asid 2025 Conference
Learning from the Past, Shaping the Future

Fragile X Care
Supporting the Future for Adults with Fragile X syndrome

Fragile X Association of Australia

Presented by Wendy Bruce
on behalf of
Fragile X Association of Australia
Centre for Disability Studies
Project Team
13 November 2025

CDS
Centre for Disability Studies

FragileXCare

ADULTS AND AGEING

“Ageing is the most important problem for our kids.” – Fragile X parent

Challenges associated with Fragile X syndrome

Physical	Cognitive	Behavioural & emotional
Hypotonia	Developmental delay	Anxiety, hyperarousal
Connective tissue disorders	Intellectual disability (most males; 30% females)	Sensory defensiveness
Recurrent ear infections/ENT	Language & communication difficulties	Autistic behaviours eg gaze avoidance; hand flapping
Epilepsy/seizure disorders	Poor fine and gross motor skills	Autism spectrum disorder (60% males)
Strabismus	Specific learning disabilities	ADHD
Macroorchidism		Hyperactivity
Sleep apnea/disturbances		Mood disorders
Mitral valve prolapse		Aggression, self injury
Gastrointestinal issues		OCD
Tremor/ataxia onset (some males)		Making transitions

Refs: **Hagerman & Hagerman** (2025); **Genovese & Butler** (2025); **Birch, Cohen, Trollor** (2017)

Strengths associated with Fragile X syndrome	
Strong visual learners	Life-long learners
Long-term memory	High-interest responsive
Receptive vocabulary	Desire to be helpful
Empathy	Being social
Super power – X factor!	

Successful supports will account for challenges and strengths	
Strategies to address hyperarousal & anxiety	Educational supports
Therapies	Predictability and routine
Modifications to the environment – school, work, place, residence, community	Medications can be helpful in symptom management

Understand & meet functional and health support needs as they evolve.
The key to supporting a future of optimal health, wellbeing and quality of life.

Refs: **Herring.** (2024)

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ADULTS AND AGEING

1. **Exploring Support Needs, Health & Wellbeing**
2. **Building Capacity of Support Professionals**

Research Study
2024-2026

Mixed methods

1. Research & Data	2. Knowledge Translation	3. Outcomes & Advocacy
Surveys Family Members Disability/Aged Care Teams	**E-learning Resources** for support teams	**Care Worker Education** best practice principles
Capture Knowledge of key experts	**Practice Resources** for care settings	**Policy Position**
Focus Groups Family Members Support teams	**Resource Distribution**	**Outcome Measures**
	Future Planning Framework for Families	**Advocacy**

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Supported by:
HENROTH Group

"Ageing is the most important problem for our kids." – Fragile X parent

Co-design. Mixed methods.

Interviews

- Clinical perspectives and practice knowledge of an international cohort of specialist health practitioners in Fragile X syndrome (20+years)

A plan for living well in older age

Ageing in the community

Importance of a healthy lifestyle

Medical professionals' commentary on medication use

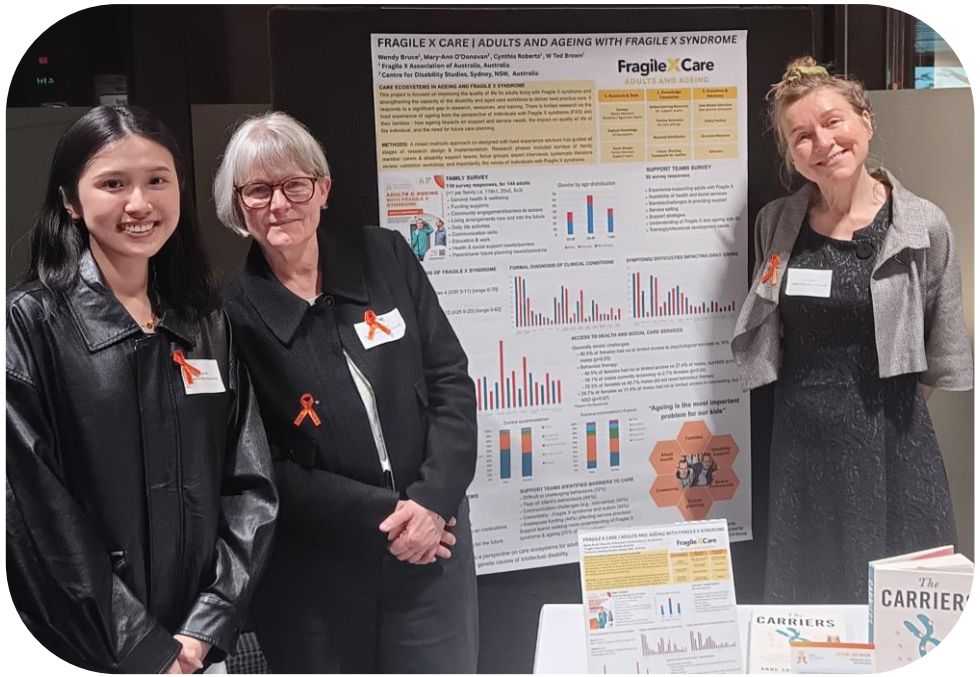
Daily purposeful activity

Validation Workshop

- Parents/carers
- Disability service providers
- Peak bodies
- Clinicians

Scoping review

- "Ageing with Fragile X syndrome"
- Health Concerns, Cognitive Abilities, Functional Skills, Behavioural & Social Aspects, Social Participation, Service & Support Needs
- 1275 papers 1990-2024 screened; 77 for analysis



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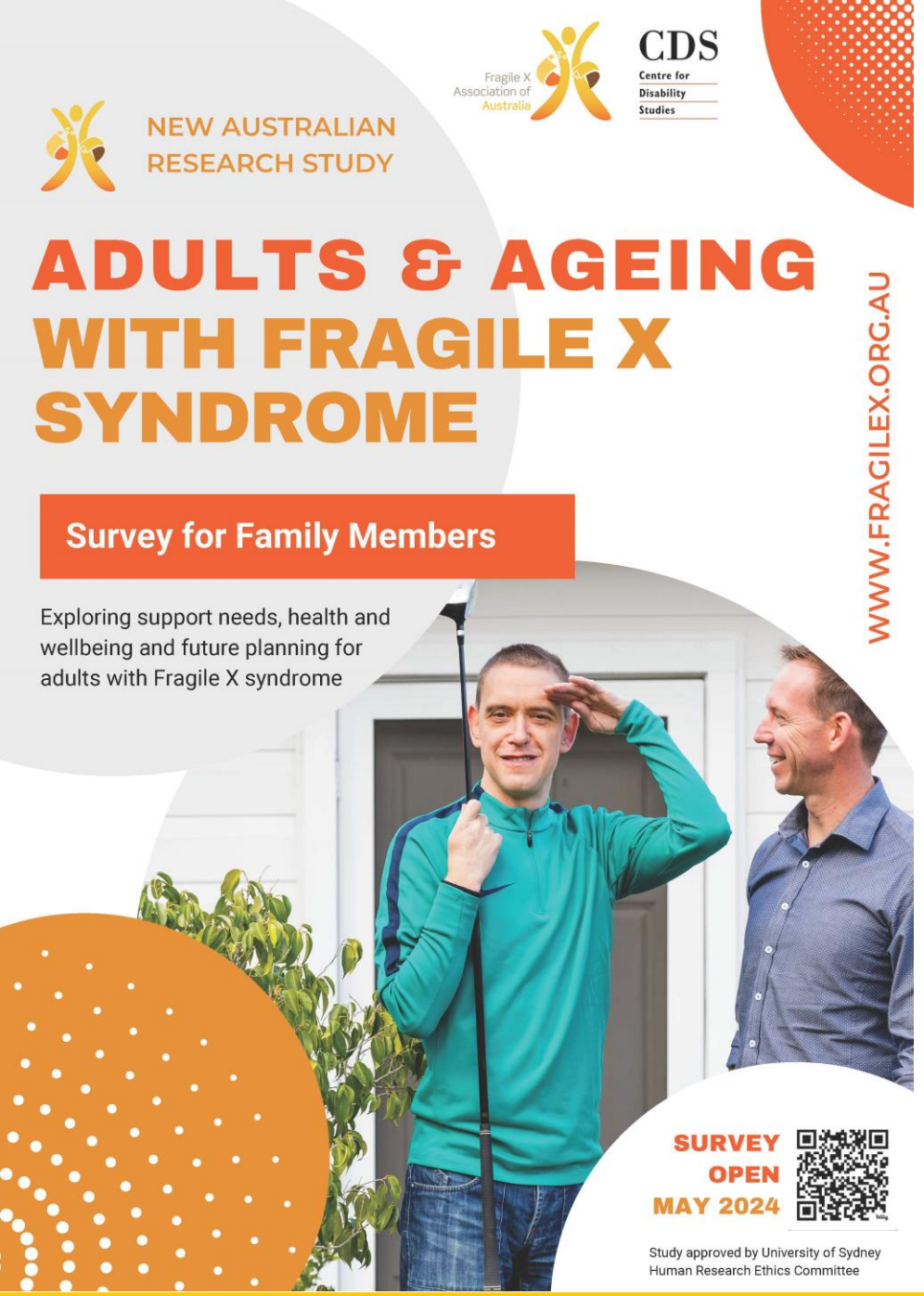
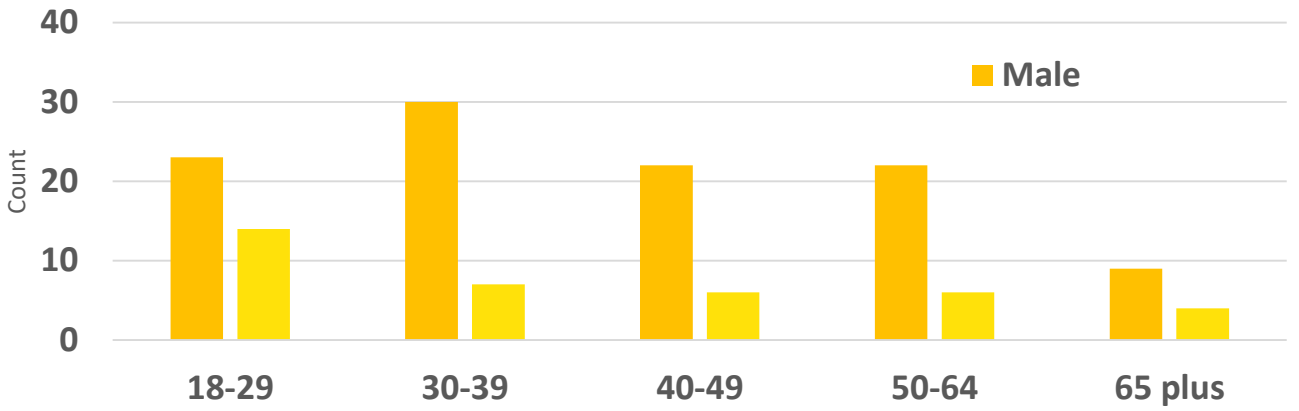
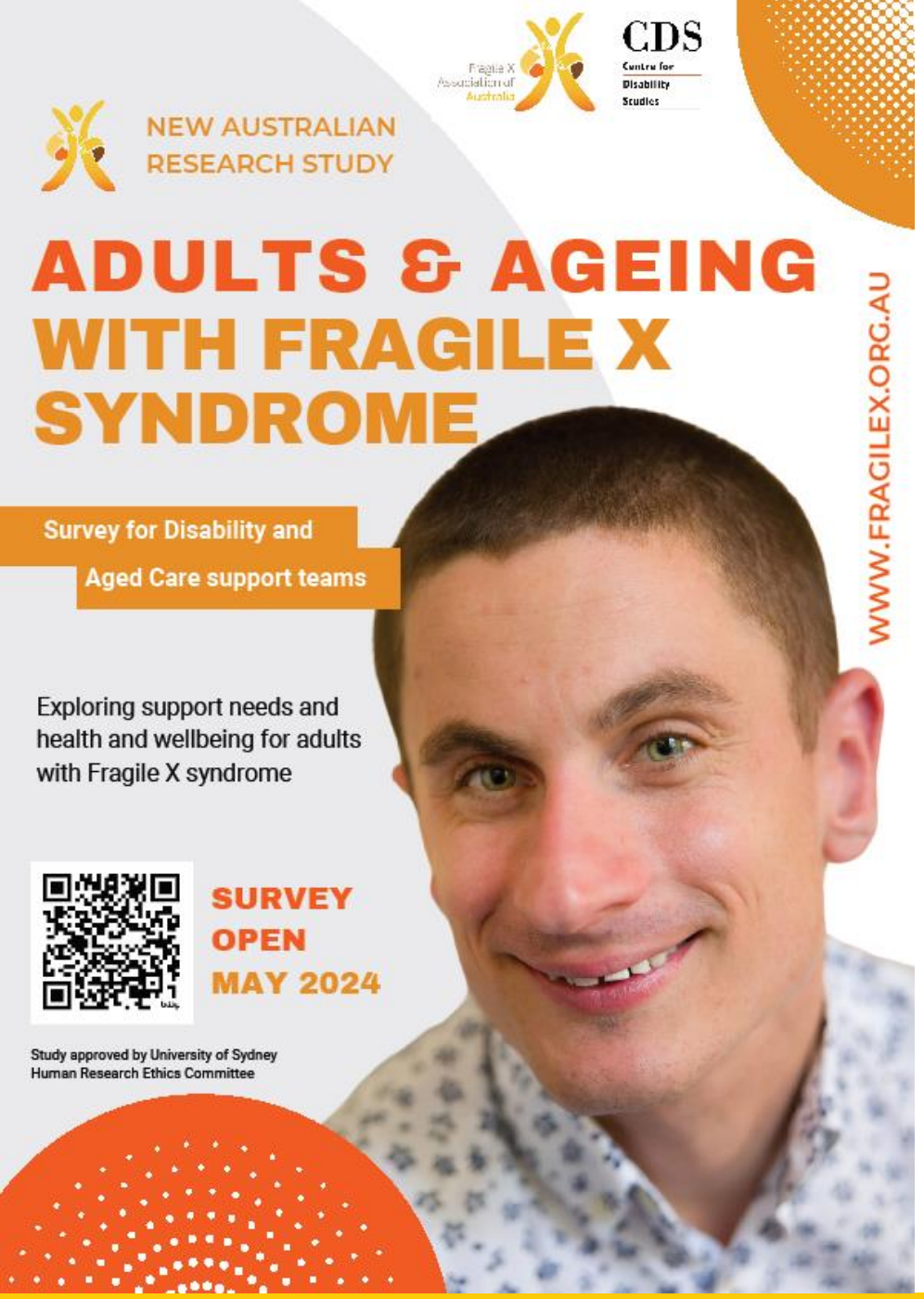


Asking About	
Year of FX diagnosis	Daily life activities
General health & wellbeing - formal diagnosis, symptoms	Communication skills
Funding supports	Education & work
Community engagement & barriers to access	**Health & social support needs & barriers to access**
Living arrangements now and into the future	**Parent/carer future planning needs & concerns for the future**

- Targetted networks and social media
- **Alternatives to online to accommodate ageing parents/carers**
- 119 survey responses, for 144 adults. 75% male





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Asking About	
Experience in supporting adults with Fragile X syndrome	Service setting
Health & social services available / not available but beneficial for clients	Strategies for supporting adults with Fragile X syndrome
Barriers/challenges in providing support	**Understanding of Fragile X syndrome and ageing with ID**
Training/professional development needs in Fragile X syndrome or ageing and intellectual disability	

50 survey responses

recruiting challenges
60% respondents had male clients
52% clients aged 31-50

Support needs

Males required higher rates of assistance with daily living activities than females: hygiene, grooming, food preparation, shopping, banking, social engagement….

Younger and older people were in greater need of continuous 24-hour support

Families played pivotal role in providing supports for younger and middle aged

- Almost ½ senior group received support from disability services

Health and wellbeing

Presence of clinical conditions

Formal diagnosis

Fragile X Care | *Adults & Ageing*, Parent/carer Survey 2024

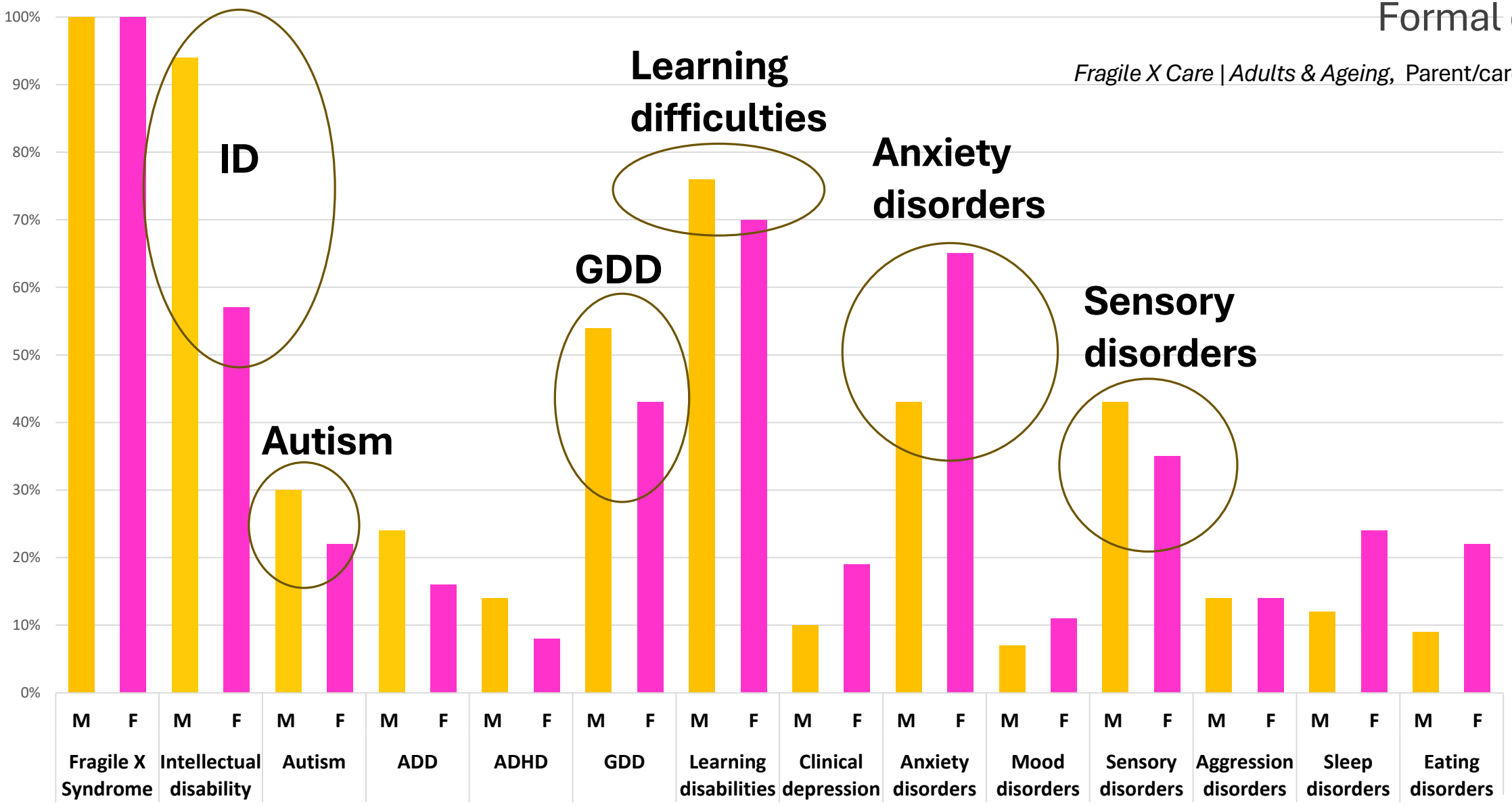

Figure 1: Distribution of the rates of the clinical conditions that adults with FXS have been formally diagnosed with. N=143, male=106, female=37

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Other symptoms and conditions

Moderate to severe symptoms or difficulties - no formal diagnosis

Fragile X Care | Adults & Ageing, Parent/carer Survey 2024

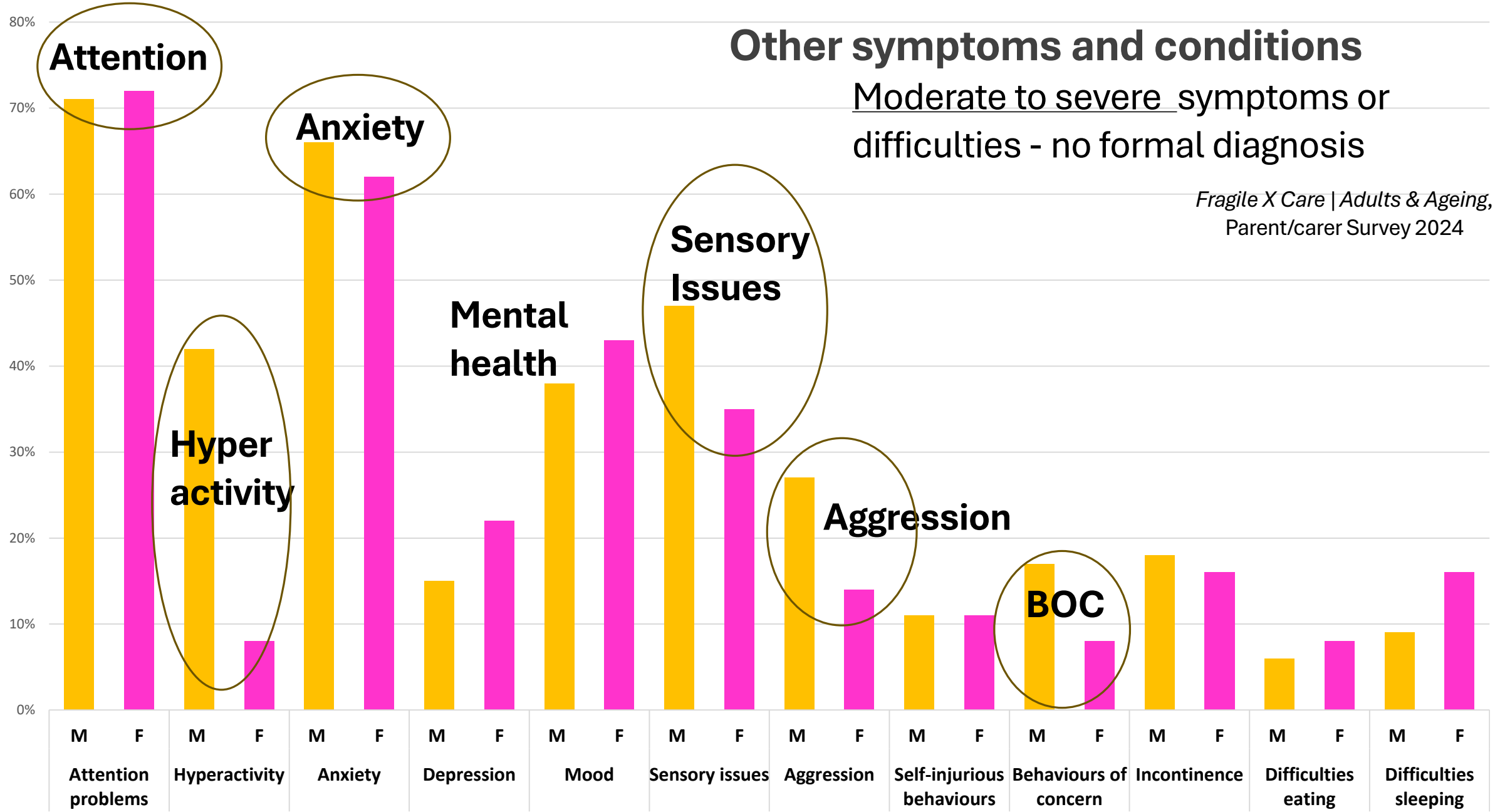

Figure: Distribution of rates moderate to severe symptoms or difficulties which can impact adults in daily living or activities. males (n=106) females (n=37)

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Health social care services – limited/no access

Fragile X Care | Adults & Ageing, Parent/carer Survey 2024

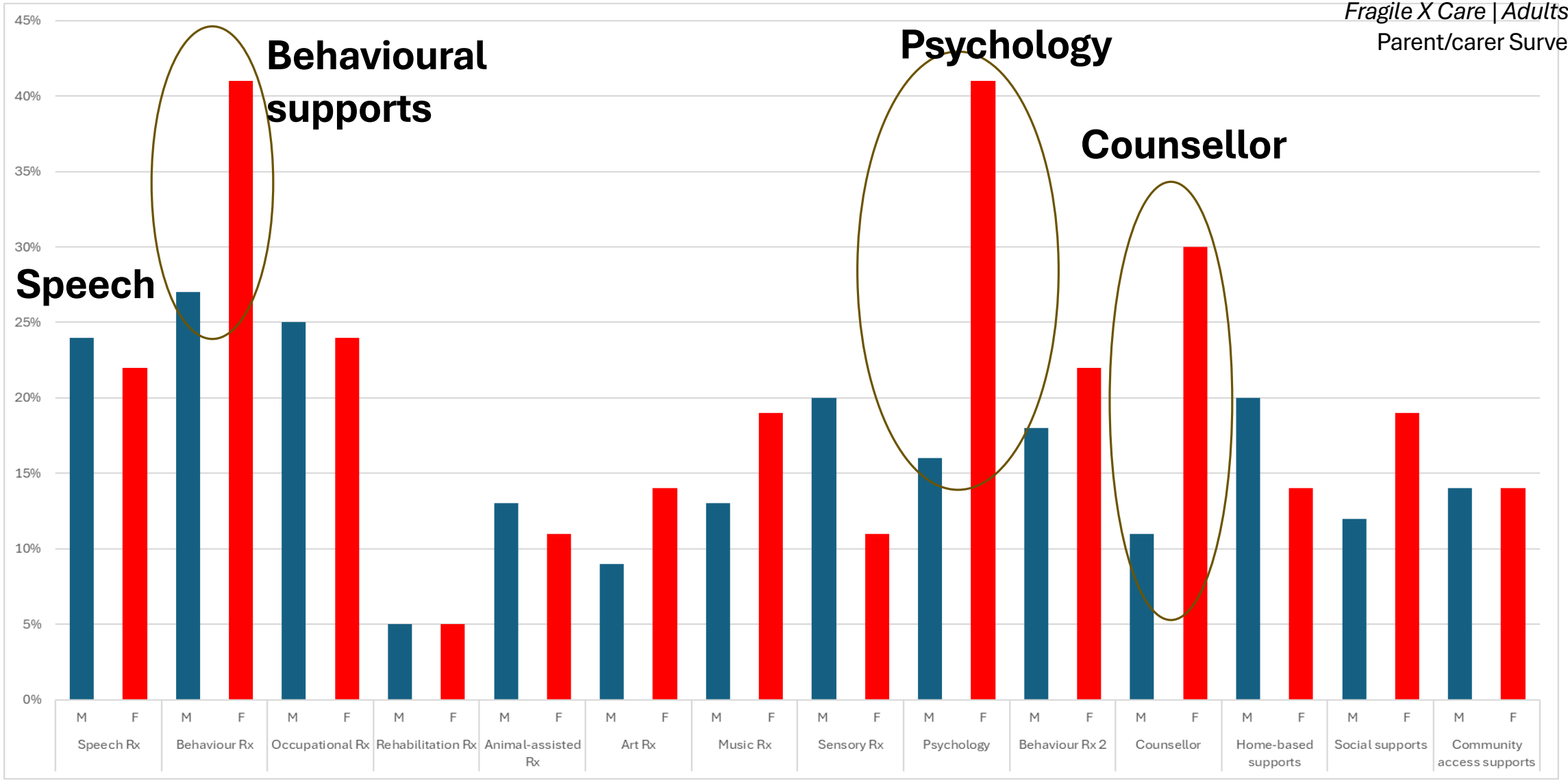

Figure: Distribution rates for both males (n=105) and females (n=37) who had no or limited access to the health and social care services

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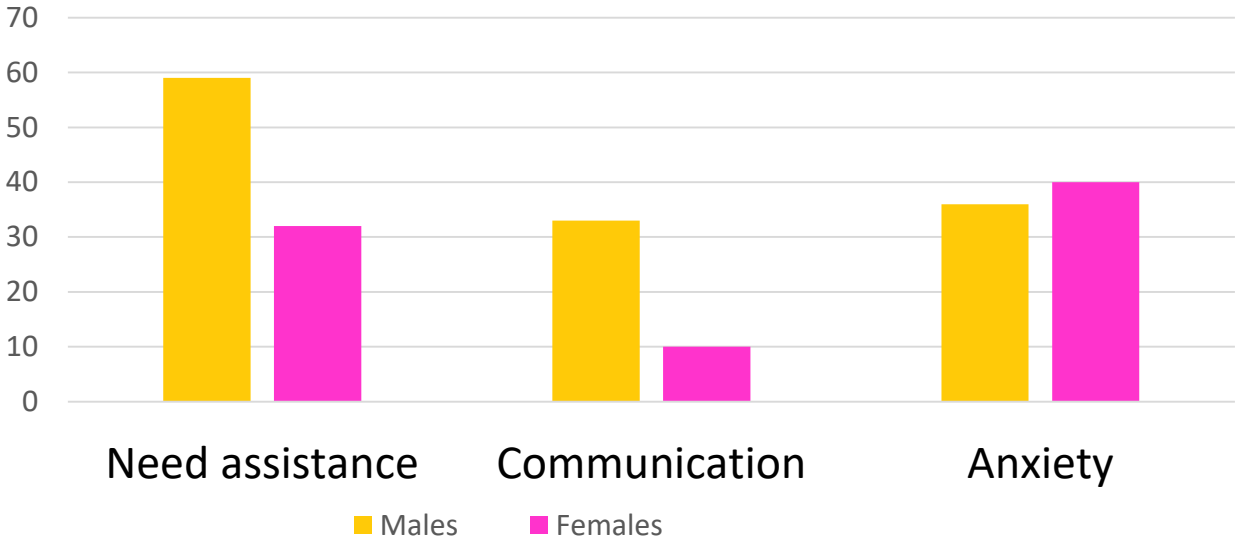
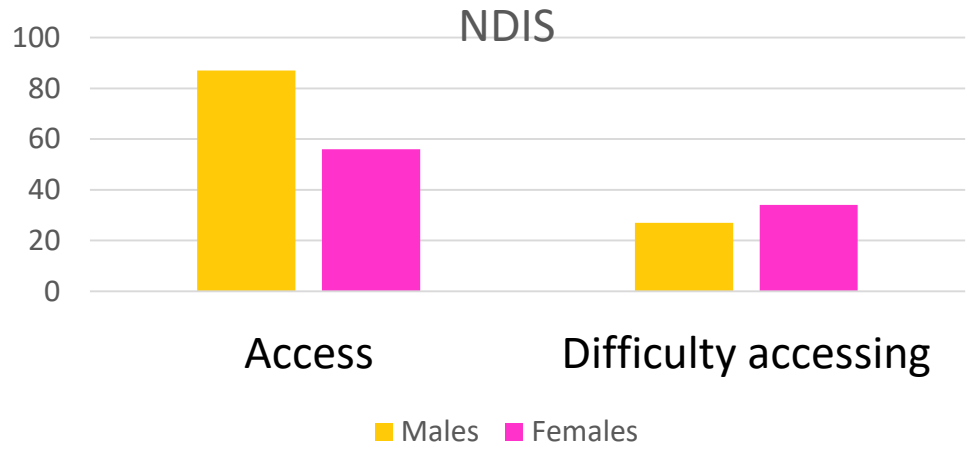
Barriers to accessing health and social services





"**Communication** can be a problem - if he gets flustered, his speech is very difficult to understand. **Anxious** - when going somewhere new for the first time, this is a challenge"

"**needle phobia** ..... significant barrier for future health care"

"**Therapists mostly deal with children** so it is hard to find someone willing to deal with an adult or their therapy is not suitable for him."

- **Availability of services** ~30%
- **Distance** ~ 24%
- **Waitlists** ~19%

Do support services meet needs??

Ageing with Fragile X syndrome

"complex and multifaceted"

- **Normal life span expected** where care & supports are in place
- **Cognition:** likely plateau in cognitive & language skills development and early cognitive decline in males; no evidence of dementia
- **Possible decline in independence** in daily living skills
- **Behavioural problems** may generally improve with age
- **Autistic traits** – mixed findings: decrease vs little to no change
- **Existing adult service landscape** often inadequate
- **Mental health** - eg: impact of retirement /loss of employment and daily life routines
- **More research** needed on service and support needs
- **Clinical guidelines and targeted training needed for care providers**

Refs: **Genovese & Butler (2025);** Wu, J et al. **Ageing with Fragile X syndrome: A scoping review** [Unpublished manuscript]. (2025)

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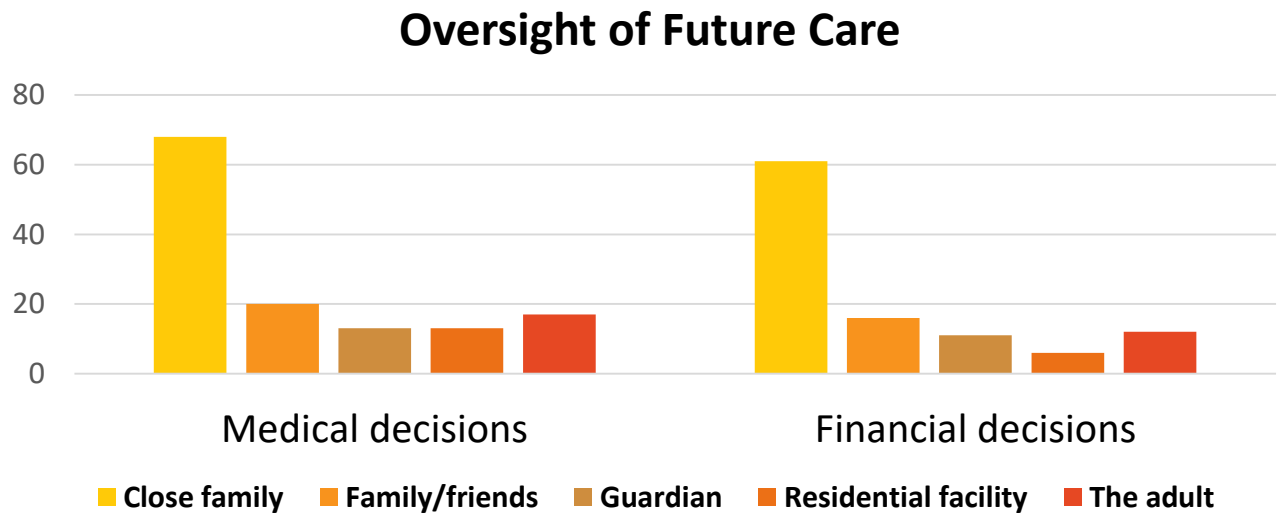
Planning for the future

Parent/caregiver concerns for adult's future	
Health & wellbeing	66%
Support services – quality & availability	66% / 63%
Transitions to different long-term supports	63%
Engagement in the community	48%
Safety	48%
Financial support	48%

60% of survey respondents exploring support plans for their adult's future



Fragile X Care | Adults & Ageing, Parent/carer Survey 2024

Planning for the future

- **“Not sure where to start** and not ready for him to be out of home as we have concerns about if he will be looked after properly or treated well”
- “The **NDIS does not facilitate long term planning.”**
- “Our concerns are that the **situations might change** in a way that we can not anticipate and decisions might need to be made. Who will make them? Who will advocate for [x’s] interests?”
- “Currently **racing to train him to live safely in his own unit** that we purchased and paid up for him. So he will always have a roof over his head. We do not like him to go to care homes due to perceived risk of paedophiles**… Our concern is that he will be lonely** living alone when parents pass in and relatives are not able to visit nor include him. “
- “**planning to start the conversation with my parents, who are 80**, in the next 12 months”
- “The **FX webinars have been very helpful** It is good to talk to other parents and carers to see what other models they have. However we are a bit lost here and I cannot see a solution in [x’s] current environment. “
- **“Family support is vital in any support plans.** Family must be supported as much as FX adult.”
- “It is something that is **constantly on our minds** but hard to work out what living situation is best… He would not like living in a Group Home unlike his brother. Unfortunately **the boys are too different to each other to live together.”**

Barriers to support identified by support teams

Difficult or challenging behaviours

72%

Communication challenges

70%

How to work with FXS and autism

54%

Fear of client's behaviours

44%

Inadequate funding

44%

Past experience trauma / abuse

34%

Health problems

26%

Professional development needs identified

- **Behaviour Support Strategies**
- Understanding adults / ageing in Fragile X syndrome
- Health considerations
- Communication supports
- Future and transition planning

"Get to know the individual with Fragile X syndrome rather than basing your care on just their condition

-Use clear and concise cues that the individual would understand when you are trying to teach them something new"

"Familiarise yourself with what this diagnosis is, including general information provided by Fragile X organisations.

- Take the time to get to know the individual you are supporting - while there may be similarities amongst each individual with Fragile X, each individual is unique.

- Work actively with families and those that know the person well"

Building Disability & Aged Care Workforce Capacity

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E-learning

- 2 modules @ 30 minutes
- Free
- Suitable for a range of learning styles
- Foundational learning
  - Understanding Fragile X syndrome
  - Supports for health & wellbeing
  - Supporting regulation & behaviours

National Centre of Excellence in Intellectual Disability Health

We want to help disability and aged care staff understand and support adults who are ageing with Fragile X syndrome

Resources & References

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Fragile X Association of Australia

- **Systematic Review: Fragile X Syndrome Across the Lifespan with a Focus on Genetics, Neurodevelopmental, Behavioral and Psychiatric Associations.** Ann C Genovese, Merlin Butler. Genes, 2025.
- **The Joys of Fragile X: Understanding the Strengths of Fragile X and Delivering a Diagnosis in a Helpful, Holistic Way.** Jonathan Herring, Kirsten Johnson et al. Neurodiversity. 2024
- **A Holistic Approach to Fragile X syndrome Integrated Guidance for Person-Centred Care.** Kirsten Johnson, Andrew Stanfield et al. Journal of Applied Research in Intellectual Disability, 2024.

Webinar Recordings

www.fragilex.org.au

YouTube

Listen on Apple Podcasts

Spotify

Acknowledgements

Project Team

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