



# Developing Clinical Pathways for Psychiatry Care for Children with Rare Disorders

## 22q11.2 Deletion Syndrome

Faculty of Child and Adolescent Psychiatry Annual  
Conference, Manchester, 2025

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Liaison Psychiatrist*

*Children's Health Ireland at Crumlin*

# Disclosure

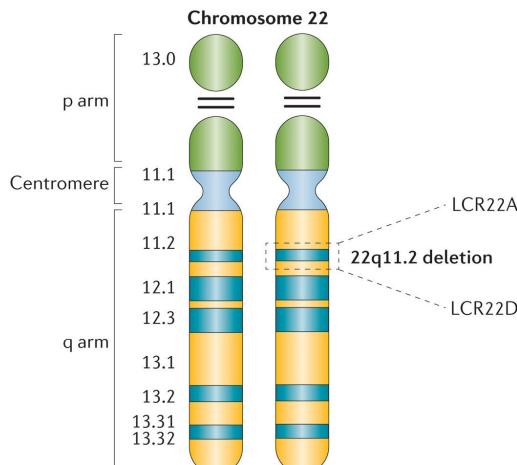
I have no conflicts of interest to disclose.

# 22q11.2 DS Overview

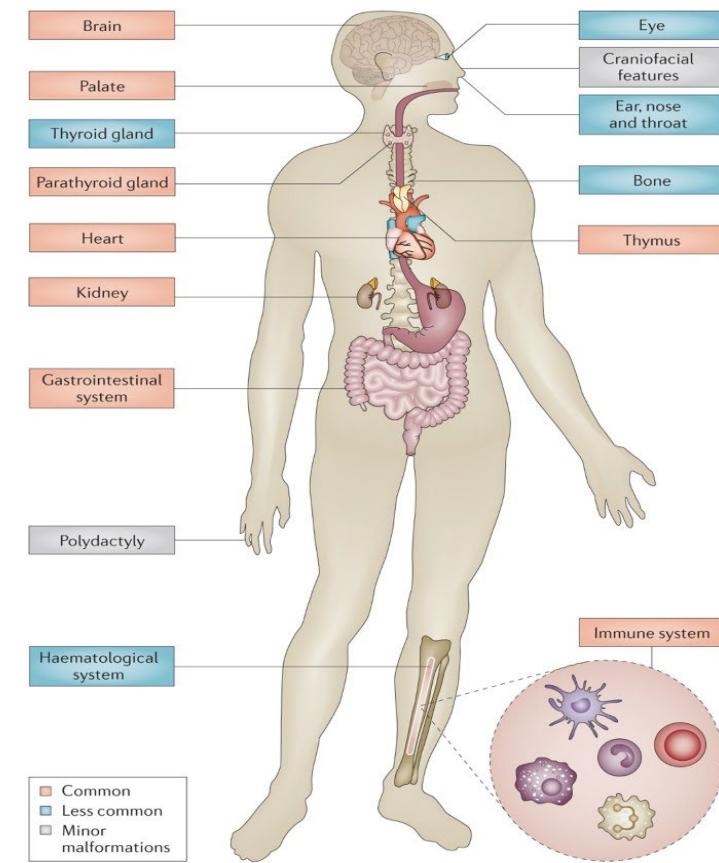
Di George or Velocardiofacial syndrome

## Genetic background

- 22q11.2 region includes 6.6 million base pairs (6.6 Mb)
- *De novo* rather than familial
- Prevalence – 1:2000 – 1:3000  
(Blagojevic C et al. CMAJ Open 2021)

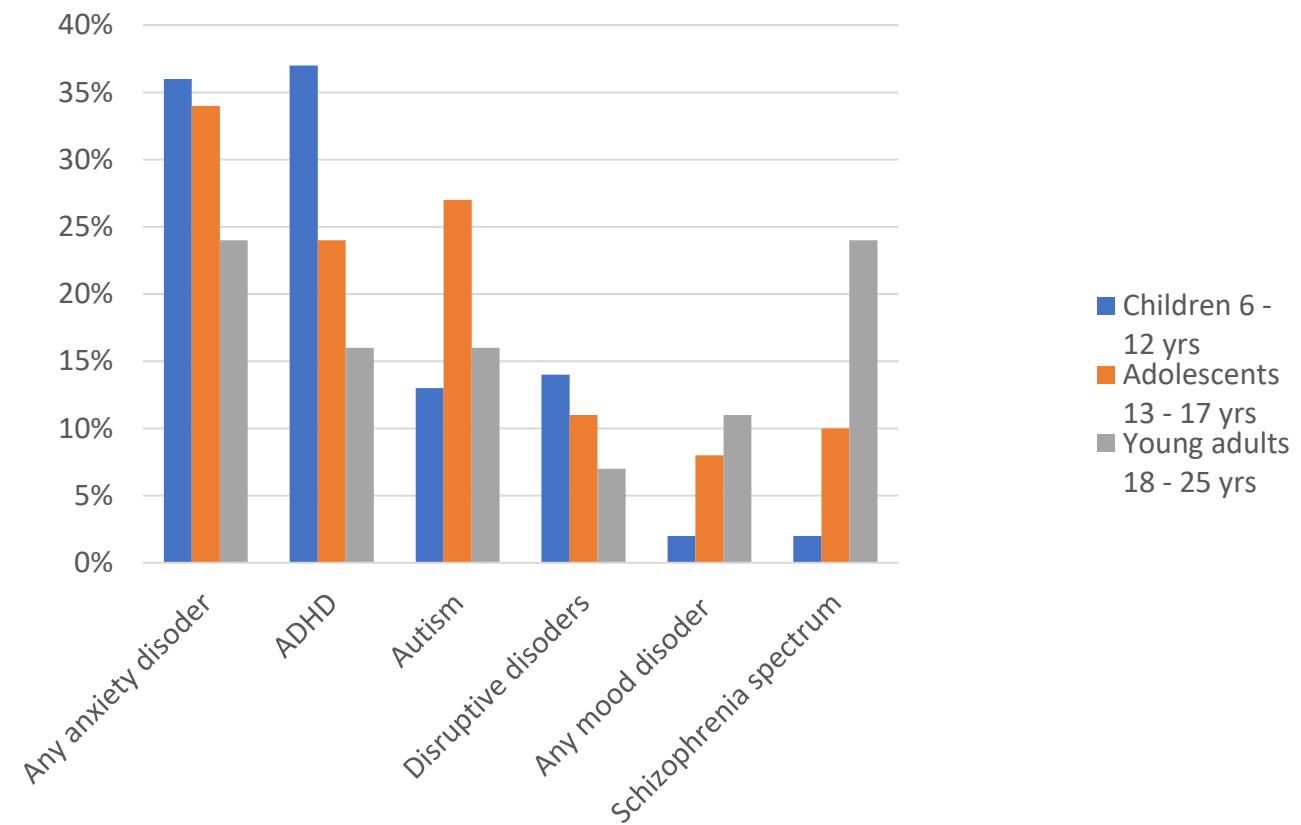
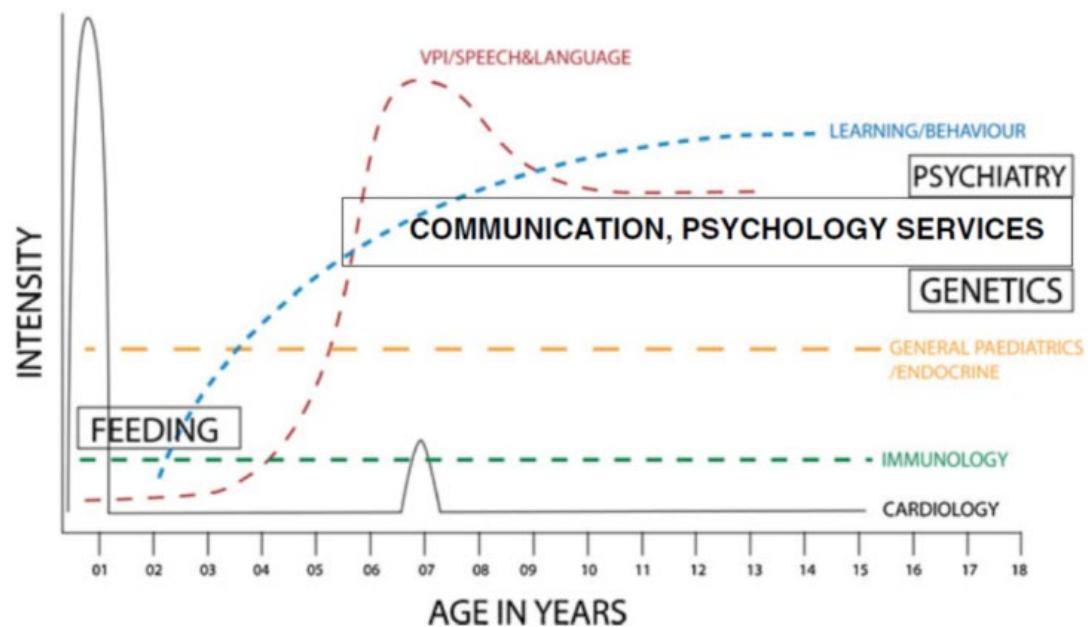


## Common features



## Why considering specialist psychiatry clinic?

## NEED OF SPECIALTIES BY AGE OF 22q 11 DS CHILDREN



Habel et al. Eur J Pediatr 2014

Data derived from Schneider M, et al. Am J Psychiatry, 2014

# Background

- *22q Ireland family support organisation*, Dept of Liaison Psychiatry and other clinicians:
  - Established YEEP (Young Person by Experience) group
  - Help develop, evaluate services & disseminate findings at conferences

Psycho-educational interventions

Monthly sessions for parents

Parenting programme & video material

(<https://www.youtube.com/@22qpsychoeducation78>)

Youth group work ("Working things out")



22q11  
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ag Cromghlinn  
**CHI**  
Children's Health Ireland  
at Crumlin



# Outcomes

- Monthly psychiatry clinic
- 3 paediatric clinic per month
  - Lead paediatrician, 2017
  - Clinic co-ordinator, 2021
    - Health passport
    - Transition to adult services
    - Family events



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Ir Med J; January 2023; Vol 116; No. 1; P716

January 19<sup>th</sup>, 2023

## Transition from Paediatric to Adult Services for Patients with 22q11.2 Deletion Syndrome

V. Gadancheva<sup>1</sup>, E. Molloy<sup>2,3</sup>, F. McNicholas<sup>1,4</sup>

Science (1971-) (2020) 189:761–769

ORIGINAL ARTICLE



Ir Med J; March 2025; Vol 118; No. 3; P42  
March 20<sup>th</sup>, 2025

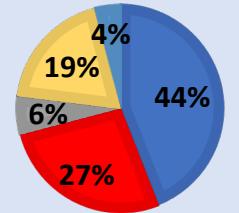
## Evaluation of a newly introduced parenting support programme for families of children with 22q11.2 Deletion Syndrome

A. Khan<sup>1</sup>, N. Mazeri<sup>2</sup>, V. Gadancheva<sup>3</sup>, W. Mulcahy<sup>4</sup>, S. Kelleher<sup>4</sup>, F. McNicholas<sup>1,3,5</sup>

# 22q Clinic at CHI at Crumlin

- Paediatric Clinic, n= 249 open cases
- Psychiatry referrals, n=145
- 109 psychiatry assessments
- Mean age 10.8 years (5-19years)

## REASON FOR REFERRAL



- Screening
- Anxiety symptoms
- ADHD query
- Behavioural/ emotional difficulties
- Depressive symptoms

The image displays three versions of the Connors 4 Teacher's Report Form for ages 6-18. The top version is a sample with a red 'SAMPLE' watermark. The middle version is a sample with a green 'SAMPLE' watermark. The bottom version is a standard white version with the Connors 4 logo and text.



# 22q Clinic at CHI at Crumlin

- Outcomes
  - Referral to local community psychiatry clinic
  - Follow-up in liaison psychiatry – short/ long-term
- Challenges
  - Limited access to SLT, OT, psychology within the hospital
  - Access to community services – Disability network teams, Primary care services
  - Access to broader psychosocial interventions – school support, social clubs, etc.

Diagnosis	Percentage
Anxiety	41%
ADHD	21%
Autism	4%
Depression	30%
Psychosis	1%
ODD	1%
No Axis I Dx	2%

# Transitional Care



- **Pilot Transition Clinic**
- Joint effort between **CHI Crumlin Children's Hospital** and **St. James' Hospital**
- **Model:**
  - Joint review between pediatrician and adult clinician in a paediatric clinic
  - Followed by a joint review in the adult setting
  - One follow up review in the adult site after one year
  - Ongoing management by GP
- **Challenges:**
  - Low interest from adult clinicians
  - No formal supports or resources for the initiative

# Acknowledgement



- Young people and their families
- Prof Fiona McNicholas and Liaison Psychiatry Dept at CHI Crumlin
- 22q Clinic Paediatric Colleagues and care coordinator
- Psychiatry trainees and UCD medical students

