with similar ideas. They may suggest things like family, friends, community, work and vocational opportunities, the freedom to live their life as they want, a chance to pursue interests and passions, a sense of belonging, personal development, enriching experiences, spiritual expression, travel, their own space and a place to call home.



# good life look like?

As human beings we all share similar desires, needs and aspirations for our lives regardless of whether we have a disability or not. It is important to remember that a good life for your child with disability has much in common with a good life for anybody.

Whatever the age of your child, you can look at what other children of a similar age want and do as a guide to what your son or daughter can also be doing. For example, young children like to have fun, need to learn to socialise and be encouraged to see and try new things. Play dates and joining dance, sporting or kid's clubs are important for all children. For a child with disability there may need to be some careful thinking and planning to provide the right support to make this happen. Not everything will be easily achieved but it is important to work towards making these positive life experiences.





# A good life for Joscelyn

from Meg Sweeney

When our daughter was born, her older brother was 16 months' old. Her birth was not a disappointment to us, as she was our much loved and valued baby girl, and as loved and valued as our son.

From the very start we wanted both our children to have the same life opportunities. We wanted people to see our daughter as we did – a beautiful little girl with a great life to lead! For this reason we have always had big dreams and high expectations for Joscelyn.



# Creating a

Many parents have written a



# VISION

**vision statement to keep them motivated.**

A vision can consist of simple, clear statements, about what you consider important for your child to have a good life. This can help you stay focused on what really matters and help with your decision making to choose and do things that support the goals of your vision.

As your child gets older, and you become more aware of their preferences and interests, the vision may become more specific. It can include the things they want to achieve or are important to them. For example, some vision statements have included the person's desire to travel, work with animals or become an artist.



# A Vision for Danielle

- For Danielle to know that she is a much loved and valued member of our family.
- For Danielle to be recognised for her individual personality, interests, preferences and contributions.
- For Danielle to have the opportunity to experience lots of interesting things and have choices that will allow her to grow.
- For Danielle to always be in community and have the opportunity to meet lots of different people and form a variety of connections and friendships.
- For Danielle to lead a meaningful and fulfilling life with educational, work, social and vocational opportunities and her own place she can call home.

You don't have to know how the things in the vision will be accomplished right away, as more planning can come later. You just need a sense of what you are aiming for to help guide your decision making.

Families have said that writing their vision down helps clarify their thoughts and enables them to share it with others. Being clear and confident in what you are seeking will make it easier for you to encourage others to share the vision of your child achieving the good things in life.





# Getting more people involved

Having a clear vision can certainly help parents imagine what a good life for their child could look like, but the question remains - how do you make it happen? Some families have realised that they need more people involved to help with the thinking and planning. Possibilities can multiply when you have more people who can offer their ideas and networks as a resource. This kind of support helps to reduce the pressure on parents to have all the answers and can result in fresh inspiration and perspective.

Keeping your family connected to other people is really important for your son or daughter. Your child may need your support to facilitate connections with others. This can be more easily achieved if your family is purposeful about being involved in community and intentional about inviting others in to support the vision you have for your child.



A circle of support is one idea families can use to get more people involved. It is a way of inviting a small group of people you respect from your family, friends and the community to help you think of ideas to plan your child's good life. Circles meet every six weeks to three months and can discuss a person's goals, no matter their age. Circles for young children can assist with things like creating a vision, planning play dates, transitioning to school, joining local kids groups and trying new experiences.





# Rhiannon's



# circle

from Di Samuels

My daughter Rhiannon has a circle of family and friends that meets every other month to work out ways to make her goals a reality. One of the goals for Rhiannon was to give her the opportunity to have an extracurricular experience she would enjoy and develop skills around. Someone from the circle offered to find out if Rhiannon could join gym classes. Some circle members also volunteered to come with me and check out the situation.

I really appreciated the moral support because sometimes a lot of stuff seems so hard and even impossible. The gym, however, has proved a great success. The manager welcomed Rhiannon and saw no reason why she couldn't join with the other kids. She fits in well with the class and her ability to work with others has really grown, so she no longer needs my support in the classes. Afterwards, I drop Rhiannon's brothers at soccer practice and she comes along to watch as well as meet other families.

The circle helps me see that the upcoming challenges are not mountains but molehills, especially when it helps me break them down into doable steps. People in the circle offer support in other ways that are often a natural extension of things they would typically do. Some have organised trips to the coast so that the kids can swim, which is an opportunity for Rhiannon to keep up a skill she is good at. I am a busy person but starting a circle and reaching out to the wider community is worth the effort because it multiplies opportunities for Rhiannon that I didn't even imagine could happen.



# The power of a positive introduction

As you have a key role in facilitating your child's connections with other people, how and what you communicate about your son or daughter will have a significant impact on how other people perceive and interact with them. By providing positive information, you can help others to know how to welcome your child and communicate with them.

The most important thing to remember is that your child is a child first and has more in common with all other children, rather than differences due to disability. Your child has a unique personality and individual gifts to bring to the world, which may be more about who they are than what they do.

In some settings, especially among professionals, you may have had to use language that focuses on disability and medical conditions, but you don't have to talk in those terms with your family, friends and the general public.





You can introduce your child as a very much loved member of the family and talk about their place within it, as a brother or sister, cousin or grandchild. You can talk about particular interests they have and the things they like and do. It may help to make a list of these things and then draft a few ideas about how you can make a positive introduction. If you look at Suzie's example, on the next page, there are lots of things she is and does that could make good conversation starters.

Some parents have prepared a short booklet of information with lots of photos showing who their child is in relation to family, personal interests and favourite things. The booklet is shared with others to help them get to know their child and have positive things to talk about with them. This can be helpful as a positive introduction to people you meet in play groups, childcare centres, preschools and schools.





Meet

# Suzie

Treasured grandchild  
Preschooler  
Keen swimmer  
Loving daughter  
Kid next door  
Little sister  
Friendly greeter  
Book lover  
Flower-girl  
Sign language learner





# Making community connections

Relationships and connections with other people are what makes life good for all of us at any age. The local community is a great resource for developing social networks. The best way to meet people is to be in places where people come together; such as playgroups, parent groups, preschools, regular classrooms, local clubs, sports associations, interest groups, work places, faith communities, public libraries, sports centres, gyms, community colleges, TAFEs and universities. Attending these places regularly, and at the same time as most people, increases the chances of becoming known and getting to know others.



Children learn and develop best when in contact with other children who can be positive role models. So it's really important that your child has lots of opportunities to meet other children by becoming involved in community groups such as kids clubs, music and dance groups, sports clubs, art clubs, scouts and girl guides.

As your child gets older you can discover their particular interests and encourage their involvement in community groups around those interests. It is often more natural for people to make connections with others around shared interests and experiences. Your child may need assistance to join in community events and groups, but it is important that they have these opportunities, and that time and effort is put into finding ways to ensure they are included.



# Creating valued roles

Developing valued roles for your child can be an effective means for developing community connections. Age appropriate roles tell people something about us, provide opportunities for us to develop our skills and can also enhance our image with others.

Referring to family roles such as son, daughter, sister, brother or grandchild makes a good impression about how your child is valued and connected within your family.

Another possible role for children is birthday party host. Lots of parents put considerable time and effort into creating memorable parties with lots of fun, so that all party goers have a really great time. Children can talk about Sarah's or Tom's awesome party for weeks and the child who played host is certainly viewed positively as a result.





As they become older, children will naturally adopt other roles, such as preschooler and school student. You can support your child to fulfil the role of the typical student well by making sure they look and act the part. Do they have the right uniform and school bag that helps their appearance of belonging? By finding out what is considered to be the coolest lunchbox or schoolbag by your child's peers, you can support your child to not only be in the role of student but cool student.

Consider the roles your child already has and enhance them. Is there a way not just to be a grandchild but a caring grandchild, perhaps by being assisted to send grandma greeting cards? What about roles in the home? Can your child be helped to be the good pet carer, table setter, garden waterer or cook's assistant? Think about developing your child's interest into a role, so that people meet a dancer, train enthusiast, card collector or basketball fan.





# Parramatta football fan

from Marianne Brazier

Gerard is a keen Eels supporter. This is not something that Gerard could tell us, but because we know him well we are aware that he is devoted to watching league games on TV. He is particularly excited when Parramatta is playing and is more interested in this team than any other.

I once went to a workshop about the importance of valued roles for connecting people with disability to the good things in life. I was determined to find an authentic role for Gerard around something that interested him. A Parramatta Eels fan was a role appropriate for a teenage boy and something people could relate to in his local community. To make the role recognisable for others, Gerard saved his Christmas and birthday money and bought the hat, jersey and scarf of the Eels football club to wear during the season.

When Gerard is in the role of Eels supporter it immediately breaks down barriers and people start chatting to him about football. They are not disconcerted that Gerard does not speak back to them. Before Gerard assumed the role of football fan he often seemed invisible to people when we went out in public, as no one would approach or speak to him. Now, people seem to find it easier to connect with Gerard because they no longer simply see a boy in a wheelchair but an Eels fan.

As Gerard gets older we can support him to fulfil this role even more. He could join the local football club and meet other football enthusiasts at games and social events.



# Involving brothers and sisters

Brothers and sisters can have significant lifelong relationships. Due to advances in healthcare, people, including those with disability, are living much longer. This means that your children are more likely to be in each other's lives longer than you are. Natural and supportive relationships make life good for everyone and so it is important to nurture the connection between your children.

Some parents feel it should solely be their responsibility to support their child with disability, and try to shield their other children from becoming too involved. It is, however, very natural for brothers and sisters to be involved and help each other. Brothers and sisters often know how best to include their sibling in what is happening around them and they regularly do this from a very young age.





As your children become older they may wish to contribute to the positive vision for their sibling with disability and this can foster good relationships and help build strong family ties. A circle of support is a great way to involve brothers and sisters as they are likely to have ideas about what makes a good life for people their age. It also gives siblings a strategy for keeping a support network around their brother or sister to uphold the vision beyond your lifetime.



That is





# what families do

from Daniel and Monica

We cannot really say when we became aware of Joscelyn (Jos) having a disability, as it became part of the natural process of growing in our knowledge of each other. Our parents made an effort to resist the pressure that Jos be involved in things separate from us and so we went through the ordinary, typical life experiences that brothers and sisters share. We travelled on the same school bus, played with the neighbourhood kids together, made all sorts of games and, of course, fought like any other sisters and brothers. At some point we realised that Jos sometimes needed more help around certain things, but our family was very strong in encouraging us to appreciate each other's value and contribution within the family.

We were eventually to realise, however, that not everyone thinks this way. We became very aware of times when Jos was being excluded or rejected from the ordinary things that we were automatically accepted into. This made us stick together because that's what families do. The three of us have found strength in this support and it will always continue because we care about one another. Jos is equal to us in this, she calls to find out if we're ok and wants to contribute in the things we do together.

Now that we have finished school we are thinking a lot about our own lives. What are we capable of? How should we use our time? What contribution will we make to society? It makes us more aware of these questions in Jos' life and we feel committed to helping her reach her full potential and to have ongoing opportunities, like we would want for ourselves. When we think about the future we know that we are free to go and do our own thing, to follow our dreams and plans, but our connection to each other is also important to us. We may make decisions in future years to live closer, maybe as mum and dad get older, but this is part of the closeness we have. We have always been involved in each other's lives. It is who we are as a family.



# What about education?

Thinking about education choices can be exciting yet daunting for families. Choosing an early childhood setting and then a school are important decisions and you will need to do some research.

If you start thinking about school a couple of years before your child is due to start, the process is likely to be easier. Many families have used the vision they have for their child to consider which school is most likely to achieve the life they want for their child. If being known and valued by other people is an important aspect of your vision, then belonging to a typical preschool and school community can be a significant start.

Finding a school and classroom that welcomes children of differing backgrounds and abilities can provide good role models.



Role models are important when you consider how much children readily learn from, and how frequently they imitate each other. It also offers everyone valuable lessons about understanding and appreciating diversity.

One of the first communities a child can belong to is a preschool and school. It is a place to meet lots of different people, learn social skills, share experiences and be together. These early experiences of community can also be the foundation for developing connections in the wider community after leaving school.







# Lessons in the community

from Wendy Stroeve

As a result of 13 years spent in mainstream classrooms Alex, has become widely known in our local community. He is known not only by the actual students with whom he shared classes but by their siblings, parents, aunties, neighbours, the school staff, teaching and ancillary, the bus driver and so on. When Alex is met downtown he's greeted by people who know him by name. Our focus as a family is to use this direct knowledge of Alex and wider interest in his life, acquired through school, to build his links with his broader community.







# Living with choice and control

One aspect of the good life is the freedom to live life the way you want. This includes how your paid supports are arranged and delivered.

Many people with disability and their families are seeking supports that are individualised, personalised and tailored to their exact needs and goals. They wish to self-direct these supports and some choose to self-manage them completely and take responsibility for arranging, staffing and financially managing their supports.

This maximises control, flexibility and choice over their daily lives.



# My life



# the way I want

from Sylvana Mahmic

My son, Abdul-Karim, has left school and our family has chosen to self-manage his supports, so that he can arrange his life the way he wants. He has joined a number of community classes where he meets lots of people and learns new skills. His current interests are dance, drumming and martial arts.

Though there were some challenges, it hasn't taken as much time as I thought it would to make decisions and manage Abdul-Karim's supports. It is also better for him not to have to run to someone else's timetable.

My son's life is now on his terms and his confidence is growing. He is becoming motivated to try new things and get to know more people in the community. He is pictured here with new friends he met at some of his community classes and with whom he also spends time outside of class. Our family really enjoys seeing Abdul-Karim's sense of self developing as he discovers the things that truly interest him.



# Supporting your child's best interests

There may be times when you have to speak up on behalf of your child to ensure they are receiving the care, attention and opportunities to which they are entitled.

In order to do this well, it is helpful to have good information that supports your efforts. Keep yourself informed by going to events, information sessions, subscribing to newsletters, joining mailing lists or relevant social media platforms. By doing this you are more likely to find out about the right person or information that can assist you.

Advocacy organisations can be a source of information and advice in relation to particular issues you may need to consider on behalf of your child. They may also be able to help you with ideas and information about becoming more effective in speaking up for your child's best interests.

Family Advocacy is an independent NSW advocacy organisation that works with families to promote and defend the rights and interests of people with developmental disability.

You can contact Family Advocacy on 1800 620 588 if you need advice around a specific issue of concern to you.



# Tips for speaking up



## **Be confident**

You know your child best.



## **Decide what you need**

Think about what you and your child need in the situation.



## **Know where you stand**

Get information from advocacy organisations and community groups. Ask about relevant policies, procedures and laws.



## **Be prepared**

Develop a plan about what you want to say. Prepare notes listing each of your concerns. Consider asking a friend or advocate for help and to support you at a meeting.



## **Use good communication skills**

Stay calm and express yourself clearly. Be a good listener; what you hear may be as important as what you say.



## **Keep a record**

Make notes, including the name, title and telephone number of each person you speak to and a summary of the conversation.



## **Use the chain of command**

Be sure to speak to the person who has the authority to resolve the issue or concern.



## **Get clear answers**

Do not accept a verbal denial of your request either in person or over the telephone. Submit a written application and ask for a written decision.



## **Ask for help**

Do not give up. If you need assistance, contact an advocacy organisation.





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