



March 2022: Issue 4 The Monthly Newsletter GeneEQUAL



We hope you have been safe and well this past month!



GeneEQUAL will make genetic health care better for people with learning and intellectual disabilities.



We want to hear from you!

Where we are up to:



- 14 people have been interviewed by Iva and Julie
- We want to talk to 6 more people

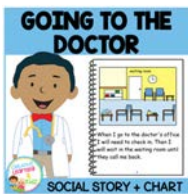


If you know anyone who is interested in the study, please contact Iva and Julie using the details on page 3



We had an Advisory Workshop in February.

People in the workshop:



- Shared some traumatic experiences they had faced, for example being bullied
- Felt that trauma informed care was important
- Mentioned that genetic information could be hard to understand
- Shared ideas to make genetic information easier to understand, for example social stories

People recommended using:

- positive language, for example use the word "condition" instead of "disorder"
- different ways to communicate with people who don't use verbal language, for example key signs

We will have another Advisory Workshop in May



WHO can join GeneEQUAL?

People who:

- have learning and intellectual disability
- Are of any age
- Can consent
- Live in NSW
- Have had genetic testing and/or counselling, even as a child

Do you or someone you know want to find out more about GeneEQUAL ?

If so, please let Iva and Julie know:

- Email: i.strnadova@unsw.edu.au
- Mobile phone: 0426 959 172