

LIVING WITH FASD: IMPACT ON FAMILIES

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PRESENTER DISCLOSURE

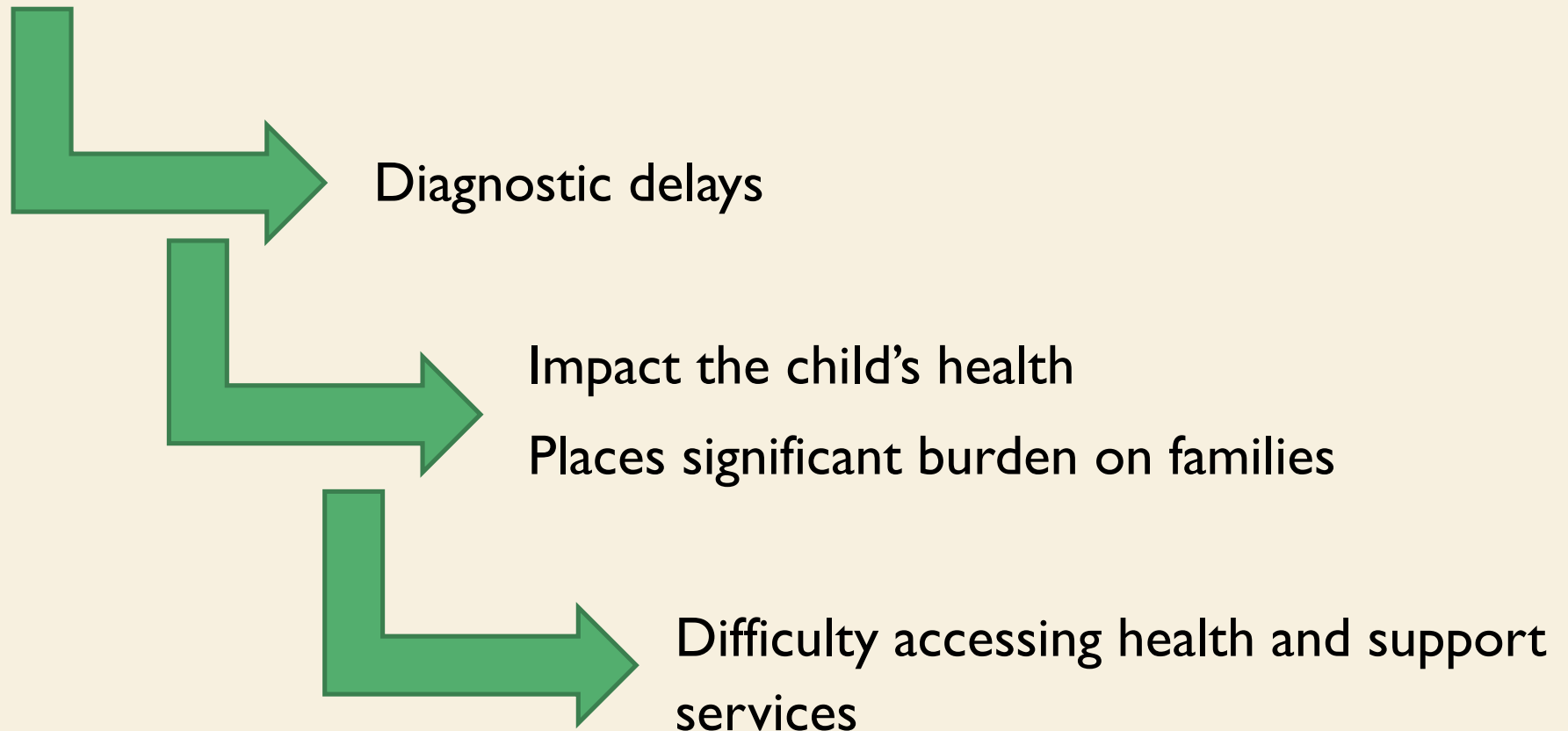
- Dr Natalie Lynette Phillips
- Relationship with commercial interests:
 - None

MANAGING POTENTIAL BIAS

- Non applicable. Nil disclosures/conflicts of interest.

BACKGROUND

FASD frequently goes unrecognised and undiagnosed



OBJECTIVES: STUDY / LEARNING

1. To inform health care practices required to enable timely diagnosis of FASD
2. To determine the impact of FASD on child health-related quality of life and psychosocial impact on families caring for a child with FASD
3. To identify barriers to accessing appropriate specialist health care and support services

METHODS

- Families of **42** children diagnosed with FASD
- Recruitment
 1. *NSW FASD Assessment Service*
 - CICADA Centre NSW
 2. *Advertised Australia Wide*
 - No FASD Australia

cicada
the **childr^{en}**'s hospital at Westmead
Care and Intervention for Children and Adolescents
affected by Drugs and Alcohol

n  **fasd**
australia | National
Organisation
for Fetal Alcohol
Spectrum Disorders

Self-administered online survey

- Developed for Australian children and families living with rare diseases (Anderson et al., 2013; Zurzynski et al., 2017)
- Psychometrically validated measures
 1. *Child health functioning*
 - Royal Alexandra Hospital for Children Measure of Function (Dossetor et al., 1996)
 2. *Family functioning*
 - The Impact on Family scale (Stein et al., 2003)

METHODS

Demographics

Experiences of diagnosis

Child health functioning

Impact on the family

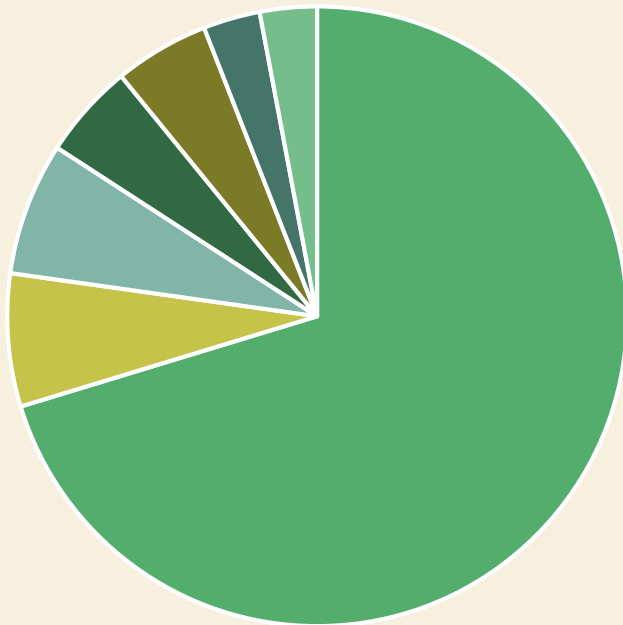
Use of and needs for health services

Use of an need for financial and support services

PARTICIPANTS



CAREGIVERS



- Foster carers
- Adoptive
- Other family
- Birth parents
- Legal guardian
- Birth father
- Step parent



CHILDREN/ADOLESCENTS

Child demographic	M or %	Range	p
Age(y)	M = 9.5	1.2-17.8	-
Sex (male/female)	55/45%	-	.644
Ethnicity			
Caucasian	52%	-	.755
Indigenous	45%	-	
Other	2%	-	
Diagnosis			
FASD + 3 SFF	19%	-	<.001
FASD < 3 SFF	76%	-	
Age, Diagnosis(y)	M = 7.2	Birth-17.3	-



EXPERIENCES OF DIAGNOSIS: DIAGNOSTIC DELAYS

DIAGNOSTIC DELAYS

***First signs &
symptoms***

4 years (on average)

***Diagnosis of
FASD***

DIAGNOSTIC DELAYS

First signs & symptoms

4 years (on average)

Diagnosis of FASD

72% consulted 3+ doctors

73%

believed a diagnosis could have been made sooner

PERCEIVED REASONS FOR DIAGNOSTIC DELAYS

01

Lack of knowledge among health professionals

62%

02

Lack of family awareness at early stages

37%

03

Long waitlists to see specialists

28%

04

Diagnostic tests not available

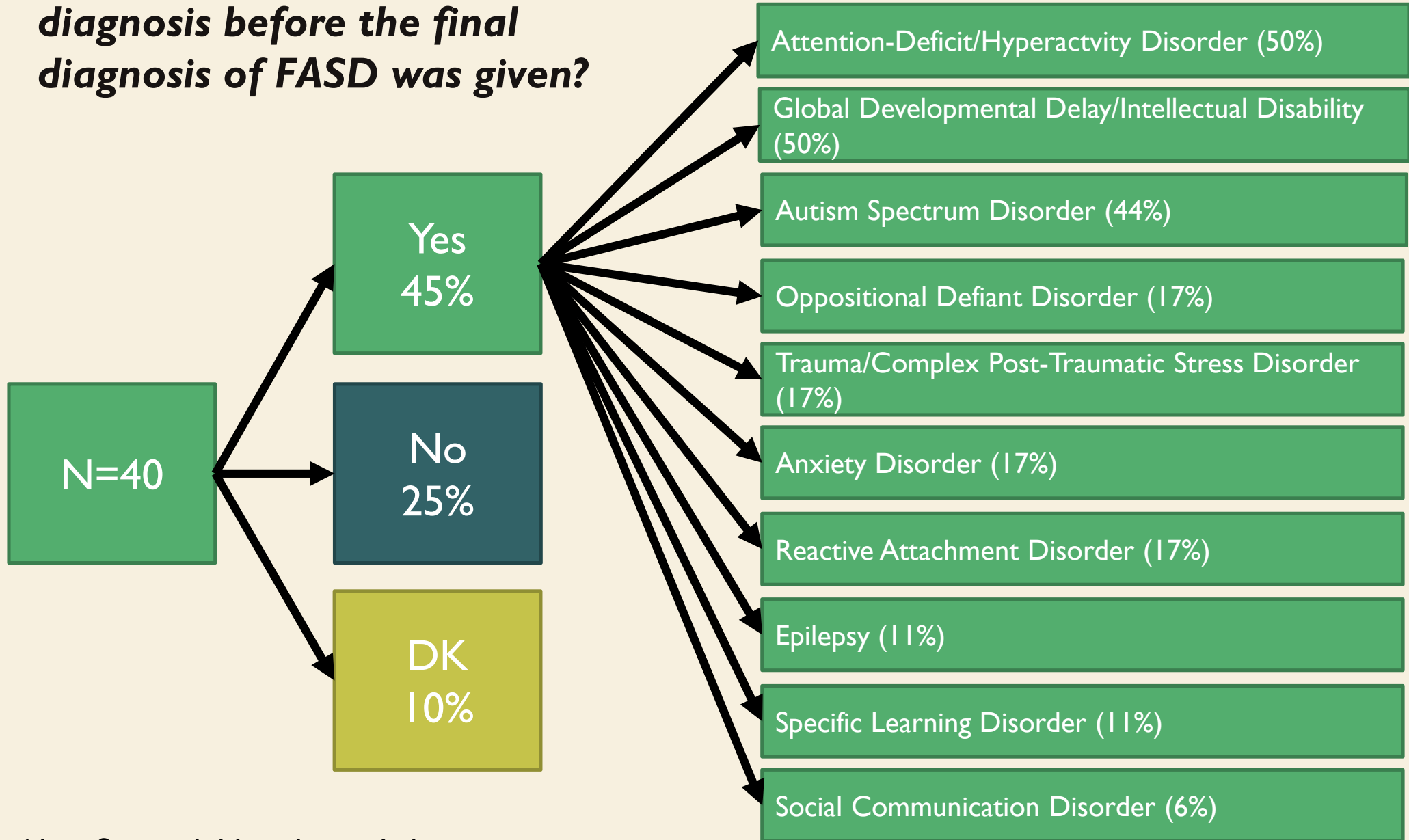
17 %

05

Other (e.g. lack of info. re birth history)

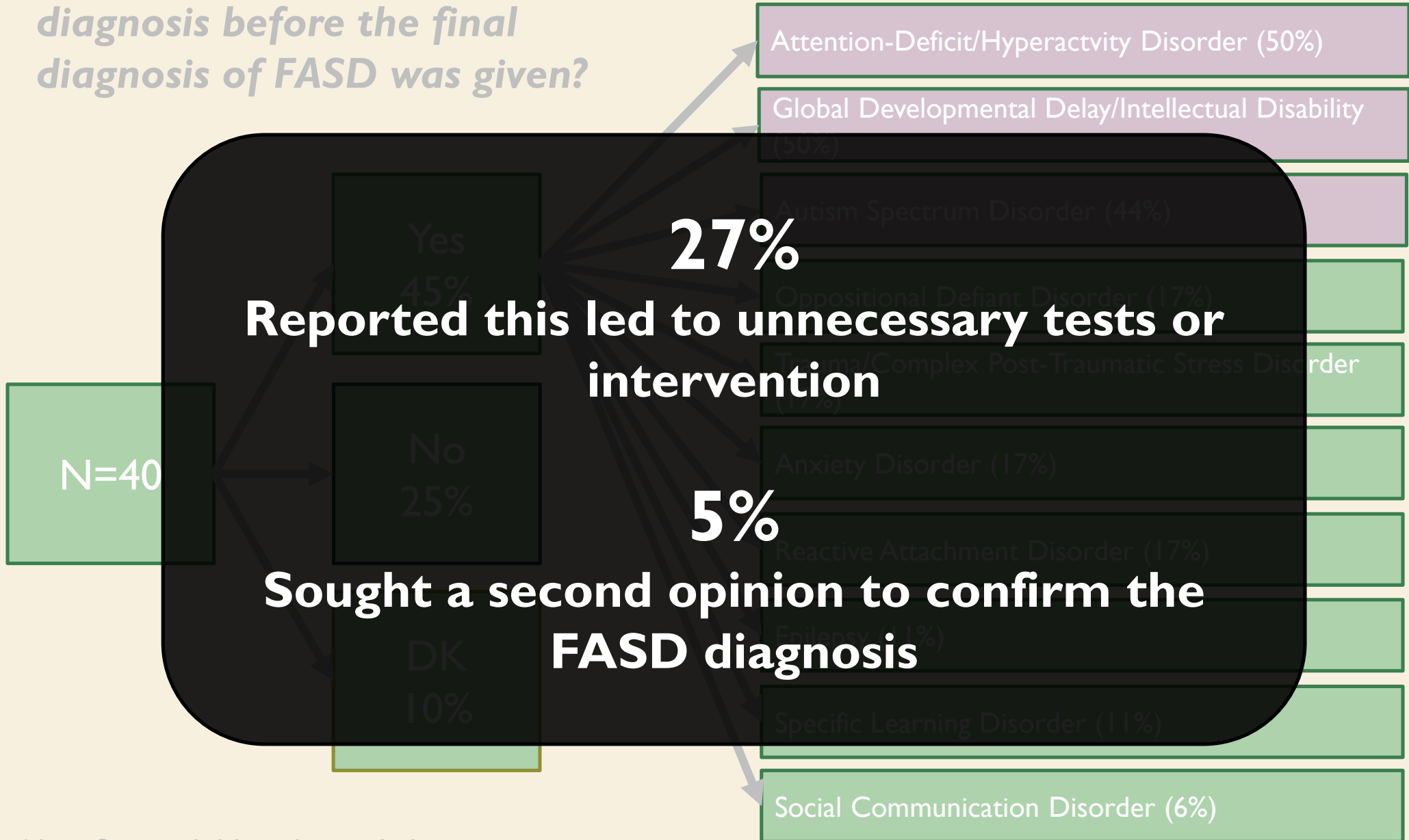
20%

Was your child given any other diagnosis before the final diagnosis of FASD was given?



Note. Some children has > 1 diagnosis

Was your child given any other diagnosis before the final diagnosis of FASD was given?



Note. Some children has > 1 diagnosis

EXPERIENCE OF DIAGNOSIS

- **93% were very satisfied or satisfied** about how they were told about their child's diagnosis

- At diagnosis, **64% were offered counselling/psychological support**

69% believed this support should always be offered

- At diagnosis, **48% were made aware of support groups**

100% wanted information about support groups

INFORMATION AT TIME OF DIAGNOSIS

Type of information at diagnosis?	%
How the diagnosis will affect your child's daily life	71%
Prognosis or what to expect in the future	62%
Specialist medical centers related to the disorder	53%
Support organizations related to the disorder	50%
Information about the disorder and what causes it	45%
Respite care options	31%
Other (e.g., behavioral strategies, therapy, research)	7%

How would you like to receive this information?	
Written/pamphlet	81%
Website reference	64%
Orally	38%



CHILD HEALTH-RELATED QUALITY OF LIFE & FAMILY FUNCTIONING

CHILD HEALTH RELATED QUALITY OF LIFE (RACH MOF)

Table 1 Categories and descriptions of the RAHC MOF scale [16]

Category	Description
1. Superior	No symptoms; physically able; excellent relationships with family and friends; wide range of extra-curricular activities; doing well at school/preschool; developing normally; everyday problems never get out of hand.
2. Good in all areas	Virtually no symptoms; usually copes well; physically able; good relationships; normal play & leisure activities; school/preschool OK; may have problems when stressed but these are short lived and only occasionally get out of hand.
3. No more than slight problems	Some significant symptoms, only briefly get out of hand; sometimes child gets distressed; short term or little interference with mobility or relationships or play & leisure activities; school/preschool may be slightly affected or affected for a short time.
4. Some difficulty in a single area but generally pretty well	Mild symptoms which recover quickly with treatment; any distress or disability does not stop child from doing most things at that age; some anxiety or irritability or brief mood changes; minor effect on mobility or school/preschool or relationships or play & leisure activities; problems may persist but may only be recognized by those who know the child.
5. Variable problems in some but not all areas	Moderate symptoms have significant disabling effect on child; minor to moderate effect on mobility; school/preschool may be affected; may need special education; in some situations may seem O.K.; mainly managed in outpatient clinic or family doctor.
6. Severe problems in one area <u>OR</u> moderate problems in most areas	Severe symptoms having a major effect on child's life; restricted mobility; relationships or play & leisure activities are affected; child is distressed or has difficult behavior; some relationships are maintained; learning difficulties or problems with or missing school; likely to have been seen by specialist.
7. Major problems in several areas <u>AND</u> unable to function in one of these areas.	Severe, almost constant symptoms; child is distressed, withdrawn or has strange or aggressive behaviour; significant limitations on mobility or school/preschool or relationships or play & leisure activities; specialist management needed.
8. Unable to function in almost all areas	Very severe symptoms; child is very distressed; likely to be confined to bed; unable to go to school/preschool; may be in hospital but child is not entirely dependent on others.
9. Needs nursing supervision	Confined to bed; in hospital; very severe symptoms but stable; needs help with self-care which a child the same age can do without help.
10. Needs constant supervision	High (24 hrs) medical dependence e.g. In intensive care unit; life-threatening symptoms.



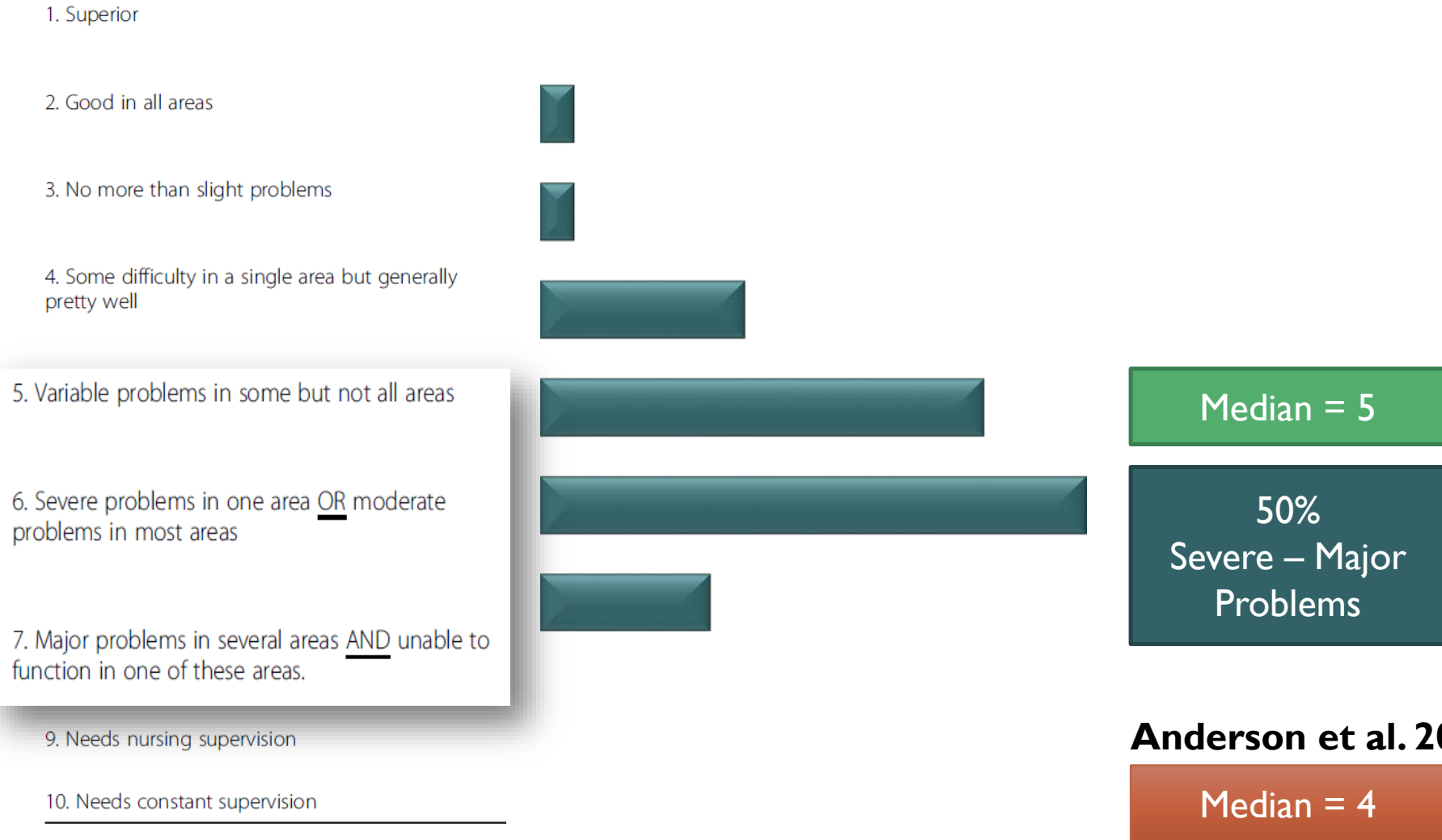
Poorer child-quality of health

10

CHILD HEALTH RELATED QUALITY OF LIFE (RACH MOF)

Table 1 Categories and descriptions of the

Category



IMPACTS ON FAMILIES SCALE

Living with FASD: The Impacts on your Child and your Family

Confidential

Impact of pediatric illness on family functioning:

- Financial
- Social
- psychological

IMPACT ON FAMILY

59. Please indicate (x) how strongly you agree/disagree with the following statements:

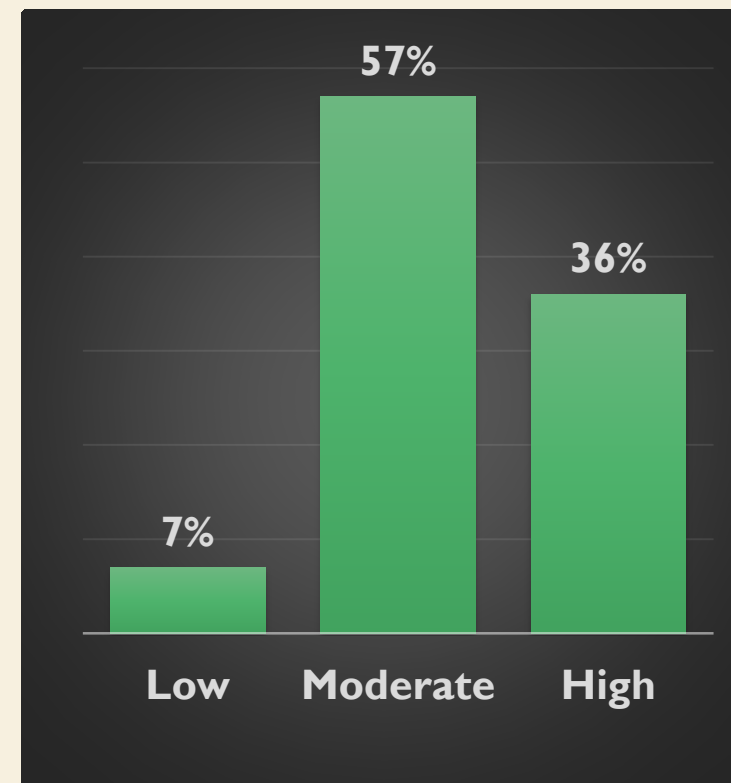
<i>Statement</i>	<i>Strongly Agree</i>	<i>Agree</i>	<i>Disagree</i>	<i>Strongly Disagree</i>
Additional income is needed in order to cover medical expenses				
The illness is causing financial problems for the family				
Time is lost from work because of hospital appointments				
I am cutting down the hours I work to care for my child				
Our family gives up things because of my child's illness				
People in the neighbourhood treat us as special because of my child's illness				
We see family and friends less because of the illness				

IMPACTS ON FAMILIES SCALE

- Higher scores on the IOF → Greater impact on family functioning
 - 15-29 = low impact
 - 30-45 = moderate/significant impact
 - 46-60 = high/very significant impact

IOF	Median	Range
FASD	42.0	26-55

IOF	Median	Range
Metabolic	36.5	19-56

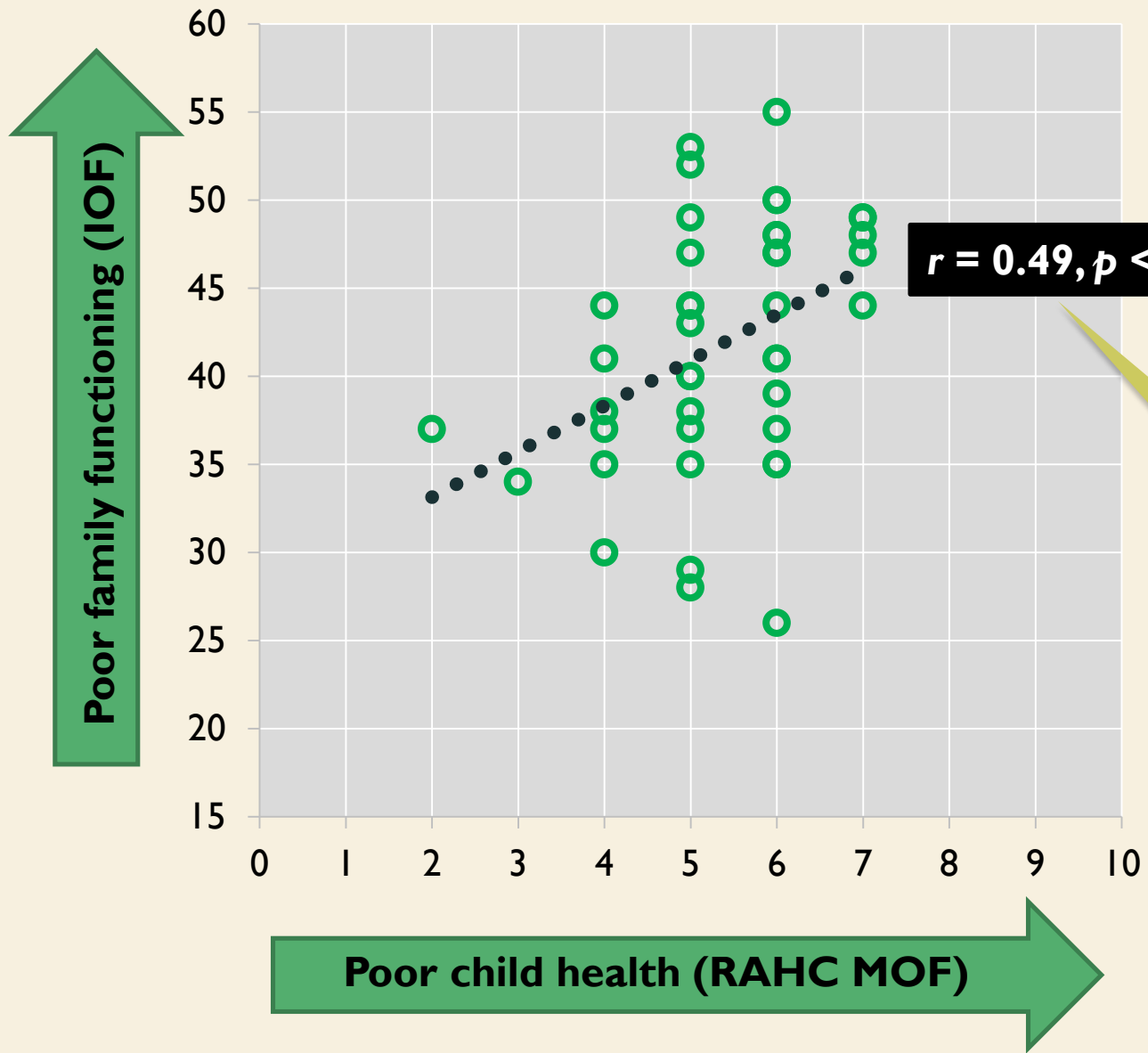


Anderson et al. 2013.

Australian families living with rare disease: experience of diagnosis, health service use and needs for psychosocial support. *Orphanet Journal of Rare Diseases*, 8.



POSITIVE IMPACTS ON THE FAMILY

Impact On Families	Agree – Strongly agree
Learning to manage my child's illness has made me feel better about myself	68%
Because of what we have shared we are a closer family	66%
My relatives have been understanding and helpful with my child	64%



**RELATIONS
BETWEEN
CHILD HEALTH-
RELATED
QUALITY OF
LIFE AND
IMPACT ON
FAMILIES**

Impacts on families was greater for families caring for a child with poorer health-related quality of life



ACCESS TO HEALTH/SUPPORT SERVICES

ACCESS TO HEALTH SERVICES

28%

Adequate access to health services

01

Long wait periods

58%

02

Distance of travel

48%

03

Care for other siblings

42%

04

Lack of health services

39%

05

Financial cost

39%

SUMMARY

- Parents of children living with FASD report diagnostic delays
 - Reasons: lack of knowledge (health professionals)
- At diagnosis parents want written information on support services and what to expect
 - Diagnostic process (timing & quality) critical to caregiver experience
- FASD has a significant impact on child quality of life AND family functioning
- Difficulties *accessing health services* exist
 - Waitlists & distance of travel

CONCLUSION / TAKE HOME MESSAGES

- This study highlights opportunities and need for:

Improvement in:

- ✓ Clinical service provision
- ✓ Assessment services and procedures
- ✓ Post-diagnosis care

Ongoing development of:

- ✓ Diagnostic and support services
- ✓ FASD-informed clinician education

CONCLUSION / TAKE HOME MESSAGES

- This study highlights opportunities and need for:

Access to:

- ✓ Support groups/organisations, psychological support, and information
- ✓ This information should be available to all parents receiving a life-changing diagnosis of FASD for their child or adolescent

Prevent avoidable diagnostic delays, promote early diagnosis and intervention, and provide ongoing support



THANK YOU

QUESTIONS

FUTURE RESEARCH DIRECTIONS...

- **Impact of FASD may vary with time since diagnosis +/- length of time caring for child, and other demographic factors:**
- How do differences in time since diagnosis impact on carer stress?
- How do differences in care situation - short vs long-term impact on carer stress and child QOL?
- Does age, socioeconomic status or remoteness impact on delayed diagnosis, family stress or quality of life?
- Compare to and/or include other assessment clinics