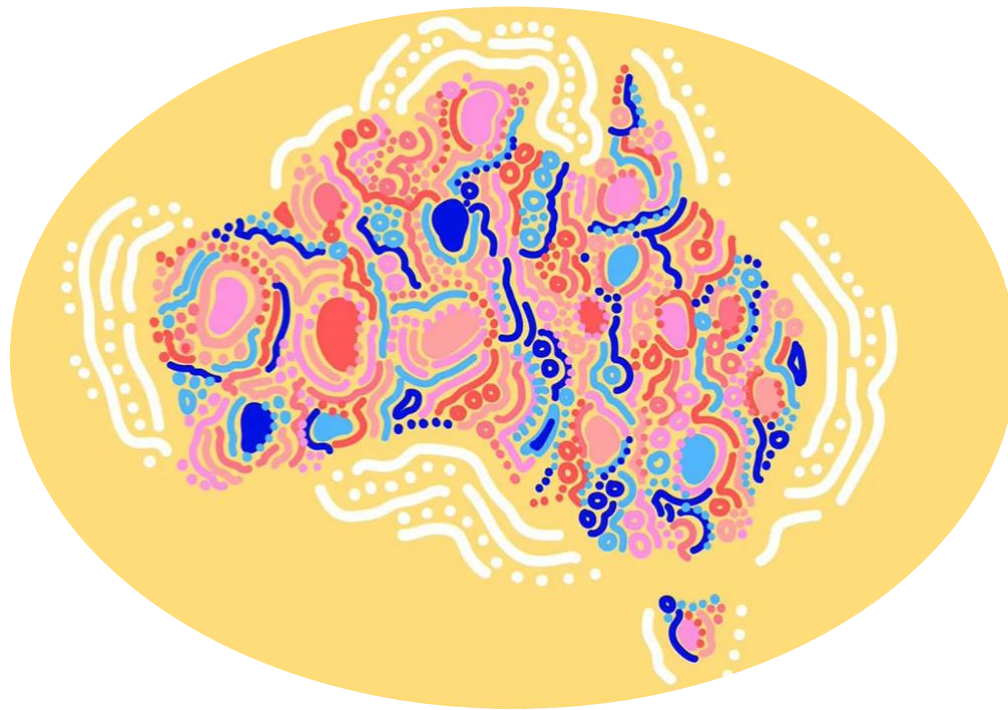


Health literacy education for students with intellectual disability.

**What students, teachers, educational
leaders and families told us about
learning health and genetics at school.**

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Jackaman, and GeneEQUAL team**



First Nations people have lived on this land for many years.

Now we live on this land together.

We respect all First Nations people and Elders.

We can learn a lot from their stories.

We can all learn from each other in our presentation today.

We acknowledge the Larrakia People.



Acknowledgement of the Lived Experience



We acknowledge and deeply value the lived experiences of people with intellectual disability.

Our advocacy are important to create inclusive systems.

Our voices drive meaningful change for all.



A little note about the slides

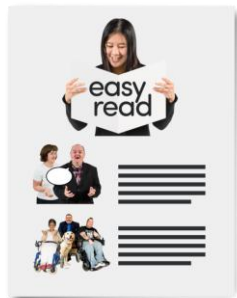


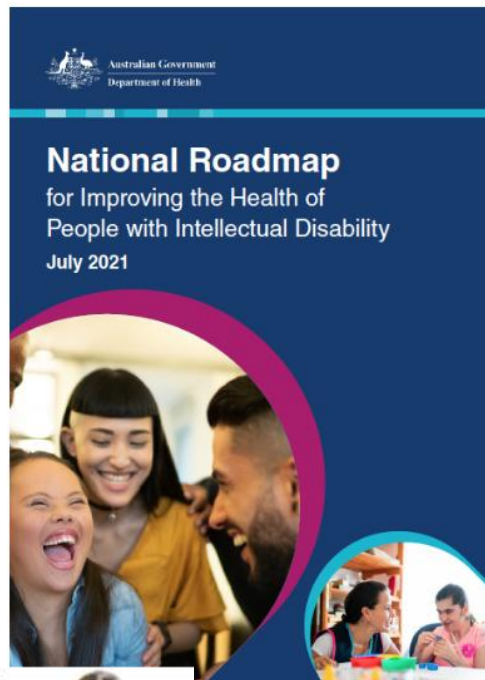
PHOTO  SYMBOLS®



- These slides mainly follow Easy Read principles
- We use many images from www.photosymbols.com
- Publications, resources and links are on our website www.GeneEQUAL.com



Why we did this work

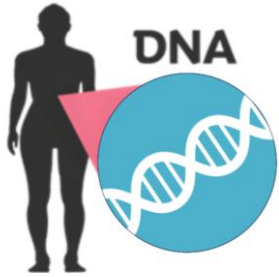


We, people with intellectual disability,

- two times more avoidable deaths
- two times more emergency and hospital admissions
-  physical and mental health conditions
-  lower rates of preventative health care.



Why we did this work



- More than half of intellectual disability has a genetic cause.
- Genetic testing is part of ordinary health care.
- To make your own health choices, you have to understand health.



The health gap was already well documented



- Health literacy is a determinant of health, and it is consistently lower for this group (Geukes et al., 2019)
- Higher health literacy is linked to better health outcomes for children with developmental disability (Lindly et al., 2020)
- Health literacy is not only what a person knows. It is produced by the systems around them (Vetter et al., 2022)



We already knew that students can learn this



- People with intellectual disability are interested in genetics and engage with it when it is accessible (Strnadová et al., 2022)
- They want to take part in decisions about their own health care (Strnadová et al., 2023)
- Science can be taught using systematic instruction and graphic organisers (Knight et al., 2013; Apanasionok et al., 2019)
- We know which practices work: visual supports, systematic instruction, video modelling, prompting and self-management (Strnadová et al., 2024)



We already knew schools were not doing it

- School health literacy programmes rarely give students a say in what is taught (Nash et al., 2021)
- Australian teachers manage functional health literacy, and struggle with critical health literacy (Peralta et al., 2021, 2022)
- Teachers around the world report low confidence teaching genetics (Cebesoy & Öztekin, 2018; Chapman et al., 2019)
- Reasonable adjustments are applied inconsistently in Australian classrooms (Page et al., 2024)



What GeneEQUAL is



- A co-produced research programme about genetic health care, funded by NSW Health and the NHMRC.
- People with intellectual disability are co-researchers, and their expertise sits alongside and before the academic disciplines.
- The health arm of GeneEQUAL kept hearing one thing: people wished they had learned this at school.



What we wanted to know



1. To what extent are students with intellectual disability learning about health and genetics at school?
2. What helps them learn, and what gets in the way?
3. Who do people think should be teaching this?
4. What would make this education accessible?



Who we talked to



- Students and young people with intellectual disability: 13
- Families: 13
- Teachers: 15
- Educational leaders: 13

54 people in total, across mainstream schools, support classes and schools for specific purposes.





What the 4 groups told us



All 4 groups agreed on a gap

“I guarantee you if I went to school tomorrow and said, “Hands up if you’re teaching genomics”, no-one would put their hand up.” Sara, teacher



“It was up to me to be curious.” Sonny, student, on how they learned about genes

“So never, ever, ever, ever, ever have I been asked these questions.” Karen, parent

“Genetics gets glazed over.” Erika, educational leader



Everyone agreed this matters



- Not one person in any of the 4 studies said students with intellectual disability should not learn about health and genetics.
- 13 of the 15 teachers called it a tool for empowerment and self-determination.
- Every parent believed in it. Every school leader could explain why it matters.
- Students talked about understanding themselves, and about being understood by other people.



Genetics is mostly not being taught



- Some teachers were teaching genetics without realising they were teaching it.
- Some students learned about genes through pictures of animals. Others learned nothing at all.
- Only 3 of the 13 parents could point to any genetics teaching at their child's school.
- School leaders were unsure whether genetics belonged in their curriculum, or where it would sit.



Nobody is sure whose job this is



- Responsibility is shared, and never actually allocated to anyone.
- Schools, families and health services each thought someone else was better placed.
- Genetics sits between science and health education, so it belongs to neither.
- Parents were told this was their job.
- The teaching falls into the space between the systems.



We already agree on how to teach it



- All 4 groups named the same approaches, in their own words.
- Visual supports, hands-on learning, real examples, repetition and plain language.
- Time, individualisation, and starting early.
- Easy Read was named by teachers, by parents and by students.



Teachers need support - every group said so



- Teachers told us they lacked training, confidence and resources for this content.
- School leaders agreed, and said workload leaves teachers no time to learn.
- Parents worried about where teachers were getting their information.
- Students said it too, without being asked.



Students are left out of their own plans



- 3 of the 13 students knew they had an individual education plan.
- 4 of the 13 parents helped set their child's goals.
- Teachers and most school leaders described student involvement in planning as minimal.
- Every group told us self-determination is the point of this education.

“I think she has capacity to be involved. But there was never that opportunity for her to be involved.” Karen, parent



Everyone wants co-production



- Teachers asked for resources made together with people with intellectual disability.
- Students wanted people with intellectual disability teaching alongside doctors and nurses.
- Parents proposed a round table of teachers, health professionals, families and students.
- School leaders wanted co-produced resources they could use in class without rewriting them.





What only some groups told us



Only the professionals talked about Life Skills



- Teachers and school leaders discussed the Life Skills pathway at length.
- They disagreed about whether it opens doors or closes them.
- Students and families barely mentioned it, although they live with its consequences.
- The students placed on that pathway have never been asked what they think of it.



Students told us about being unsafe



- Bullying, abuse and feeling unsafe at school became a whole theme in the student study.
- We had not asked about any of it - the students raised it themselves.
- Parents and school leaders raised it as well, and leaders put safety above every other health topic.

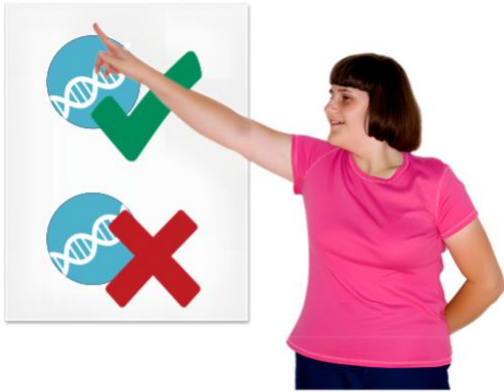




Where the 4 groups disagreed



Does teaching genetics create stigma?



- Teachers, parents and school leaders all worried that teaching genetics might feel like blame, or upset students.
- So the topic was left out, or softened, or deferred.
- Students told us the opposite, and they told us clearly.



Schools and families describe each other very differently



- Teachers described families who do not engage, or who do not acknowledge their child's disability.
- School leaders described families as both their strongest support and their biggest obstacle.
- Parents described schools that sent nothing home and never asked them a question.
- Both accounts are honest, and they cannot both be the whole story.



Sexuality education is everyone's priority, and students get very little



- School leaders put it above every other health topic, and called it an ethical duty.
- Parents called it critical, and said it is not properly covered.
- Teachers said it is one of the topics they feel least prepared to teach.
- 1 student out of 13 had been taught about consent.
- The protective intent of every adult group is not reaching the students.



Who should actually teach this?



- School leaders bring in outside programmes, and then have to adapt every one of them.
- Some parents worried that an unfamiliar visitor makes students less willing to engage.
- Students suggested something none of the adults had thought of.

"The doctor can train the teacher how to talk to them. ' Imogen, student





The policy moment we are in & What we can do about it



The Better and Fairer Schools Agreement (2025 – 2034)



- Every state and territory has now signed.
- Students with disability are a named priority equity cohort.
- It will build new national measures of access, participation and outcomes for students with disability.
- Health is not in them.
- Its wellbeing pillar is being delivered as mental health staffing, not as health literacy.



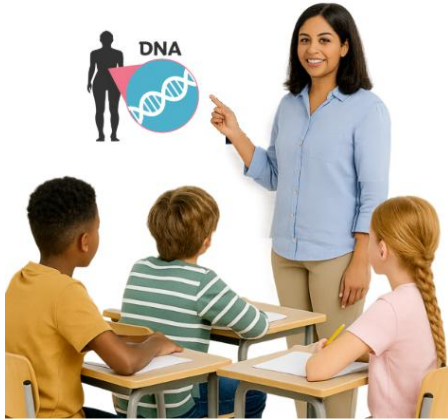
The curriculum door is opening in NSW



- Health and Movement Science started in 2025. The first HSC exam is this year. Health literacy is 1 of its 5 propositions.
- New PDHPE syllabuses for K to 6 and 7 to 10 are mandatory from 2027. Health literacy is in both rationales.
- Science 7 to 10 began this year in Years 7 and 9. Its Life Skills genetics outcome is one line: identifies personal genetic traits.



The curriculum door is opening in NSW



- From 2027 a Life Skills student can study Biology with a Heredity focus area for the first time.
- All of that is being implemented now, by the teachers who told us they are not ready.



The states are heading in different directions



- New South Wales names genetics in Life Skills outcomes, in Science now and in Biology from 2027.
- Victoria keeps its below Foundation levels for Health and Physical Education, and retires them for Science from 2027.
- So Victorian students working below Foundation will have a health pathway and no science pathway.



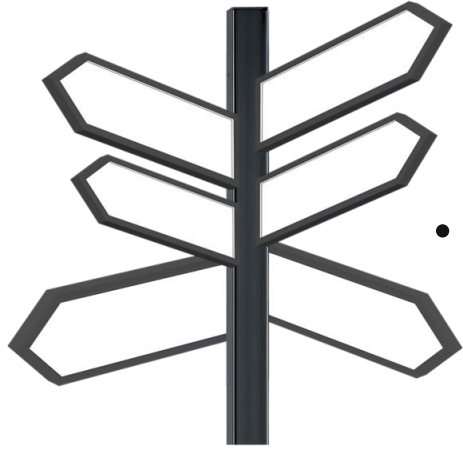
The states are heading in different directions



- Queensland follows the Australian Curriculum, where genetics is one Year 10 descriptor, with adjustments and no parallel outcomes.
- Cognitive disability is 53 per cent of the 1.1 million students receiving adjustments. This is not a small group.



Health policy and school policy do not meet



- The **National Roadmap for Improving the Health of People with Intellectual Disability** names health literacy as a goal, and has no schooling action.
- The draft **National Health Genomics Policy Framework** names public genomic literacy as a priority, and mentions curricula only for health professionals.
- **Australia's Disability Strategy** has no targeted action plan for schools.



Health policy and school policy do not meet



- **The Royal Commission** asked for a National Roadmap to Inclusive Education. It is still listed as further work required.
- Families are holding these two systems together on their own. Our parents told us exactly that.



What policy and curriculum can do



- Say where genetic health literacy belongs in the curriculum, including for students on Life Skills.
- Fund accessible, editable resources that teachers can use straight away.
- Give teachers time and training as well as materials.
- Bring education, health and disability services together, because families are already doing that work alone.
- Include people with intellectual disability in the decisions about what is taught.



What schools can do

- Decide, and write down, who is responsible for teaching health and genetics.
- Welcome students in their own planning meetings and give them time to prepare.
- Actively include students in all decisions – Nothing about us without us.
- Talk with families early, and keep talking.
- Teach about genetics openly, because the students have asked us to.



Thank you

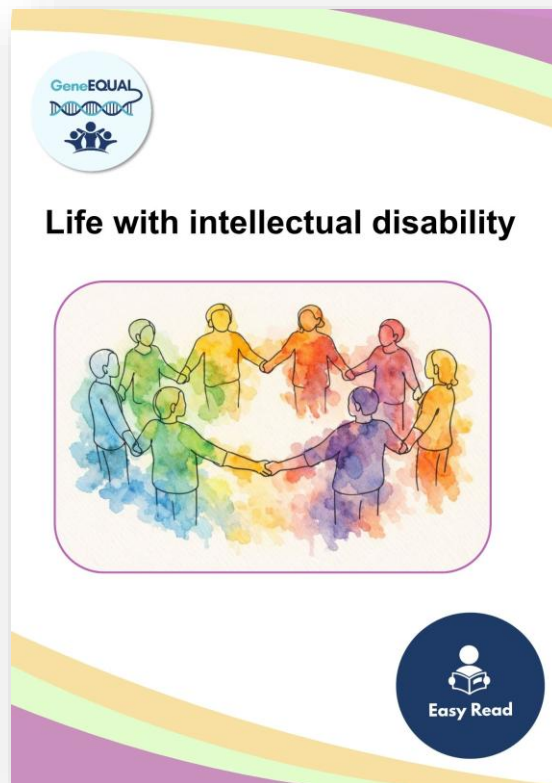


- To the 54 students, teachers, parents and school leaders who gave us their time.
- To our GeneEQUAL inclusive research team.

GeneEQUAL is funded by NSW Health and the NHMRC.



GeneEQUAL Booklets



Easy Read summary of each study



Students



Teachers



Parents



School leaders

