



South London  
and Maudsley  
NHS Foundation Trust

# Service involvement for children seen in the specialist PWS child mental health service in the UK

Supporting a multi-agency approach to food security and wellbeing  
*(and how restrictions can be liberating)*

Dr Sarah Carman, Principal Clinical Psychologist  
National and Specialist CAMHS Specialist Prader Willi Syndrome Service,  
Mental Health of Intellectual Disabilities team, SCAAND,  
Michael Rutter Centre, South London and Maudsley NHS Foundation Trust, UK.



# Who are we?

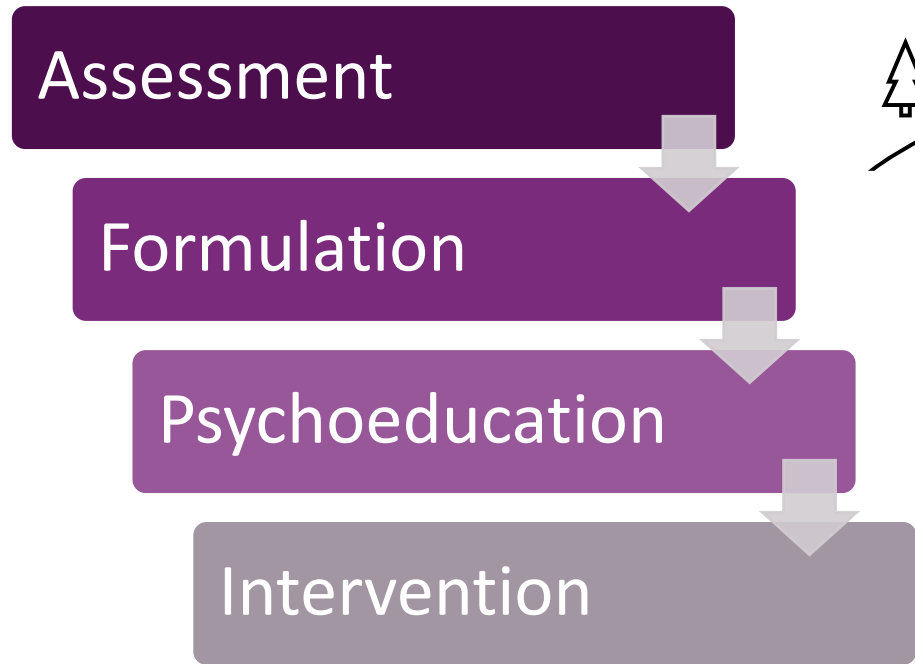
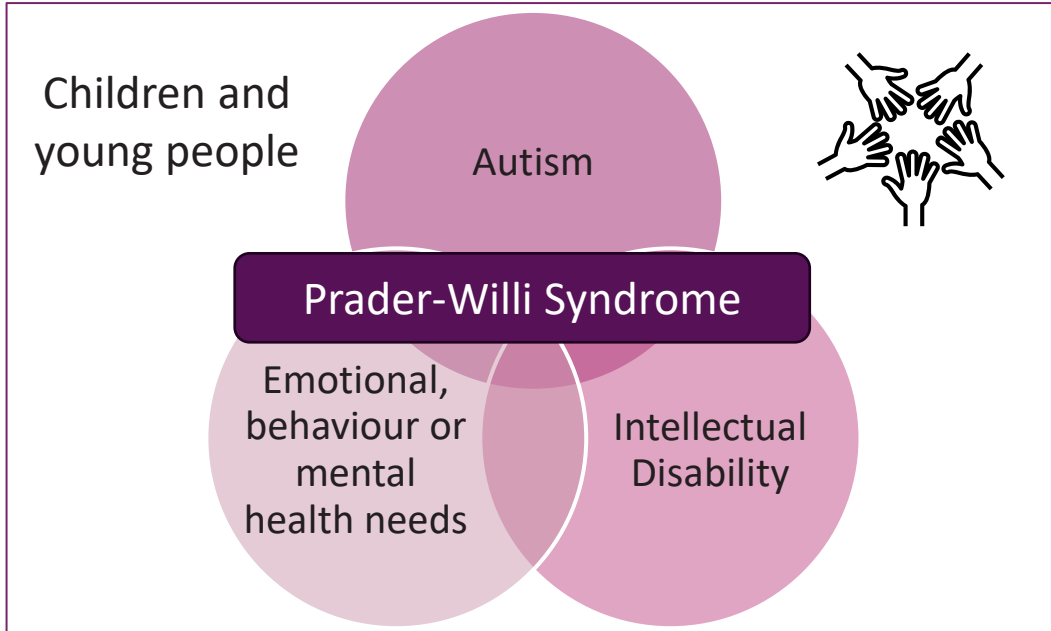
We provide multidisciplinary assessment and intervention for children and young people with PWS and associated behavioural or mental health difficulties; we are the only specialist mental health service for children with PWS in the country.

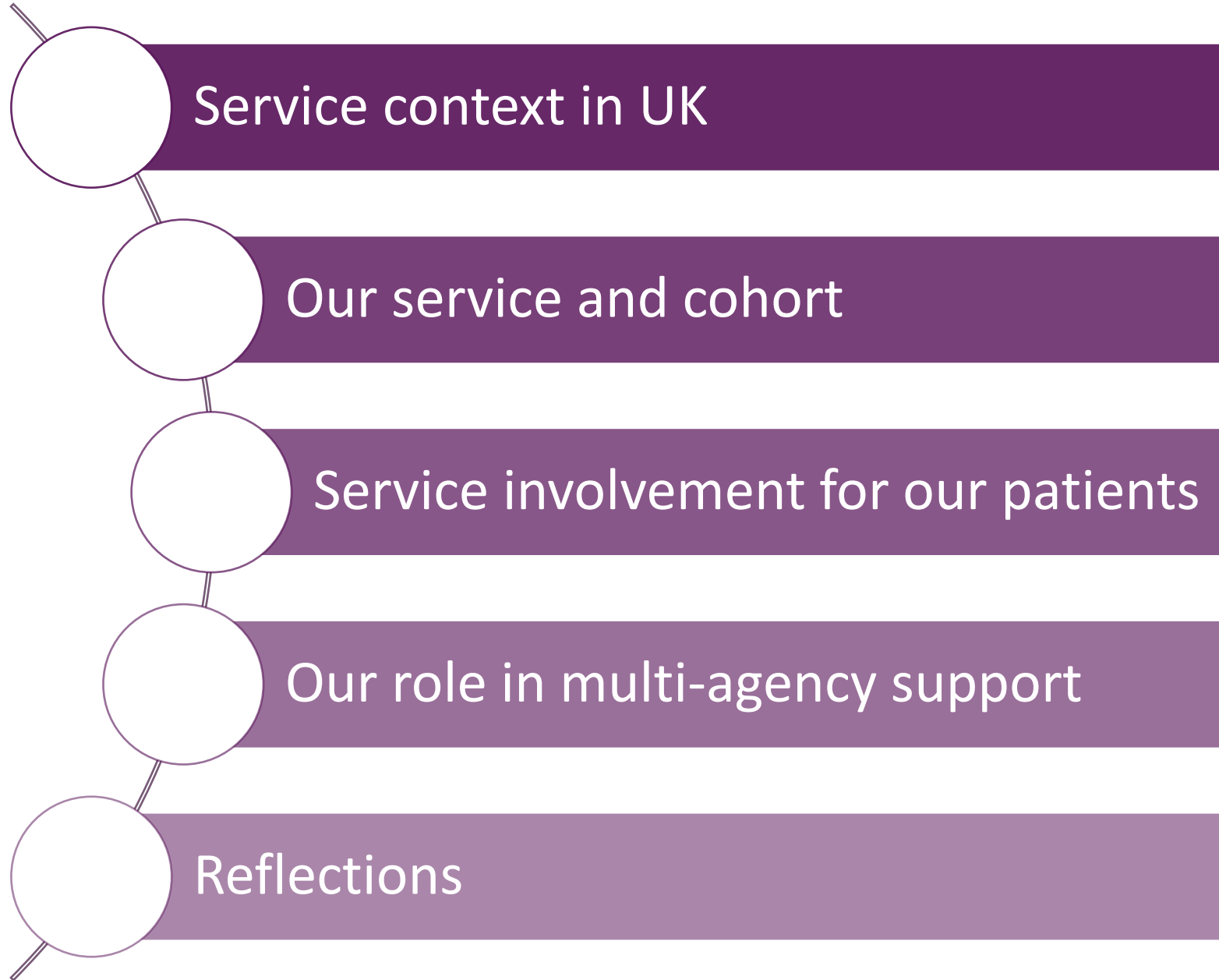


Natasa Momcilovic



Dr Sarah Bernard





# Service Context: England



Third Sector

Education



Children and Families Act



Education,  
Health and  
Care Plan



Health

Social  
Care



Child In Need Plan  
Child Protection Plan



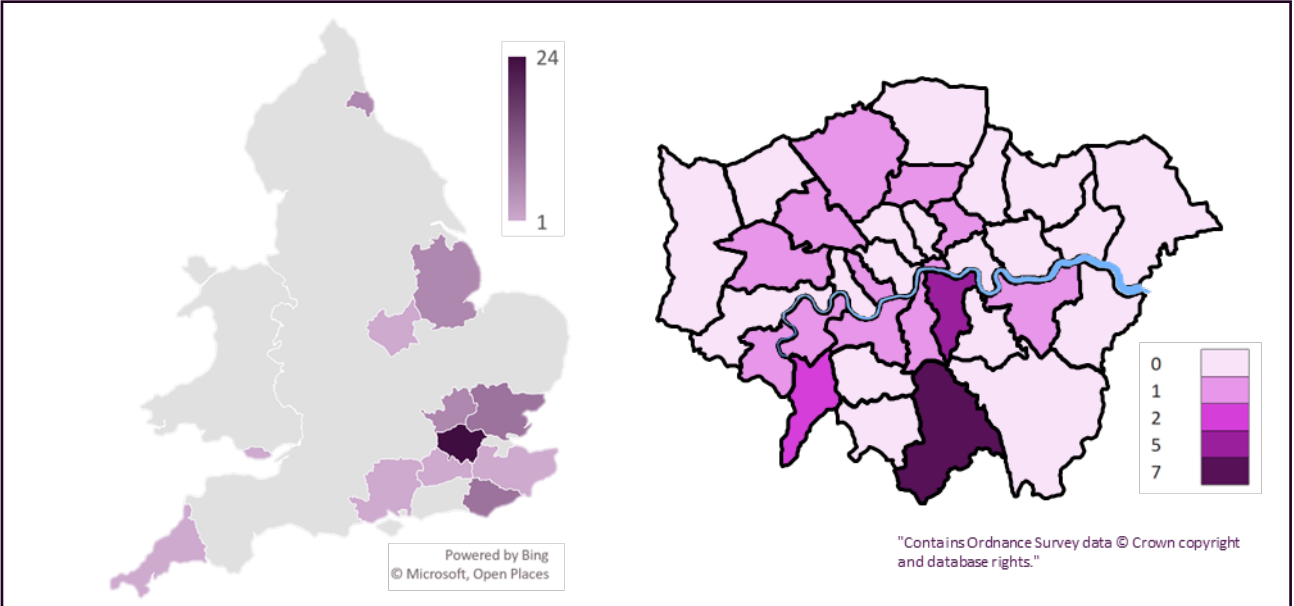
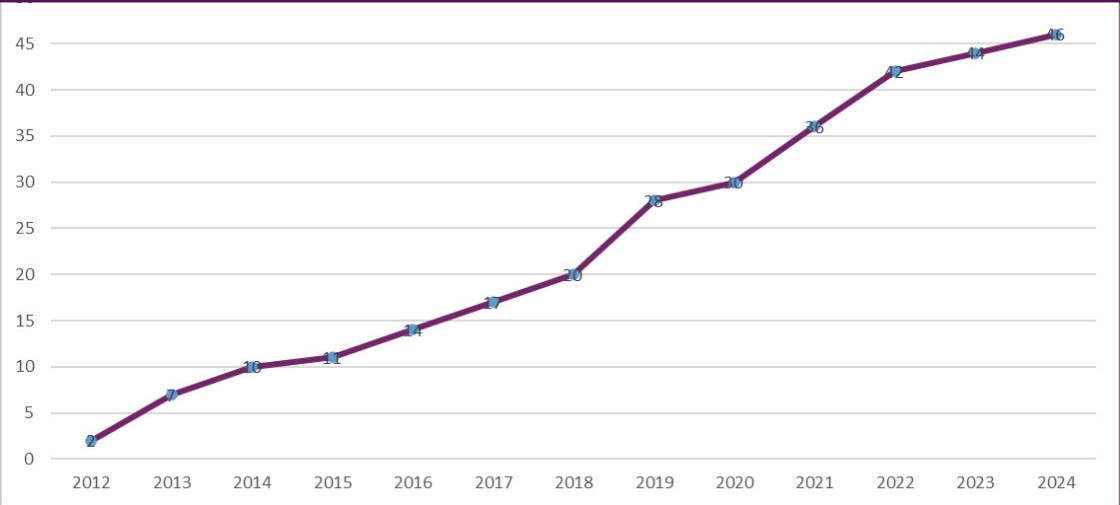
Children's Act



NHS



# Referrals: last 12 years



Referrals:

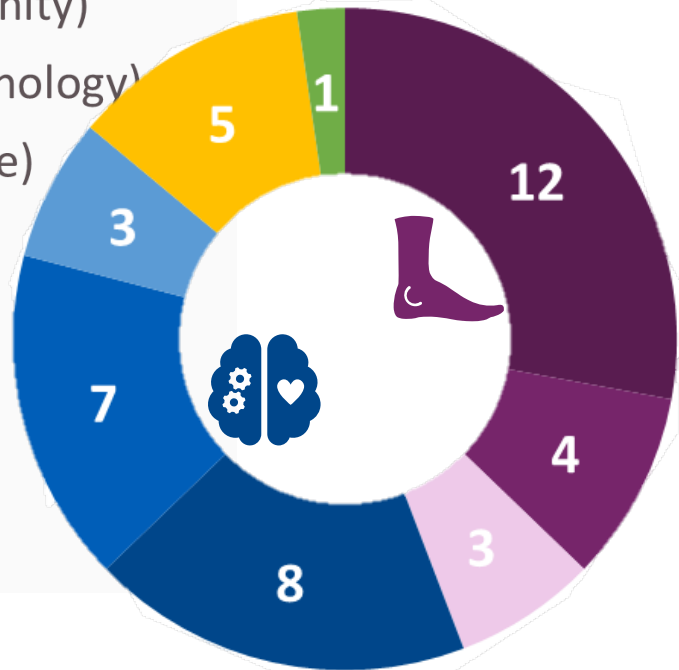
46

Individual children and YP:

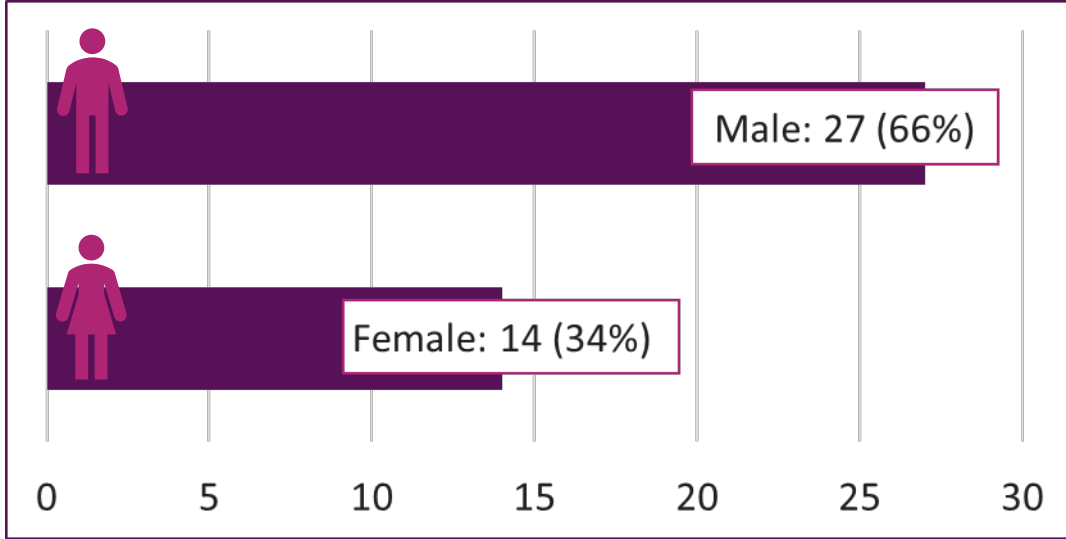

41



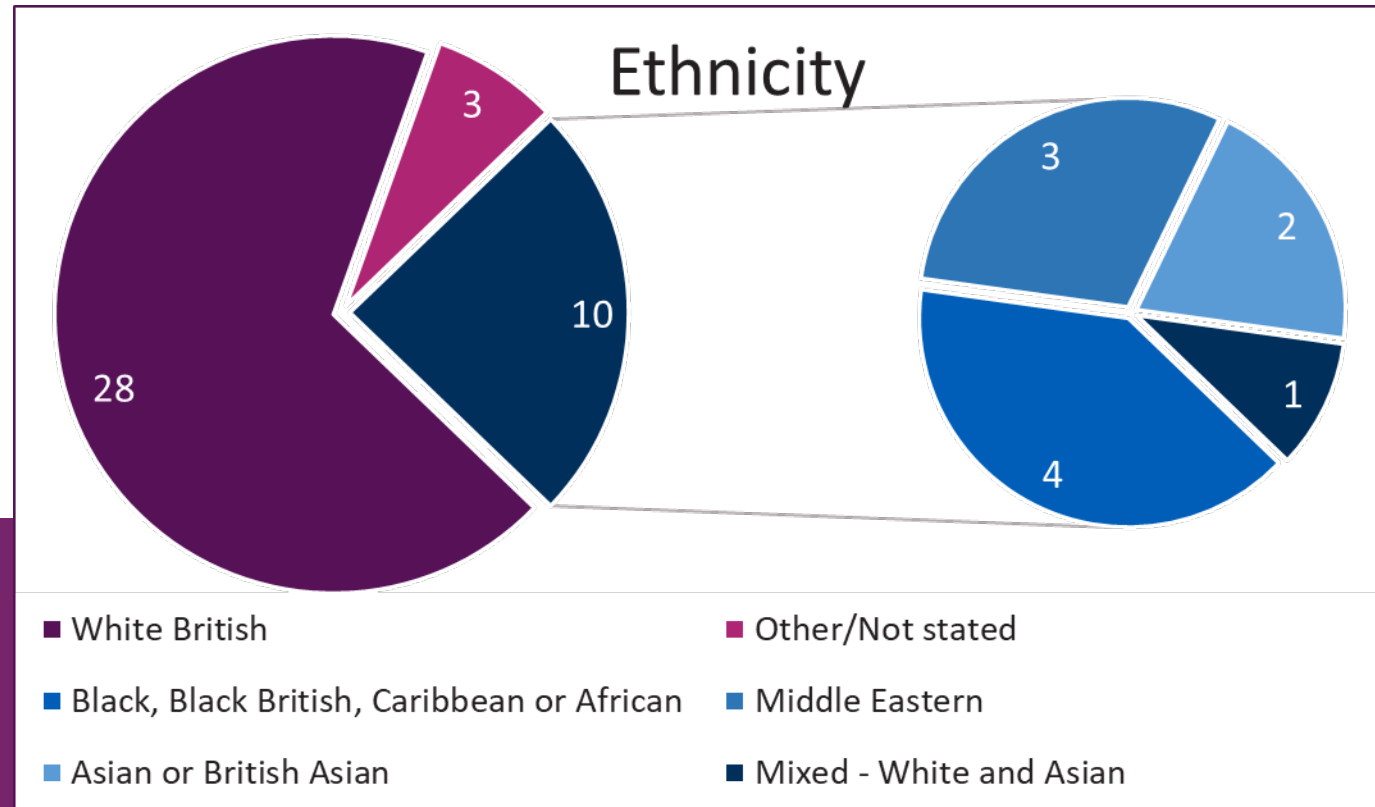
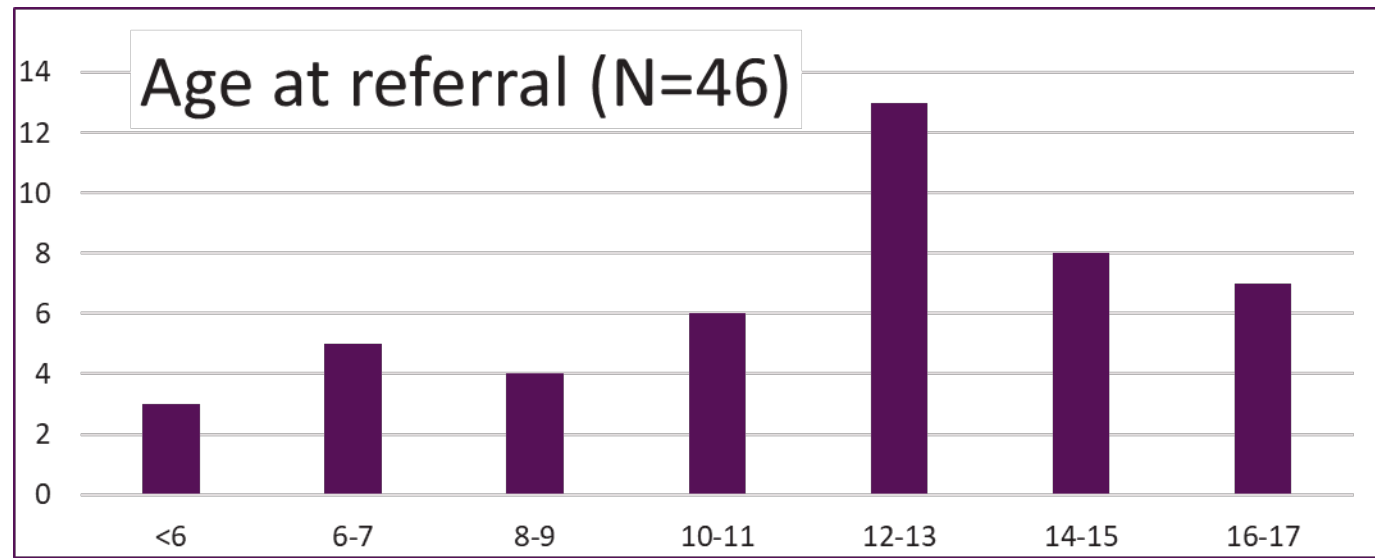
- Consultant Paed (Community)
- Consultant Paed (Endocrinology)
- Consultant Paed (2nd Care)
- Consultant Psychiatrist
- Clinical Psychologist
- CAMHS Clinician
- GP
- Social Worker



# Client group: last 12 years (N=41)

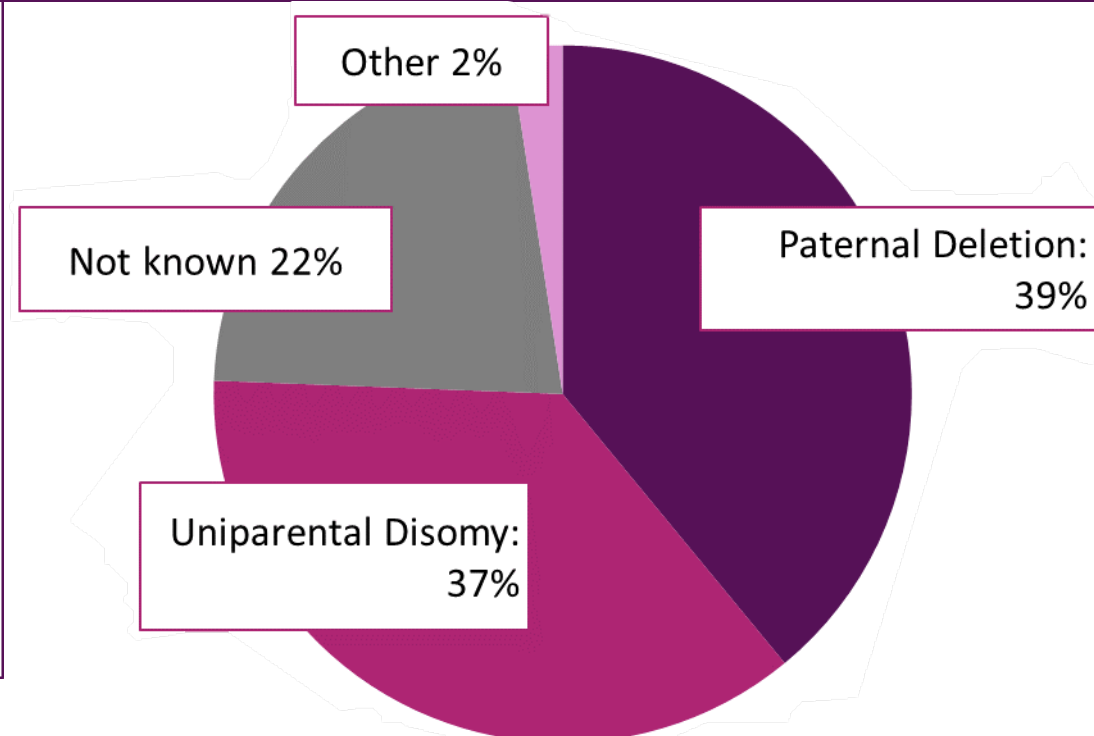
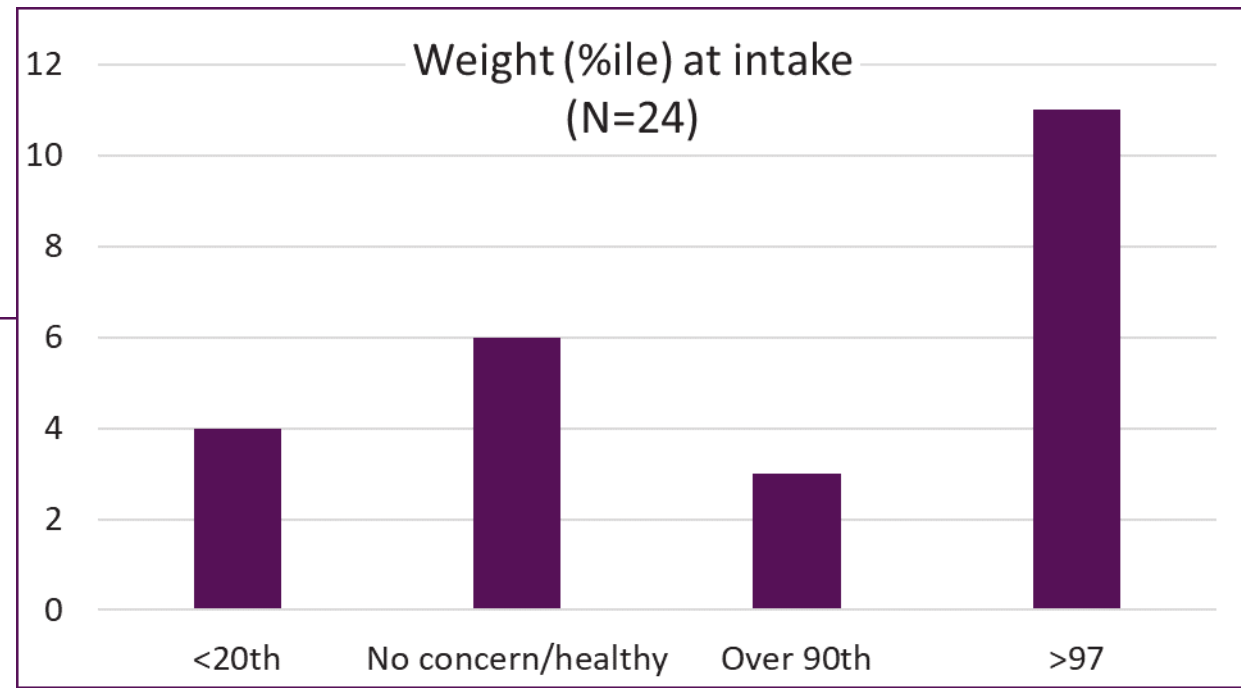
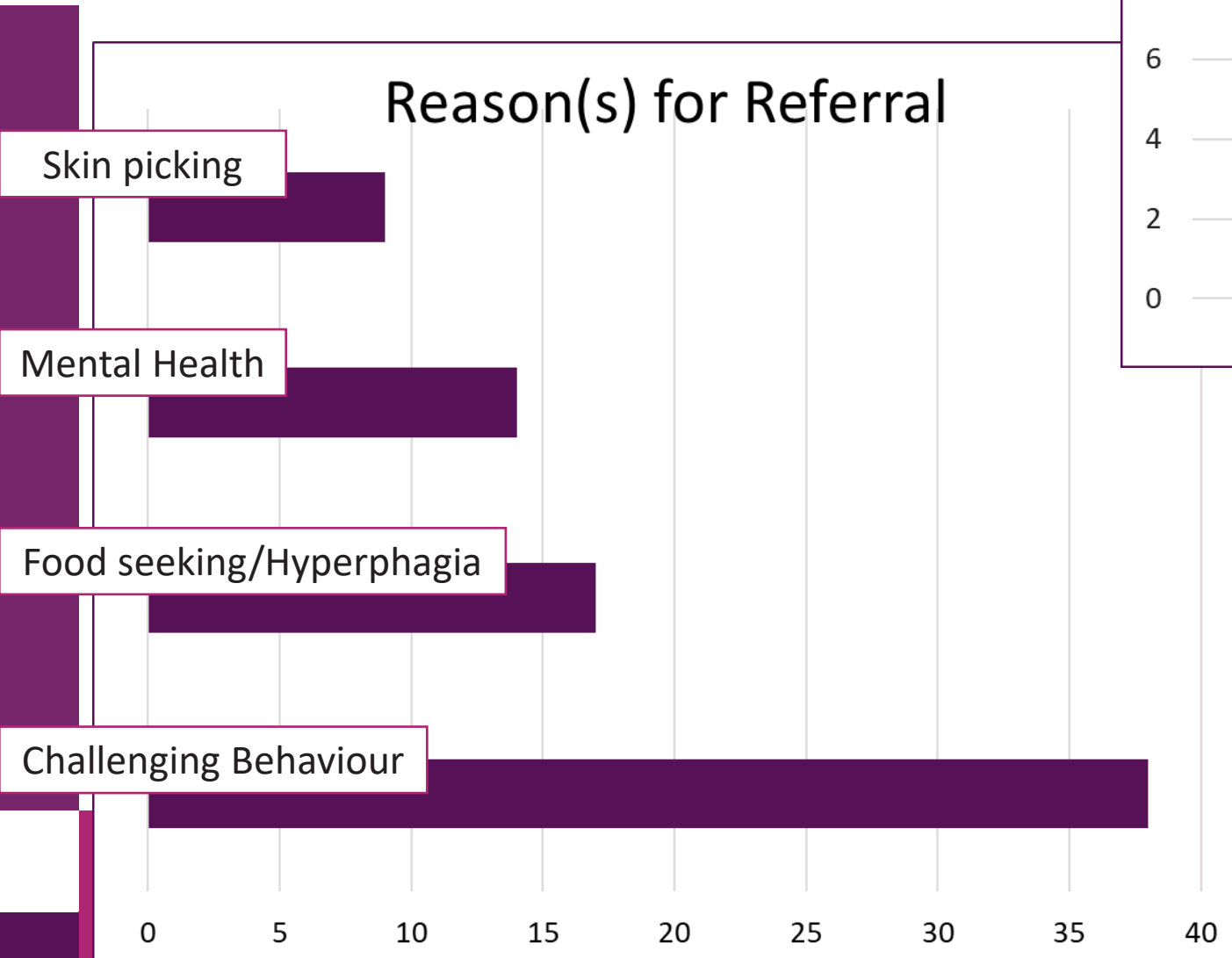



Living with birth family	37
Kinship care	1
Long term fostered	3

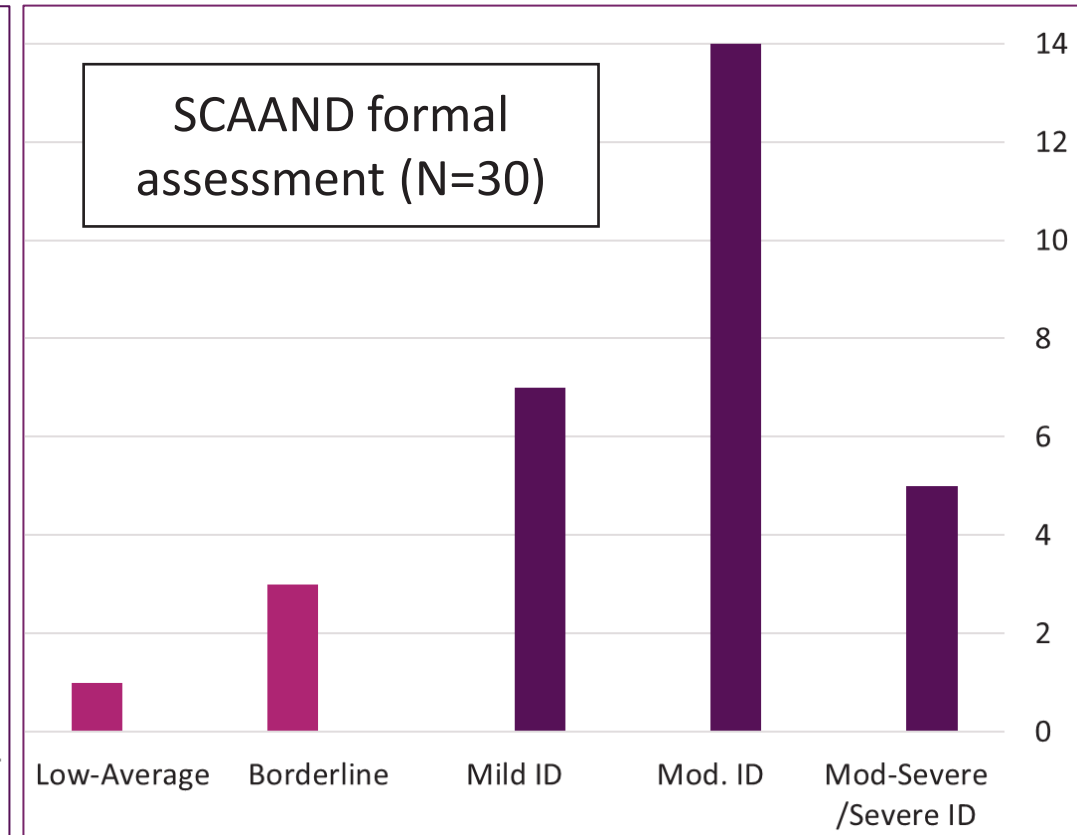
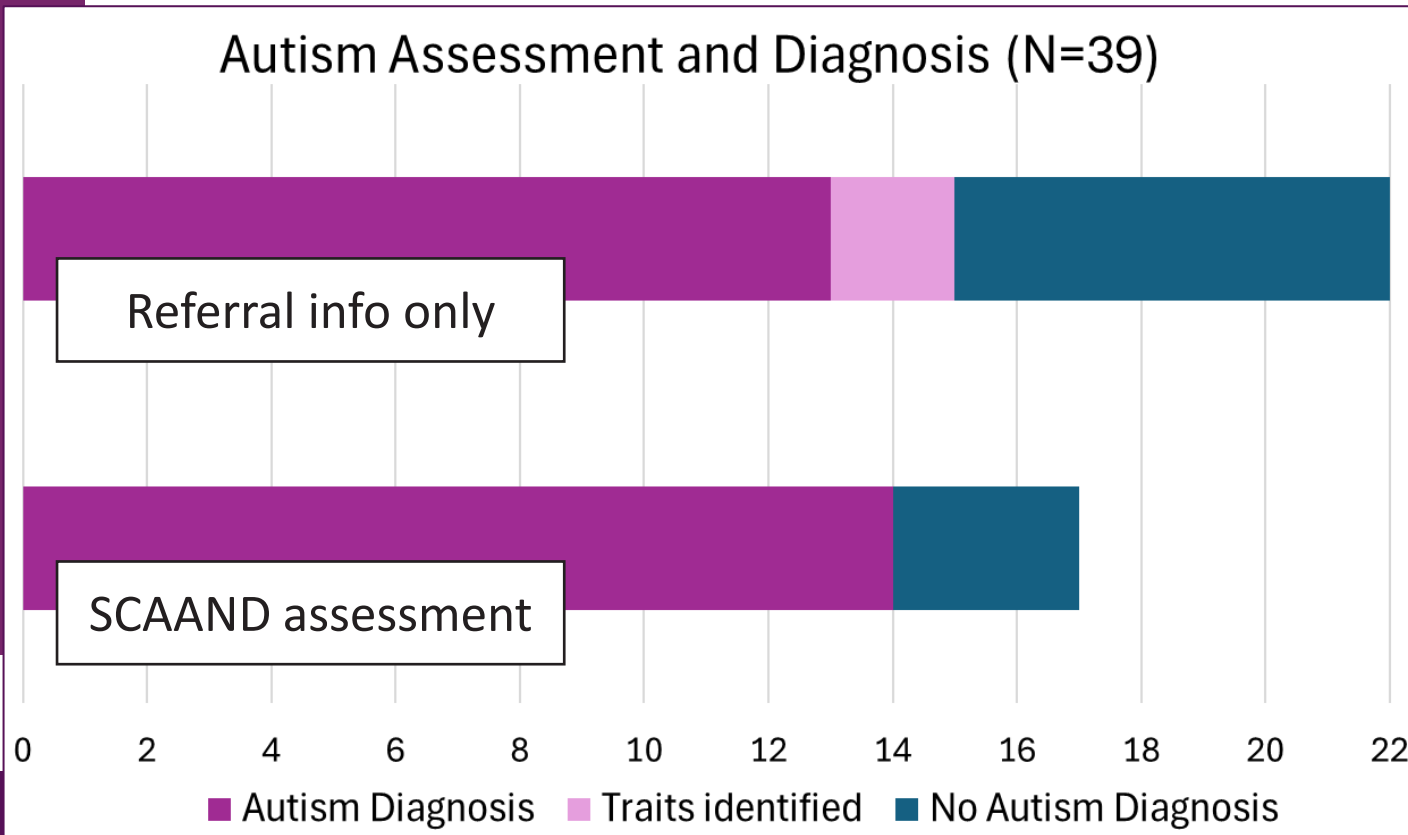
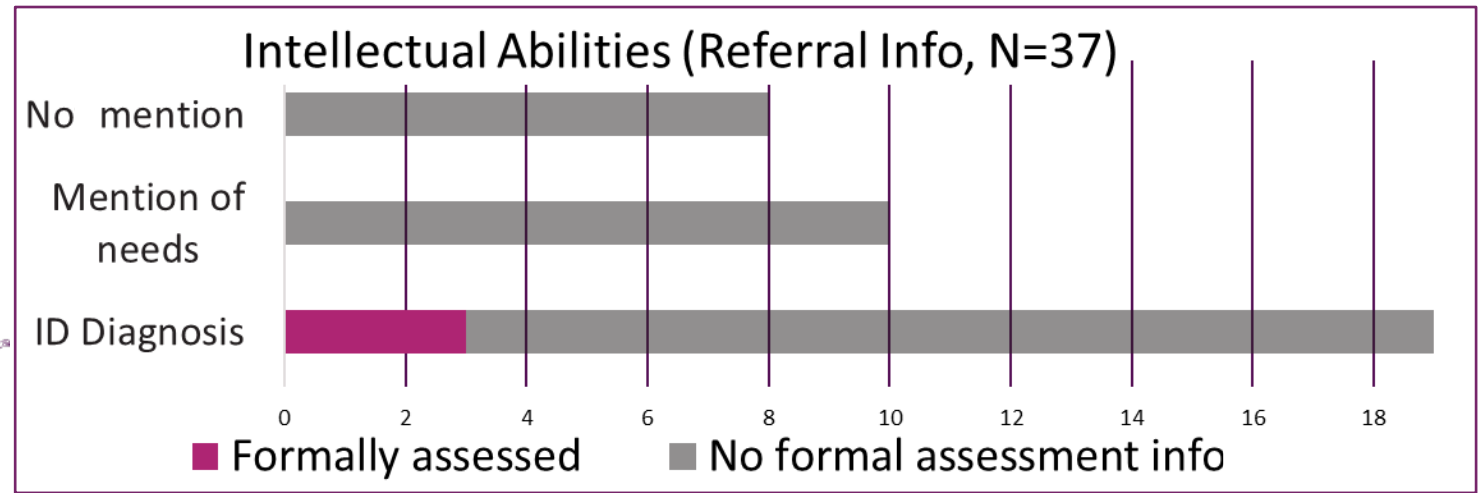


# Client group: last 12 years (N=41)

## Reason(s) for Referral

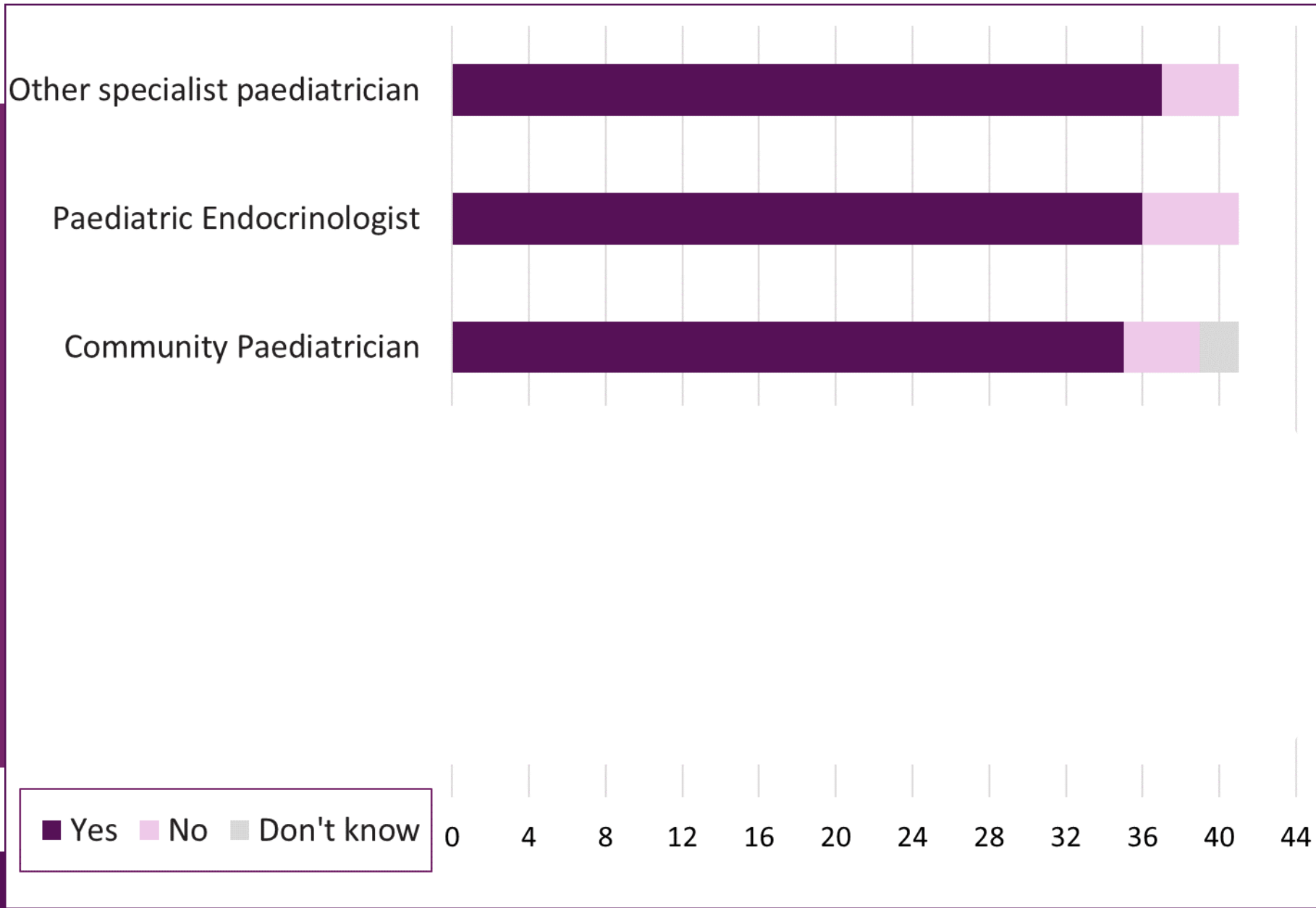


# Client group: last 12 years






## Audit findings: Services involved for our clients (N=41)




Mean paediatric specialties: 2.41

Most common

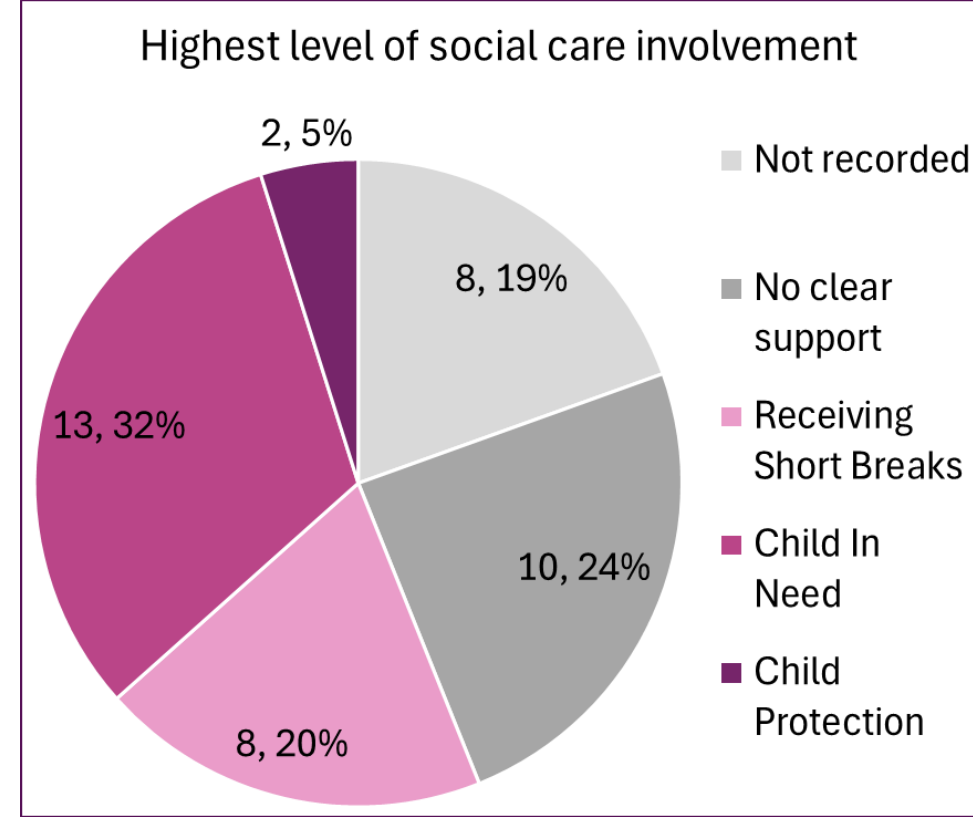
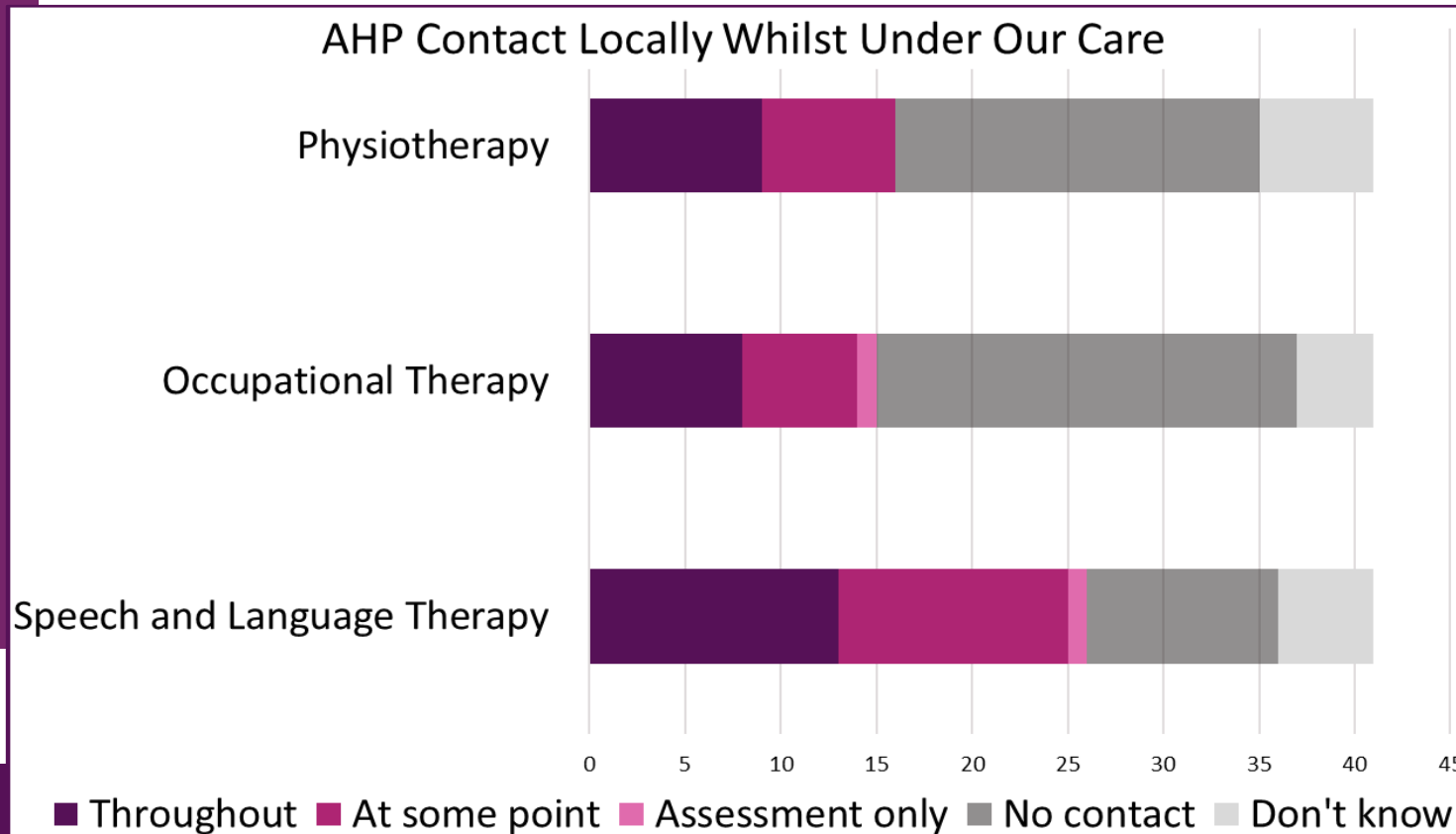
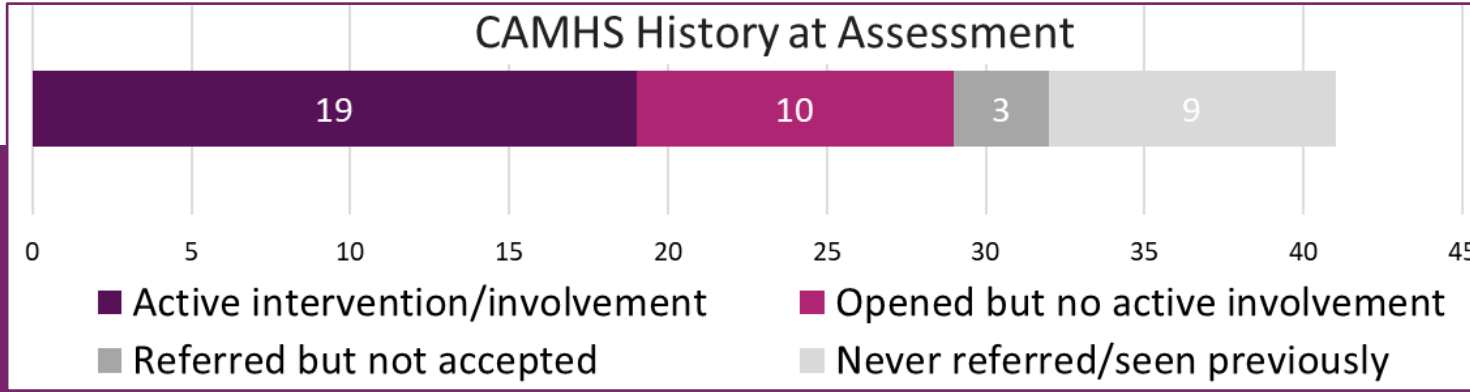


Spinal: 10



Respiratory: 10

# Audit findings: Services involved for our clients (N=41)



**16** Families also receiving support from PWSA-UK

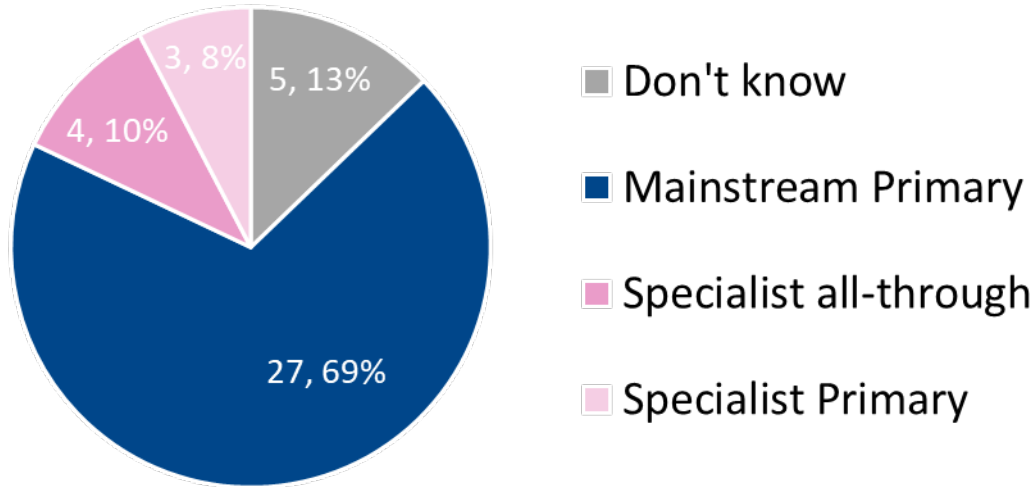
# Audit findings: Services involved for our clients (Education)



EHCP (N=41)

Referral: 38 Discharge: 40

## First School attended (N=39)



Out of education at some point:

7

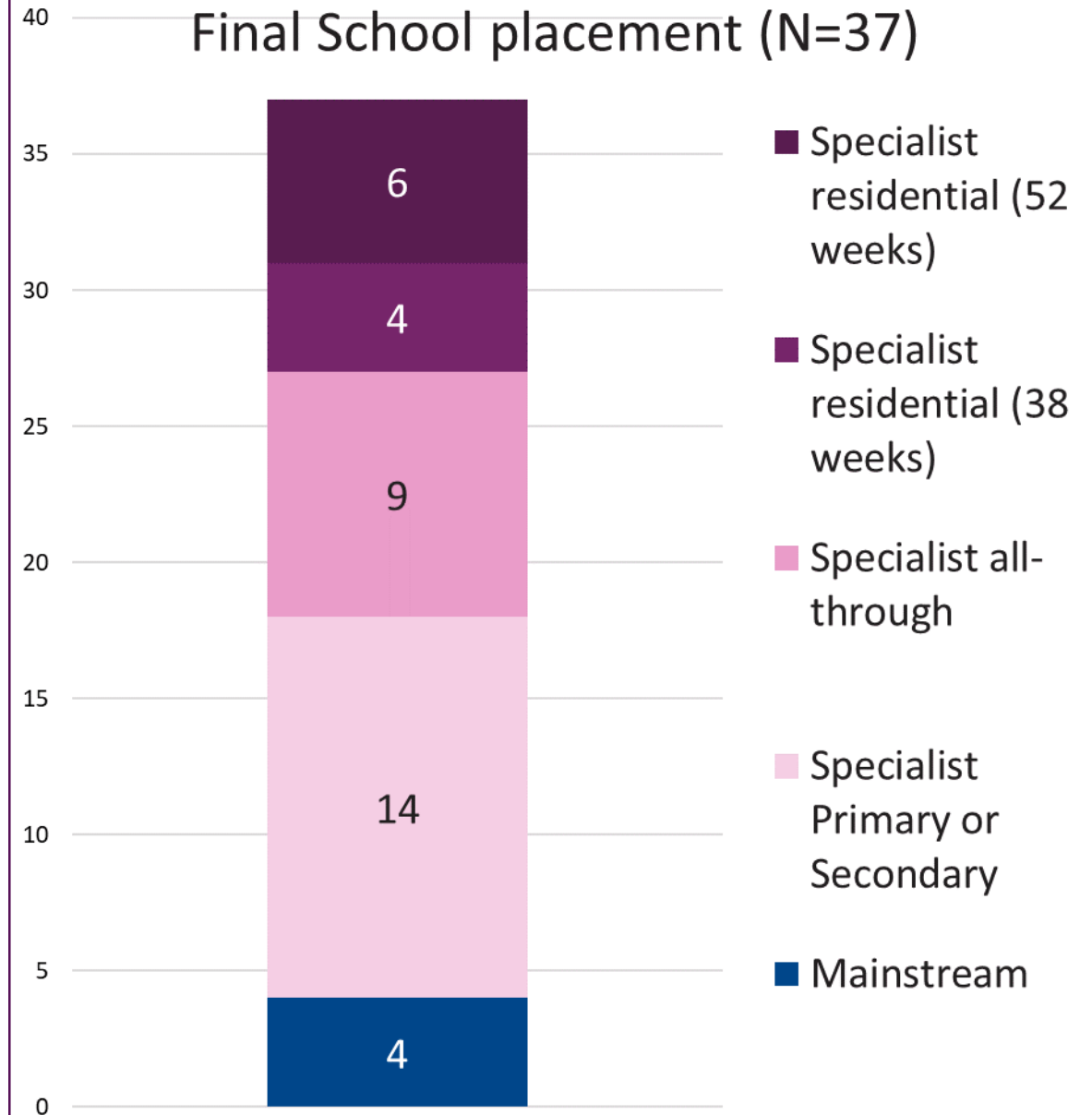


Average no. of schools:

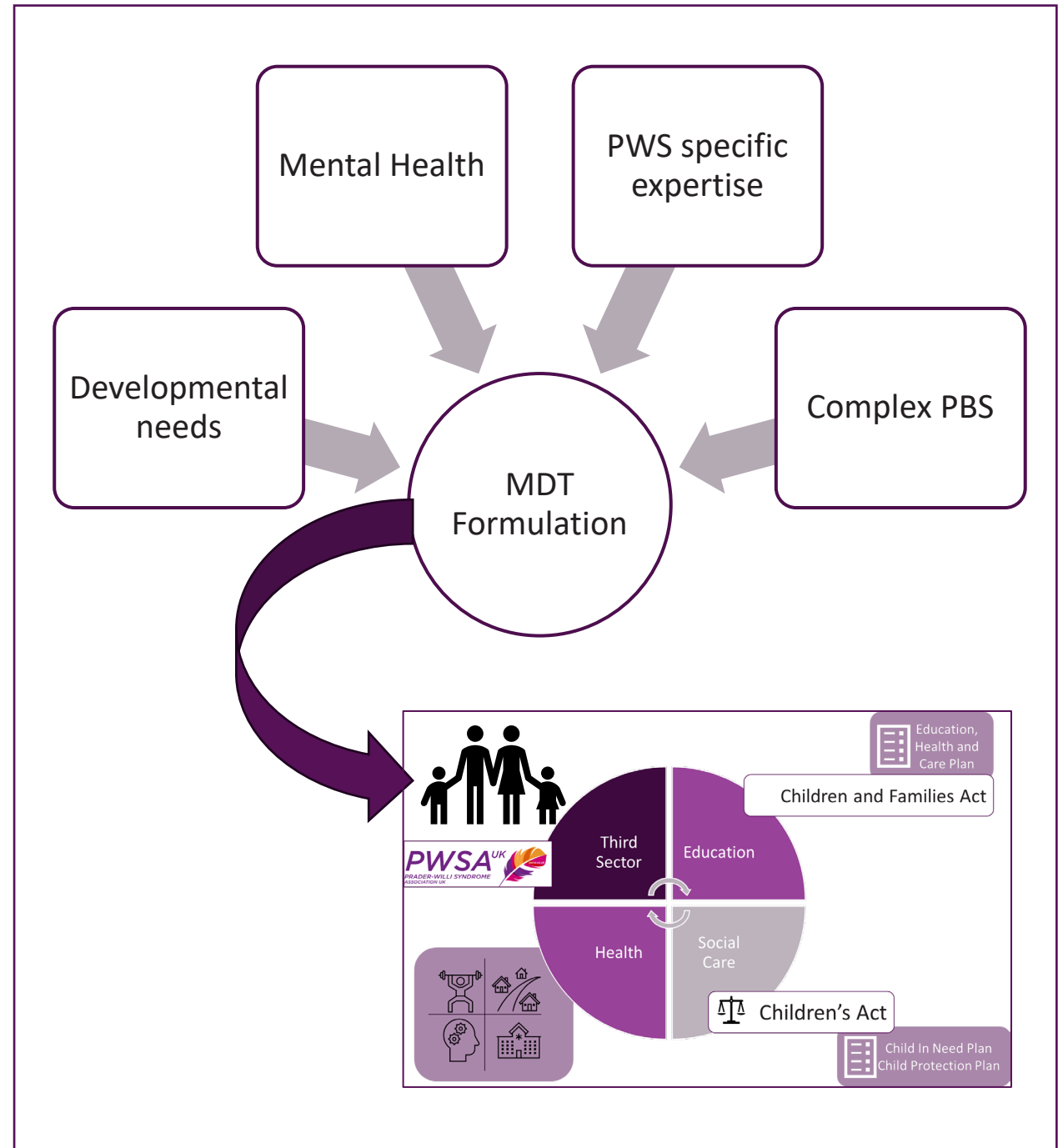
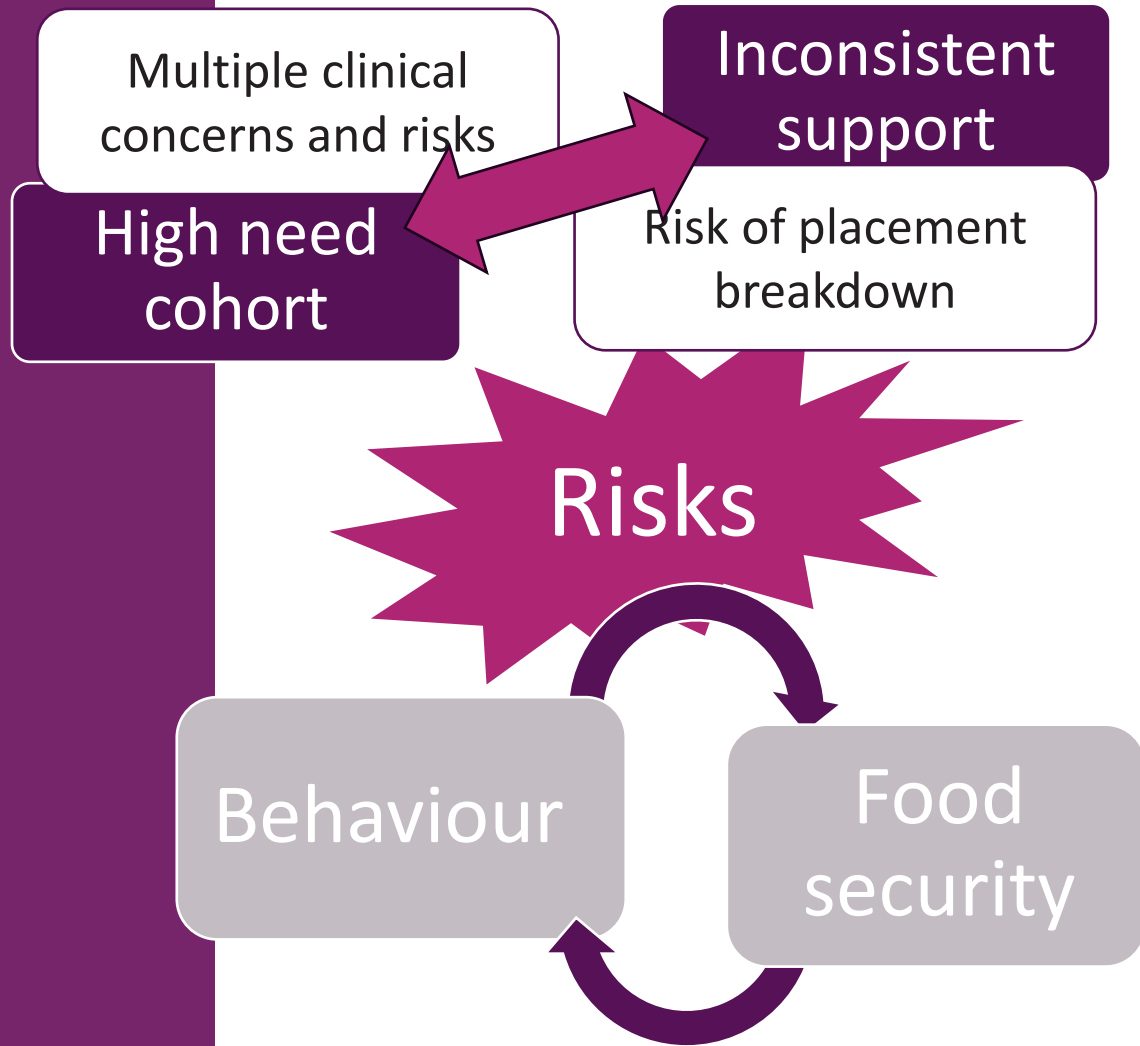
2.7



## Final School placement (N=37)



# How we work



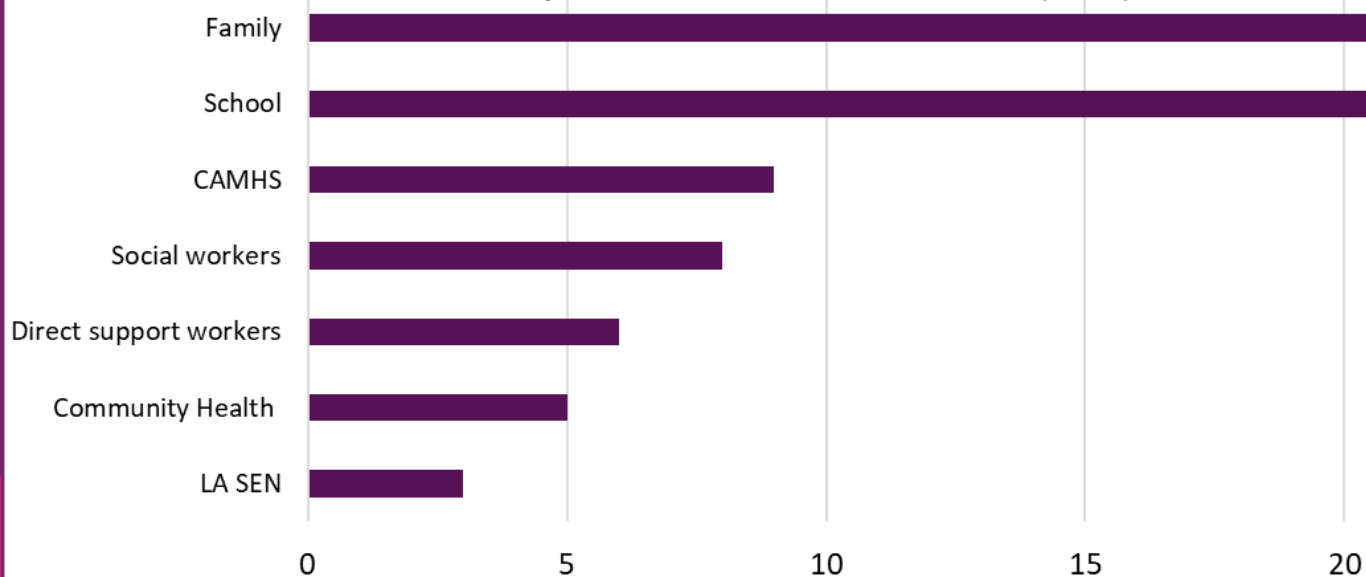
# Audit findings: Our multiagency work (Psychoeducation)

Training for family and professionals

Sessions now include

- Understanding PWS
- Individualised advice
- Relationship building within network
- Joint safety planning

Representation in sessions (/25)



30 26 204

Sessions Children Attendees

School  
124

Family  
34

Direct  
support  
workers

CAMHS  
11

Social  
work...

Communi...  
Health  
7

LA SEN 3

Total cases post-assessment

43



Contact with professional...

35

Multi-agency meeting

31

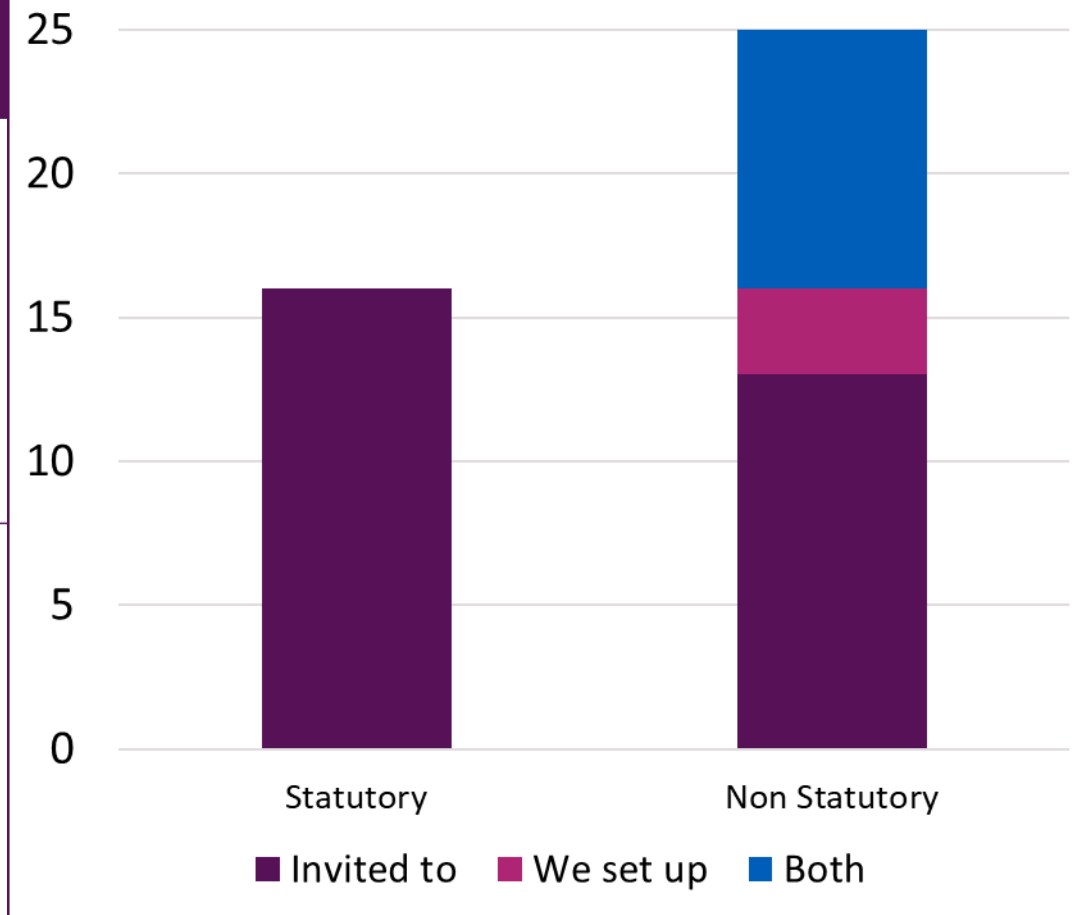
>1 kind of meeting

18

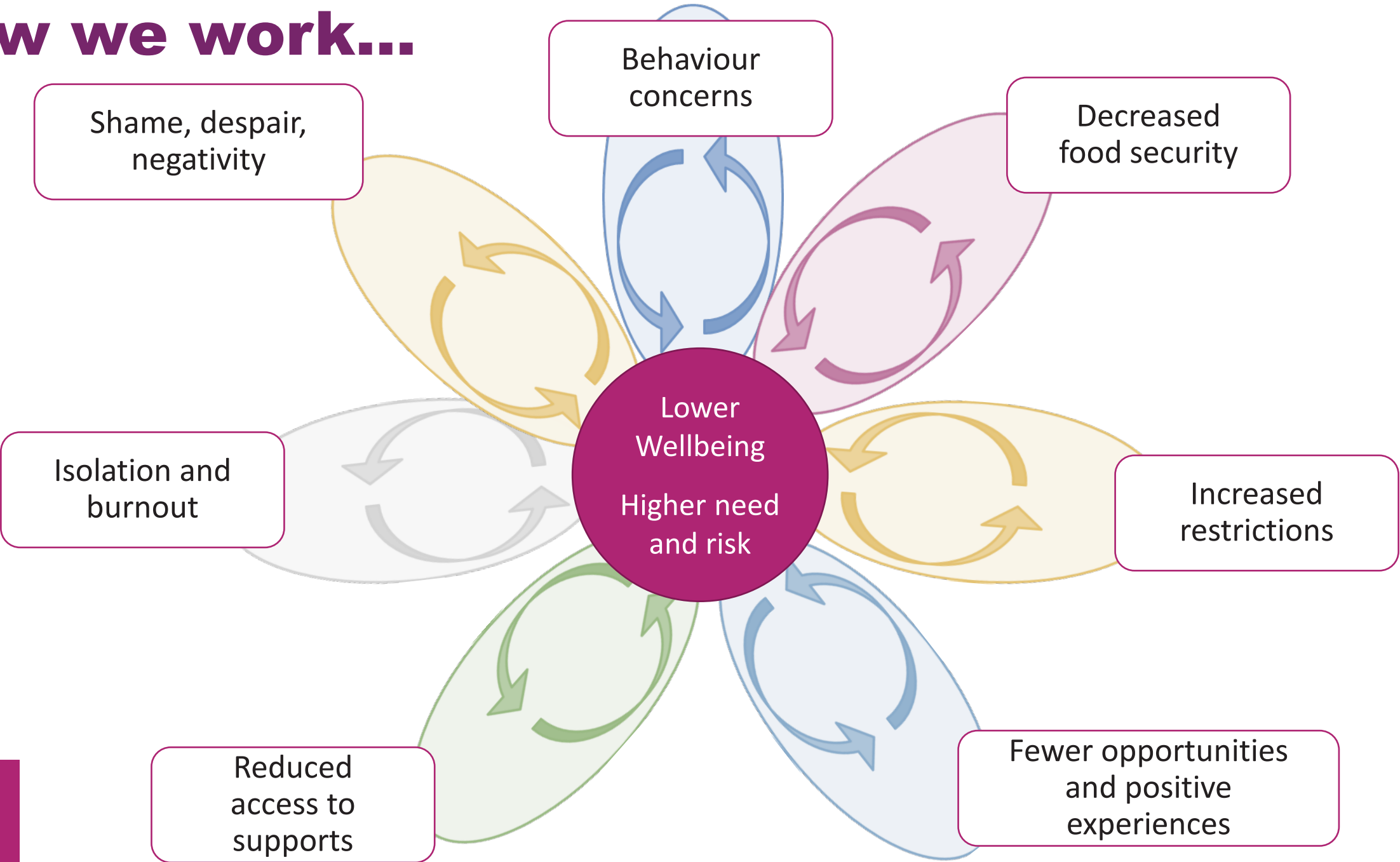
Statutory Meeting(s)

16

Cases with meetings attended (N=31)



# How we work...



# How we work...





## Reflections and Feedback

To be able to gather so many of [YP's] health professionals together for 2 hours, just highlights all the hard work, effort, and precious time you have given to enable our [YP] to live as happy and healthy a life as possible

Better understanding of the person's difficulties and how they all fit together, will inform my behavioural assessment.

We are so grateful for your unwavering support and optimism – [YP] is better for it now, and we will find our new balance as a family

We have gone back to basics... and he has, today, responded.... I couldn't be happier. Thank you! you helped me think!

We are now writing a Risk Assessment purely related to food

It will help everyone involved in her care better understand the nature of her disabilities and the far reaching effects they place on her future

“[staff], are you proud of me going to my lessons? ” ... “[staff], is Mummy proud of me?”

## Conclusions

Understanding  
whole child

Multi-agency  
working

PWS expertise

Increase  
support and  
security

Decreased  
restrictions!

## Acknowledgements

Yailin Acosta Guzman, Assistant Psychologist, PWS Service MHID

Rebecca Kingston, Assistant Psychologist, MHID

Dr Sophie Robbins, Senior Clinical Psychologist



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