

WHAT I WISH I HAD KNOWN

Research summary

What we did

We talked to 21 parents of kids and young adults with intellectual disability and chronic health conditions. We wanted to know about their child's healthcare journey and understand what skills and knowledge they learnt along the way. Some healthcare topics included epilepsy, dental care, and respiratory health.



What we found

We organised parents' stories into five themes.

1. Better interactions for parents and healthcare professionals: For parents, helpful skills (e.g., asking questions, advocating for kids) developed over time. For healthcare professionals certain traits (e.g., trusting, good communication skills) contributed to a good working relationship.

2. Navigating healthcare and disability systems: Working with healthcare and disability systems can be challenging, especially when transitioning from child to adult care and trying to get equipment (e.g., wheelchair).

3. How to get the best healthcare: Managing a health condition can be improved by reading your child's subtle health changes, being proactive to avoid illness, and involving kids in their healthcare.

4. Support: Parents need others to help them, which can come from peers, family members, healthcare professionals and organisations.

5. The right information at the right time: Different information is needed at different times and independent research is important.

Parents had advice...

Top tips from parents to parents

Managing health

Understanding your kid's disability or health problems can take time and some trial and error.

Be proactive in preventing healthcare problems. For example, regularly visit the dentist to prevent dental problems.

Try to balance appointments and treatments with enjoying time with your kid.

Supporting kids to have some control in their healthcare can get them more involved and be empowering.

Information

Do your research Information helps you to understand and make decisions about your kid's health.

Good sources of information:

- > internet
- > other parents
- > support groups
- > advocacy organisations

Healthcare system

- > Transitioning from the child to the adult system can be challenging –Be prepared.
- > Getting equipment for children with mobility issue can be difficult and takes time.

Healthcare appointments

Prepare Know what you want to get out of the appointment and bring notes.

Advocate, advocate, advocate Push for your kid's needs. This can be tough and takes practice.

Ask questions

There are no stupid questions.

Manage expectations

Explain to healthcare professionals what your kid needs before appointments.

Support

You can't do everything yourself, **lean on your village** if you have one - they may need training.

Peer support Some parents found it helpful to talk to people with similar experiences and a few steps ahead of them. Peer support can be found

- > Online or in person
- > Through disability or health condition organisations
- > Disability specific play groups (regular child health groups might not work for you).

Self-care Parents wanted to tell other parents that it's important to look after yourself (even if it's difficult to find the time).

Some parents found it helpful to

- > Exercise (e.g., walking, gym, yoga)
- > Get some fresh air
- > Do things for yourself (e.g., study, read, listen to music)
- > Have some respite

Top tips from parents to healthcare providers



Be good communicators Talk and listen to the kids (and the parents).



Be a team player Collaborate with parents and other healthcare professionals to get the best outcomes.



Be holistic Think of the kid as a whole, now and in the future.



Be sensitive Be aware that some information can be life changing and parents may need a support person with them.



Be patient Take time to do things at the kid's pace.



Be empathetic Consider point of view and experiences of the kids and families.



Be supportive of information needs Help parents to understand the condition, what to expect, and what services are available.

What are our next steps?

We are conducting further studies to find strategies that can support the healthcare management of young people and their families.

The results of this study and other studies will help us develop new support and resources for families.

How can you contact us?

If you have any questions or feedback for our team, or would like a full copy of the paper, please contact Dr Jenny Downs at:
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