




GeneEQUAL Toolkit

Key Learning Principles



October 2023

 www.geneequal.com

 geneequal@unsw.edu.au

 www.facebook.com/geneequal

 www.instagram.com/geneequal

 <https://vimeo.com/channels/geneequalhealth>

In summary:

There are **three key learning principles** to support **inclusive, person-centred and respectful** genetic health care for people with intellectual disability:

1. Make reasonable adjustments
2. Ensure genetic health care is person-centred
3. Practice trauma-informed care.



Participants in GeneEQUAL co-production workshop

Making Reasonable Adjustments



'Sunshine' by Mark Podmenik



Making Reasonable Adjustments



In summary

- Making reasonable adjustments means doing things differently to ensure people receive high quality care regardless of their individual circumstances, and are not disadvantaged or harmed.
- People with intellectual disability can often feel excluded from health care interactions if information is not presented to them in a way which meets their communication needs.
- Health care professionals and services need to make **reasonable adjustments** for genetic health care to be inclusive, person-centred and respectful for people with intellectual disability, in alignment with [NSW Health policy](#).

Key strategies:

- Adjust communication methods
- Allow additional time
- Provide information in alternative formats
- Use a communication folder
- Record the meeting
- Use the Teach Back method

Adjust communication methods

Adjust your communication methods by considering the person's communication preferences.

For example, some people with intellectual disability will prefer to communicate using augmentative and assistive technologies such as tablets. Ask ahead if such technologies are needed as they can be brought in and used during appointments.

"I reckon it's very important to be inclusive, because I think very much people can feel un-included, especially people who've got the condition and they kind of feel left out of the picture; but I think it's important for them to know the facts... in the case they want to find out more about it." - Jeremy, Health Care Consumer



Participants in GeneEQUAL co-production workshop

Allow additional time

Allow for additional time to support the understanding of complex topics.

For example, consider booking a double-length appointment or a series of appointments to support information sharing and decision making over a time period appropriate to a person's needs. General Practitioners may access Medicare Item 707 for a comprehensive health assessment appointment, which could be followed by a separate appointment (as required) for a health care management plan for people with an intellectual disability.

"...give me time to think, so as I can listen... listen to them before they reply." - Ian, Health Care Consumer

"Oh, no. If it's rushed, you can forget it, because you've confused the person already." - Richard, Health Care Consumer



Participant in GeneEQUAL co-production workshop

Provide information in alternative formats

Provide genetic information in alternative formats to support understanding of complex information.

For example, visual supports or Easy Read resources such as the [GeneEQUAL Easy Read Genetic Health Care Booklets](#) describe how to provide results, summaries and letters in an Easy Read format.

[Easy Read communication courses](#) are also available to learn how to create documents and communications in an Easy Read format.

"It wasn't Easy Read. So I don't even know how to read. I find it hard. You it's very hard to read the form, you know? Even my mum found it hard to read... Very hard to understand, like, what is this, what do you want me supposed to do." - Lillian, Health Care Consumer

Use a communication folder

A communications folder may improve communications with health care providers.

For example, the '[My Health Matters](#)' folder produced by NSW Council for Intellectual Disability has been developed by people with intellectual disability to support effective communication with health care professionals.

Record the meeting

Recording a meeting can be a useful tool to facilitate shared decision making, support understanding and may assist with remembering information under stressful circumstances.

For example, recording meetings on a smartphone or tablet that can be played back can support a person to recall clinical information. Legislation regarding consent to record a consultation varies across states in Australia and needs to be carefully considered, as summarised in this article.



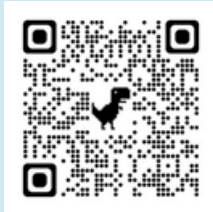
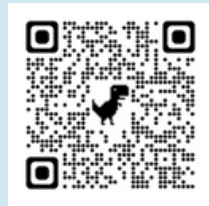

Use the Teach Back method

Teach Back is a 6-step conversational tool that can be used to check a person's understanding of important information. It involves asking the person to repeat back information in their own words.





This 6-step Teach Back factsheet provides information about the Teach Back and includes links to video examples.

"They talk too fast, or, you know, they don't explain what the term is, um, tell me what it is, like, step by step." - Lillian, Health Care Consumer

Useful links

Source	URL	QR Code
NSW Health Policy	https://www1.health.nsw.gov.au/pds/Pages/doc.aspx?dn=PD2017_001	
Raising Children Network – Augmentative and Alternative Communication	https://raisingchildren.net.au/autism/development/language-development/augmentative-communication-asd	
Medicare Benefits Schedule – Item 707	https://www9.health.gov.au/mbs/fullDisplay.cfm?type=item&q=707&qtype=item&criteria=707	
GeneEQUAL Easy Read Genetic Health Care Booklets	https://geneequal.com/genetic-resources/our-easy-read-health-booklets/	
Council for Intellectual Disability – Easy Read Communication Course	https://cid.org.au/event/learn-easy-read/	

Useful Links

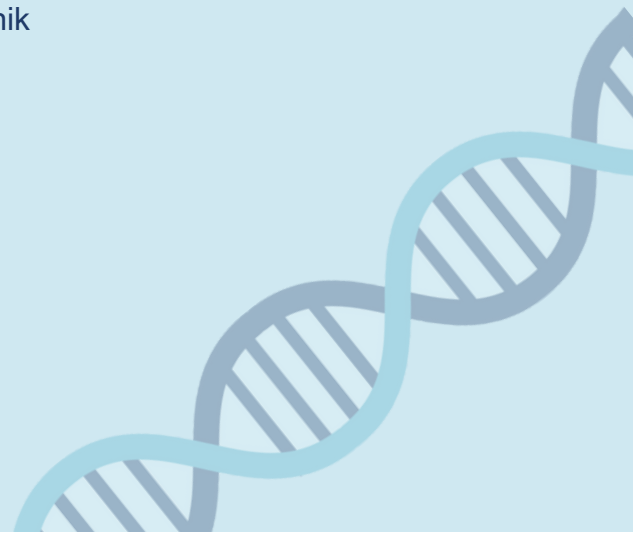
Source	URL	QR Code
Council for Intellectual Disability – My Health Matters Folder	https://cid.org.au/resource/my-health-matters-folder/	
Rimmer, A. (2019). My patient wants to record our appointment, what should I do?. BMJ, 364.	https://www.bmj.com/content/364/bmj.l1101	
Prictor, M., Johnston, C., & Hyatt, A. (2021). Overt and covert recordings of health care consultations in Australia: some legal considerations. Medical Journal of Australia, 214(3), 119-123.	https://www.mja.com.au/system/files/issues/214_03/mja250838.pdf	
Safety Fundamentals for Person Centred Communication – Teach Back	https://www.cec.health.nsw.gov.au/_data/assets/pdf_file/0006/618387/Teach-Back.PDF	



Ensuring Genetic Health Care is Person-Centred



'Flowers' by Mark Podmenik



Ensuring Genetic Health Care is Person-Centred

In summary

- Person-centred care respects and responds to the preferences, needs and values of people receiving healthcare.
- It involves working with patients, their families, carers and support people to promote shared-decision making and care planning.
- It is essential to the delivery of safe, high-quality care and fosters mutual respect and trust between healthcare providers and people receiving care.

Key strategies:

- Plan together what to talk about in an appointment
- Enable shared decision-making
- Provide tailored reports and health care plans
- Help people with intellectual disability access appropriate supports

Plan together what to talk about in an appointment

Shared agenda setting for appointments ensures that the person with intellectual disability is able to discuss topics that are important to them.

For example, in a preparatory meeting (such as an intake call with a genetic counsellor) and/or the start of an appointment, ask what topics they would like to focus on. Tip sheets of frequently asked questions or the [GeneEQUAL Easy Read booklets](#) may be useful resources in these discussions.



GeneEQUAL team in co-production workshop

"These are the things I would have expected in a genetics consultation. For them to have time, for them not to rush me, for them not to make me feel, *"Have you got any questions? No? Ok! Let's go!"*. Yeah. I'm not a number, I'm a human being now, with - I'm a very emotional human being. I need support. I'm here to get your counsel." - Maria, Health Care Consumer

Enable shared decision-making

Shared decision making involves discussion and collaboration between a person and their health care provider. It is about bringing together the person's values, goals and preferences with the best available evidence about benefits, risks and uncertainties of treatment, to reach the most appropriate health care decisions for that person.

Incapacity or reduced decision-making should not be assumed with a diagnosis of intellectual disability.

Many people with intellectual disability have the capacity and desire to make medical decisions for themselves. When clinicians make reasonable adjustments to provide patients with information that is understandable to them, patients can often provide valid informed consent.

Further learning:

- The eLearning module 'Consent, Decision-Making & Privacy - A Guide For Clinicians: Course Code 249108791' is available for NSW Health staff on HETI My Health Learning
- For non-NSW Health staff, the course can be accessed on the UNSW 3DN site

Provide tailored reports and health care plans

Genetic conditions and their associated terminology and treatment plans can be very complex and difficult to understand.

People with intellectual disability, their support people and medical teams are sometimes unable to recall the name of their specific genetic condition or what health checks and therapies they have been recommended.

Ways to provide tailored information and health care plans include:

- Write easy to understand genetic reports in plain language. Templates can be accessed [here](#).
- These [medical templates](#) in Easy Read can help you writing letters and appointment reminders.
- Provide specific management guidelines and standards of care documents to patients, family and support people, and their medical teams, including their GP. Click to access [Centre for Genetics Education patient factsheets](#) and [clinical guidelines](#).
- Provide Easy Read health check lists, that could be integrated into a person's communication folder such as the [My Health Matters Folder](#).
- Encourage people with intellectual disability to book a [yearly health check](#) with their GP.

"So, apparently, they have a - the X chromosome is the [HUWE1] gene. It's spelt like the phone, I think. You know, Huawei, I think it is. Gene. I'd have to have a look...!" - Teresa, Health Care Consumer

Help people with intellectual disability access appropriate supports

Psychological and Emotional Support


People with intellectual disability often need psychological support and counselling before and after a genetic diagnosis is made, but may experience difficulty accessing appropriate support.

Health care professionals can assist by:

- routinely talking about the importance of emotional wellbeing during each appointment.
- suggesting referrals for additional professional support. Referrals may need to be made to a psychologist or counsellor trained in supporting people with intellectual disability. For example, the [Intellectual Disability Mental Health Connect website](#) aims to assist people with intellectual disability access appropriate services and support for their mental health. It has information for people with intellectual disability, their supporters, and professionals.

Subsidised counselling sessions may be accessed using the [Better Access Scheme](#).

"...you've got to watch the way you present things to us, because we will just break down and cry and think it's other things.... see with us, you can't - like, we get very, like, broken-hearted about things. We dwell on it, we stew on it." - Katarina, Health Care Consumer



Help people with intellectual disability access appropriate supports


Peer-Peer Support

- Joining a support group with people and families who have the same genetic diagnosis can have many benefits. Some organisations have specific patient support groups for people with intellectual disability.
- To learn about connecting with patient-support groups and providing support before and after a rare disease diagnosis, clinicians can complete the [Rare Disease 101 Australia](#) online module or join the [RAReST community of clinical practice](#).

Visit these websites for information on Australian and global rare disease patient organisations:

- Rare Voices Australia [RARE \(Rare Awareness Rare Education\) Portal](#)
- National Institute of Health [Genetic and Rare Diseases Information Center](#)

"Just knowing you're not alone, and just sharing with others, sharing your story and your experience of how you've gone about living your life." - Jeremy, Health Care Consumer



Help people with intellectual disability access appropriate supports

Resources for Patients:

- Easy Read booklets about accessing support for mental health issues (available in English, simplified Chinese, Arabic and Vietnamese languages).
- Healthy Mind, an online Easy Read tool designed to support adults with mild to borderline intellectual disability to recognise and regulate their thoughts and feelings.



Participants in GeneEQUAL co-production workshop

"...it was kind of hard, because, functioning as an autistic person, it made it hard to persuade them that yes, I still need that support, and yes, I still need assistance to do things" - Jeremy, Health Care Consumer

Help people with intellectual disability access appropriate supports

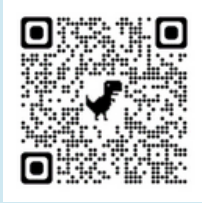

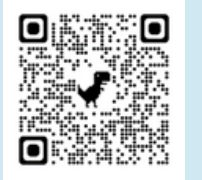
Supports in the Disability, Education and Workforce Sectors:

- **National Disability Insurance Scheme (NDIS) plans:** A genetic diagnosis can be valuable to advocate for an appropriate NDIS plan, especially if there are recognised standards of care or management guidelines detailing appropriate therapies and supports that should be implemented. The [NSW Council for Intellectual Disability](#) has several guides to support effective NDIS planning and advocacy.
- **Education and workforce:** Health professionals may supply letters to educators or employees about their patient's genetic condition. A brief summary with links to relevant support groups can be valuable to advocate for person-centred care.




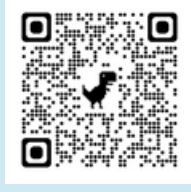




Participants in GeneEQUAL co-production workshop


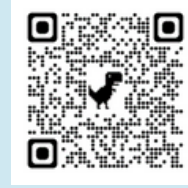
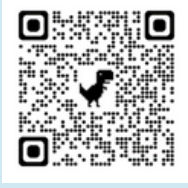
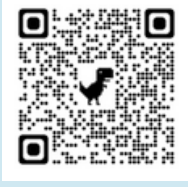
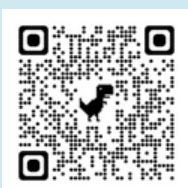
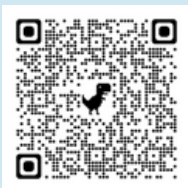
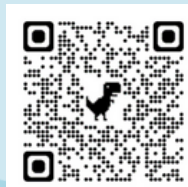
Useful Links

Source	URL	QR Code
GeneEQUAL Easy Read Genetic Health Care Booklets	https://geneequal.com/genetic-resources/our-easy-read-health-booklets/	
NSW Health E-Learning – My Health Learning	https://www.heti.nsw.gov.au/education-and-training/my-health-learning	
UNSW 3DN – E-Learning for Health Care Professionals	https://www.3dn.unsw.edu.au/content/health-mental-health-elearning	
Australian Genomics – Plain Language Genomic Test Reports	https://www.australiangenomics.org.au/tools-and-resources/plain-language-genomic-test-reports/	
Council for Intellectual Disability – Tailored Easy Read Health Letters	https://cid.org.au/resource/easy-read-health-letters/	

Useful Links

Source	URL	QR Code
Centre for Genetics Education – Patient Fact Sheets	https://www.genetics.edu.au/SitePages/Intellectual-disability-childhood-syndromes-Genetic-causes.aspx	
Adam, M. P., Mirzaa, G. M., Pagon, R. A., Wallace, S. E., Bean, L. J., Gripp, K. W., & Amemiya, A. (1993). GeneReviews® [Internet].	https://www.ncbi.nlm.nih.gov/books/NBK1116/	
Council for Intellectual Disability – My Health Matters Folder	https://cid.org.au/resource/my-health-matters-folder/	
Council for Intellectual Disability – Yearly Health Check Fact Sheet	https://cid.org.au/resource/yearly-health-check-fact-sheet/	
Intellectual Disability Mental Health Connect	https://idmhconnect.health/	
Australian Government – Better Access Initiative	https://www.health.gov.au/our-work/better-access-initiative	

Useful Links

Source	URL	QR Code
Medics 4 Rare Diseases – E-Learning	https://learn.m4rd.org/	
Rare Voices Australia – Rare Diseases Project ECHO	https://rarevoices.org.au/rare-disease-project-echo/	
Rare Awareness Rare Education (RARE)	https://rareportal.org.au/	
Genetic and Rare Diseases Information Center	https://rarediseases.info.nih.gov/	
UNSW 3DN – Easy Read Information Sheets on Mental Health Services in NSW	https://www.3dn.unsw.edu.au/consumers_information	
Black Dog Institute – Healthy Mind	https://www.blackdoginstitute.org.au/resources-support/digital-tools-apps/healthy-mind/	
Council for Intellectual Disability – NDIS Archives	https://cid.org.au/resource-category/ndis/	

Practice Trauma- Informed Care



'Rainbow' by Mark Podmenik



Practice Trauma-Informed Care

In summary

- It is essential that genetic health care professionals practice trauma-informed care to provide safe and quality health care for people with intellectual disability.
- Trauma-informed health care means understanding, recognising and responding to trauma, and seeking to prevent re-traumatisation of clients.
- People with intellectual disability report higher rates of traumatic experiences in their personal lives, compared to others and may have a significant trauma history.
- Key strategies for enabling trauma-informed genetic health care include:
 - Providing a space which feels safe, welcoming and comfortable
 - Using positive, non-discriminatory language
 - Providing adequate preparation for appointments
 - Providing options and choices.

Key strategies:

- Provide a space which feels safe, welcoming and comfortable
- Use positive, non-discriminatory language
- Provide adequate preparation for appointments
- Provide options and choices

Provide a space which feels safe, welcoming and comfortable

Providing a space that feels safe, welcoming, and comfortable reduces the risk of re-traumatisation and causing undue emotional stress. You could:

- Introduce yourself, your team members and explain your roles.
- Take time to establish rapport. For example, ask about a person's hobbies or interests at the start of an appointment.
- Ensure that there is appropriate seating and a quiet environment.
- Speak with a calm and steady tone.
- View the start of [Video 1: Best Practice](#) where the genetic counsellor takes the time to directly introduce herself to the client, explains what will happen next, and ensures seating is appropriate.



Participants in GeneEQUAL co-production workshop

"Just make them just feel at ease, and just ask them, you know, basic questions in case they want to get to know you. Like, what do you like? What do you like doing with yourself? Just so they know who you are, and they feel more comfortable talking to you about it. Easing into it, I think." - Jeremy, Health Care Consumer

Use positive, non-discriminatory language

It is important to use positive, non-discriminatory language to provide a safe and respectful environment (even if family or support people use different language). You should:

- Avoid jargon and abbreviations. See the table below for language to use and language to avoid.
- View the examples of language to avoid in the [GeneEQUAL Take One videos](#), with better options provided in the [GeneEQUAL Take Two videos](#).



Participant in GeneEQUAL co-production workshop

"They did show me, yes, you have got the bad X [referring to chromosome] on Mum's side of the family, like that, and I knew I wasn't normal to other - I know I was missing, some part of my brain has gone missing." - Aaron, Health Care Consumer

"Treat me like a person... others don't treat you like a person. They treat you like an 'it'." - Richard, Health Care Consumer

Use positive, non-discriminatory language

Use positive, non-discriminatory language	Language to avoid
Use complete terms e.g. intellectual disability	Don't use abbreviations e.g. ID
Genetic 'condition' or 'variant'	Genetic 'disorder' or 'mutation'
'General' or 'neurotypical' population	'Normal' population
'Chance' of a genetic condition	'Risk' of a genetic condition
Intellectual disability	Mental Retardation/ insufficiency/ impairment
Learning differences	Mental Retardation/ insufficiency/ impairment
Person or individual	Case

Provide adequate preparation for appointments

Clinical genetics can be confronting and anxiety-provoking for people who do not know what to expect.

You could:

- Prior to, or at the beginning of an appointment, provide a simple and clear explanation of what usually happens. This will support people with intellectual disability to prepare and reduce anticipatory anxiety.
- Download and read through together the Easy Read booklet [Get Ready To Go To The Genetic Clinic](#) to support a preparatory discussion for a person's first visit to a genetics clinic.



GeneEQUAL team member in co-production workshop

"Simple, like [my genetic counsellor] did with this information for us... And also, make it in different languages so you can understand if it's a different culture... that way, they can understand in their own language besides English, and make it easier for them to understand what it's all about." - Milly and Mason, Health Care Consumers

Provide options and choices

The provision of choices is empowering and an important part of informed consent. Many people with intellectual disability have reported being excluded from decision-making in their lives. It is important to empower people with intellectual disability to be involved in decision-making relating to their health care, wherever possible.



Participant in GeneEQUAL co-production workshop

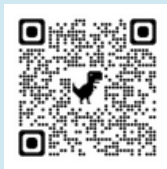
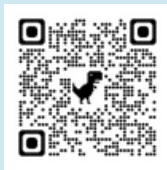
"I reckon it's very important to be inclusive, because I think very much people can feel un-included, especially people who've got the condition and they kind of feel left out of the picture, but I think important for them to know the facts in case they want to find out more about it." - Jeremy, Health Care Consumer

Provide options and choices

To empower people with intellectual disability attending clinical appointments, you could:

- Check who the person with intellectual disability would want to attend an appointment with them (if anyone) rather than assuming that they would want their parent or other support person to attend appointments.
- Always make sure communication occurs with the person with intellectual disability first, rather than ‘talking over them’ to their support person.
- Explain what would be involved in an examination, why the examination is useful, and provide choices to a person with intellectual disability about being examined or not. The same is the case for taking photographs.
- Actively involve the person with intellectual disability in decision making, for example asking for their opinion. Make sure you are reminding them that providing consent is their choice, which they are allowed to decline.
- View the [GeneEQUAL Take One videos](#) which demonstrate poor practices such as excluding people with intellectual disability from conversations. Then view the [GeneEQUAL Take Two videos](#) showing best practice, where the person with intellectual disability is made to feel the centre of their appointment.

Useful Links

Source	URL	QR Code
GeneEQUAL – Poor Practice Video 1	https://geneequal.com/genetic-resources/our-health-videos/	
GeneEQUAL – Best Practice Video 2	https://geneequal.com/genetic-resources/our-health-videos/	
GeneEQUAL Easy Read Genetic Health Care Booklets	https://geneequal.com/genetic-resources/our-easy-read-health-booklets/	