

Thinking about your child's future

It's natural for parents to plan for and talk about their child's future. However, parents of children with a disability can often feel anxious because their child's future seems so uncertain. They have the stress of not only experiencing the everyday challenges of raising a child with a disability, but also wondering what will happen when their child is an adult.

Your thoughts about what comes next in your child's life can be just as overwhelming and stressful as going through the diagnostic process and can negatively impact on your day-to-day living if supports and services are not put in place¹.

Important things to remember

You can't predict what will happen in the future

It's natural to wonder about the level of care and support your child will need throughout their life. Some common questions you may be asking include:

- Will my child be ok?
- Will my child go to school?
- Will my child have a job?
- Will my child get married and have a family of their own?

It's important to remember that even for typically-developing children, we can't predict what will happen in the future².

One parent described how she felt regarding her child's future by saying:

*"For me...it was the not knowing...is my child going to have an intellectual disability, is my child going to be able to SPEAK, is my child going to be able to attend school...at first that's all I could think of. It just made me come up with a thousand different questions that no one can answer because... we don't KNOW yet, whereas now, a year and a bit later...we're just taking one step at a time...let's deal with today."*¹

Tips for managing uncertainty

Ask questions

Find out all you can about your options and don't be afraid to ask questions. Gathering information is key to understanding your child's diagnosis and to making decisions around what will work best for your child and family.

Organise early intervention

Early intervention will provide your child with the best opportunity to learn and become more independent in the future³. Research has shown that early intervention can improve children's skills and lead to improved outcomes in different areas such as communication, self-help, social and play skills, and lead to improved functioning later in life⁴⁻⁶.

Which intervention is best for my child?

You may be wondering which intervention is best for your child as there are many different options available. [Here is a website](#)⁷ which provides some general information about what early intervention is, what interventions are available for children with a disability and some ideas on what to look for.

Get involved at home

Family involvement is important for early intervention to be effective². You and your child's family members are the ones who interact most with your child every day. It is essential that your child continues practicing what they are learning in early intervention.

Talk to the health professionals involved in your child's early intervention about ideas for incorporating things they are working on into everyday activities (e.g., during meals, baths, when reading books, and playing games). This is a good way for you to support your child at home and will provide continuity and a sense of routine when everyone in your child's life is on the same page. This will also give you some control in managing the diagnosis¹ and allow you to better support your child.

Set goals for your child

While it's natural to be thinking about what you want your child to achieve in the future, the goals you set should also be appropriate for your child to work towards and achieve now. Goals should be relevant to your child's current strengths and challenges, and they should be specific rather than broad. For example, 'I want my child to use gestures, such as waving hello to their friends' is a more specific goal than 'I want my child to interact better with other children'.

When thinking about goals, it can also help to consider your child's interests and strengths. As your child progresses you will need to revisit these goals from time to time to make sure they're still appropriate.

Be confident

Try not to doubt yourself during this process and don't underestimate your ability to support your child. Your involvement in providing supports will lead to better outcomes². You know your child best and you can give valuable information to the health professionals working with them.

Self-Evaluation

What am I most worried about for my child's future?

What can I do now to help prepare my child for the future?

What are some ways that I can be involved in my child's support and services?

References

1. Rabba AS, Dissanayake, CA, Barbaro, J. Parents' experiences of an early autism diagnosis: Insights into their needs. Res Autism Spectr Disord. 2019; 66: 101415.
2. Rabba AS, Dissanayake, CA, Barbaro, J. The development of a family support package for parents following a child's diagnosis of ASD: What do parents want? PhD [dissertation]. Melbourne: La Trobe University; 2019
3. O'Reilly B, Wicks K. Australian autism handbook: The essential resource guide to autism spectrum disorder. 2nd edition. New South Wales: Jane Curry Publishing; 2013. Retrieved from <http://ebookcentral.proquest.com>
4. Prior M, Roberts J, Rodger, S, Williams K. A review of the research to identify the most effective models of practice in early intervention of children with autism spectrum disorders. 2006; Australia: Australian Government Department of Health and Ageing.
5. Vivanti G, Paynter J, Duncan E, Fothergill H, Dissanayake C, Rogers S. Effectiveness and feasibility of the Early Start Denver Model implemented in a group-based community childcare setting. J Autism Dev Disord. 2014; 44: 3140-3153.
6. Howlin P. Prognosis in autism: do specialist treatments affect long-term outcomes? Eur Child Adolesc Psychiatry. 1997; 6:55-72.
7. <https://raisingchildren.net.au/disability/services-support/services/early-intervention#therapies-and-services-nav-title>