



The Dalglish Family  
22q Clinic

# **A Voice for an under-recognized condition - 22q11.2 Deletion Syndrome (22q)**

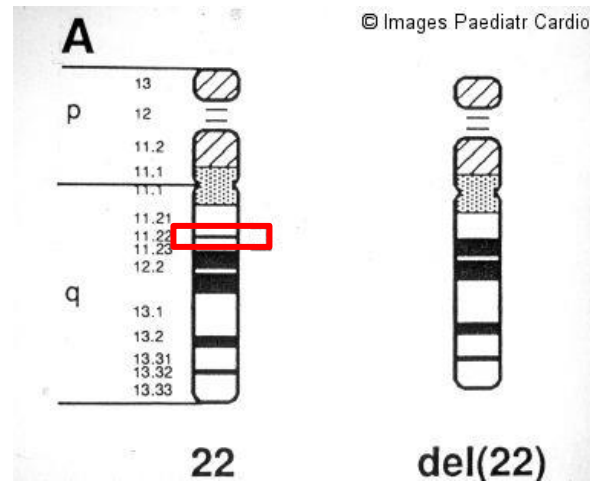
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# Outline

- What is 22q?
- Common developmental, medical and psychiatric features.
- Strategies for supporting individuals with 22q.
- What we provide at the Dalglish Family 22q Clinic at UHN.

# What is 22q11.2 deletion syndrome?

*“DiGeorge Syndrome” or “velo-cardio-facial syndrome”*

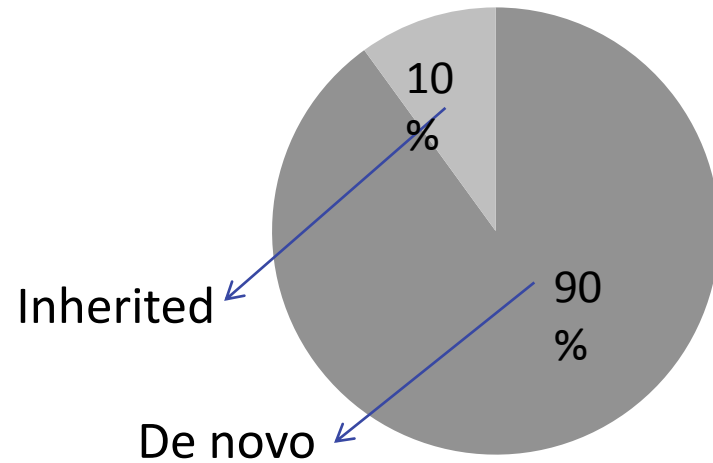


A genetic condition where a piece of chromosome 22 in our DNA is missing



Affects > 1 in 2000 live births

# What is 22q11.2 deletion syndrome?

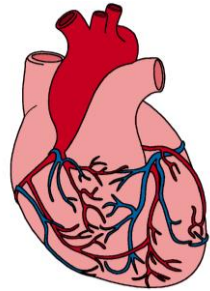


Usually a new genetic change in a family - only 10% are inherited from a parent



Expression of the condition is  
**Highly variable**

# Common clinical features



Cardiovascular



Palatal abnormalities



Mental Health



Calcium / thyroid



Intellectual disability

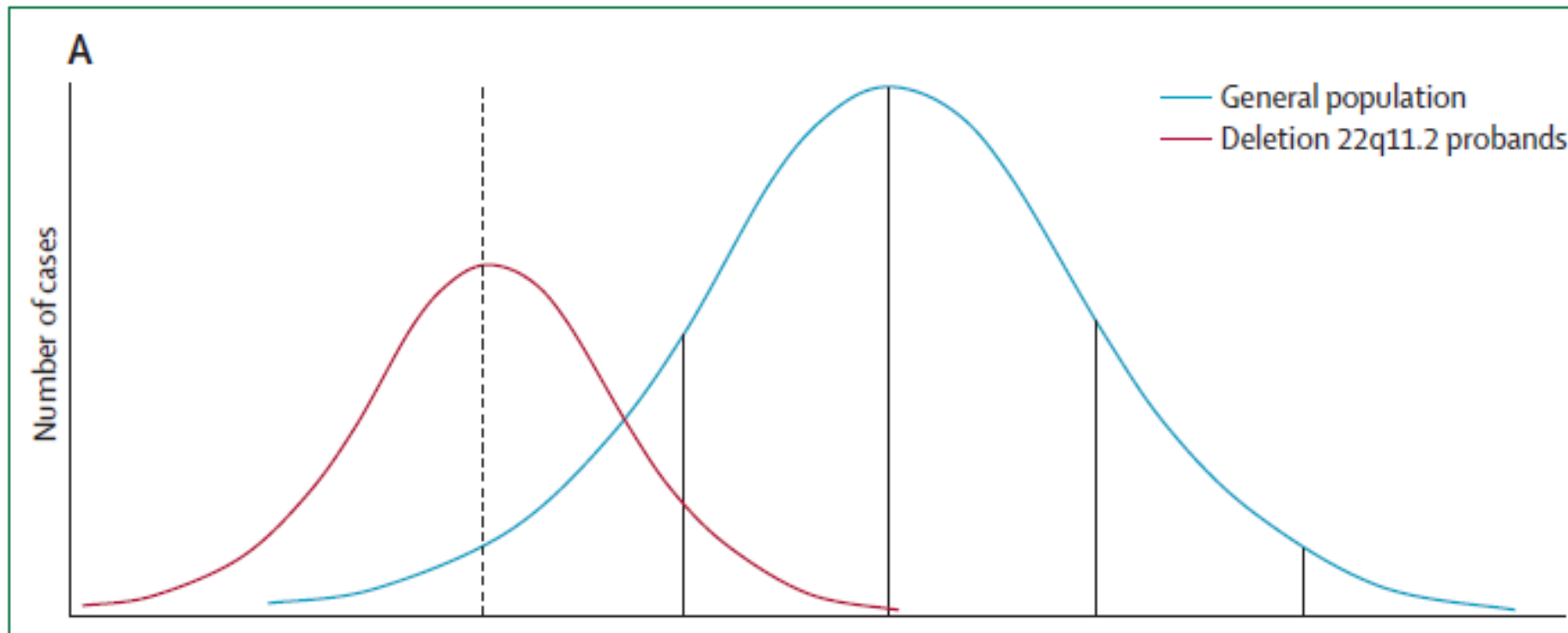
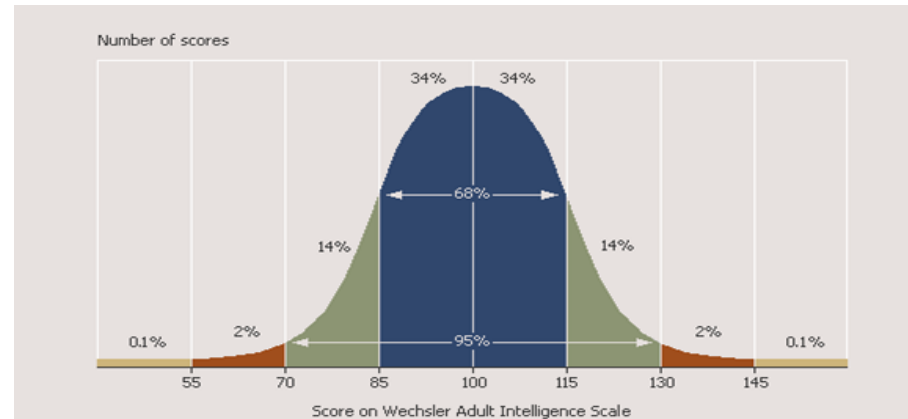


Neurological disorders

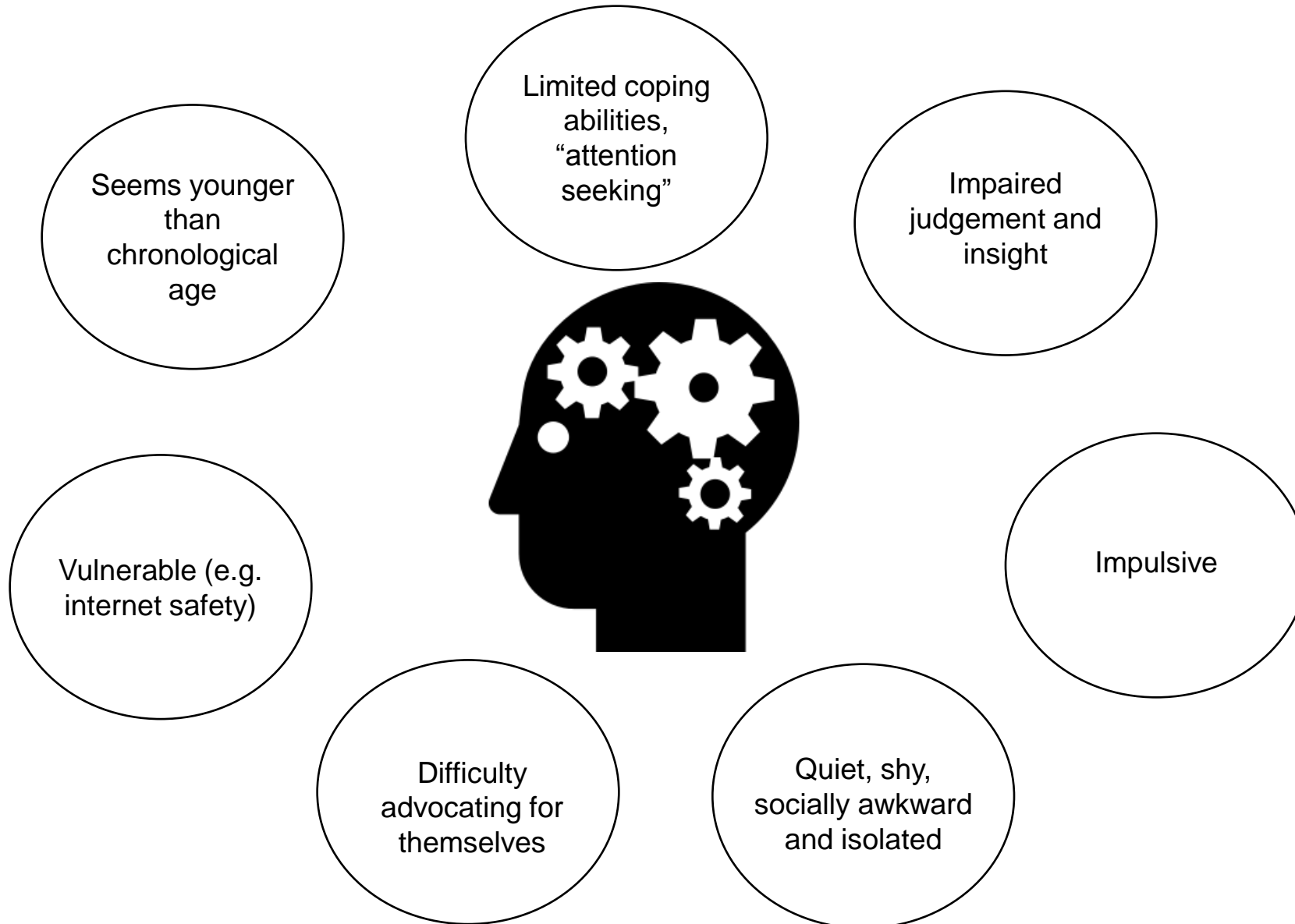


Skeletal

# Intellect on standardized testing



# Common behavioural characteristics



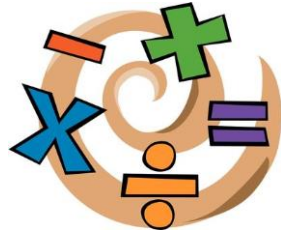
# Common areas of relative strength

- Rote verbal learning and verbal recognition
- Reading; decoding and spelling
- Computer skills/visuals
- Concrete, sequential learning styles
- Better experiential than auditory learners
- Willingness to learn/wanting to please



# Strategies for support

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Match expectations to cognitive and social capabilities and limitations

Give **one** instruction at a time - simple

**Repeat** your instructions

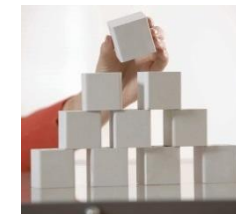
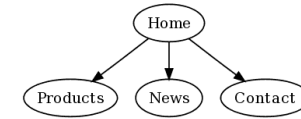
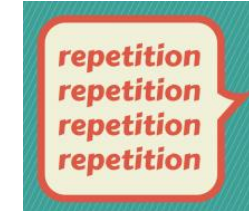
Avoid abstract concepts and analogies

Use simple **diagrams** or **visuals**

Involve **caregivers** as soon as possible

Give a **structured** environment

Give **written summaries**





**We accept referrals from anyone**

# Our Clinic's roles

- Multidisciplinary team assessments and treatment
- Individual and group education sessions
- **Diagnostic testing**
- Consultations and coordinated care within the University Health Network
- Referrals and liaisons within the community
- Transitional program with The Hospital for Sick Children (HSC)
- Public and professional education
- Internationally renowned research



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# Thank you!

If you have any questions, please contact us at:

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Check us out on our website at: [www.22q.ca](http://www.22q.ca) or on Facebook

