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)

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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.
Service context in UK

Our service and cohort

Service involvement for our patients

Our role in multi-agency support

Reflections
Service Context: England

- Education
- Health
- Social Care
- Third Sector

- Children and Families Act
- Education, Health and Care Plan
- Child In Need Plan
- Child Protection Plan
- Children’s Act
Referrals: last 12 years

Consultant Paed (Community): 12
Consultant Paed (Endocrinology): 4
Consultant Paed (2nd Care): 5
Consultant Psychiatrist: 3
Clinical Psychologist: 7
CAMHS Clinician: 1
GP: 8
Social Worker: 3

Individual children and YP:

Referrals: 46
Individuals: 41
Client group:
last 12 years (N=41)

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

Gender:
- Male: 27 (66%)
- Female: 14 (34%)

Age at referral (N=46):
- <6: 1
- 6-7: 3
- 8-9: 3
- 10-11: 6
- 12-13: 10
- 14-15: 7
- 16-17: 10

Ethnicity:
- White British: 10
- Black, Black British, Caribbean or African: 4
- Middle Eastern: 3
- Asian or British Asian: 2
- Other/Not stated: 1
- Mixed - White and Asian: 3

N=46
Client group: last 12 years (N=41)

Reason(s) for Referral

- Skin picking
- Mental Health
- Food seeking/Hyperphagia
- Challenging Behaviour

Weight (%ile) at intake (N=24)

- <20th
- No concern/healthy
- Over 90th
- >97

Paternal Deletion: 39%
Uniparental Disomy: 37%
Not known 22%
Other 2%
Client group: last 12 years

Autism Assessment and Diagnosis (N=39)

SCAAND assessment

SCAAND formal assessment (N=30)
Audit findings: Services involved for our clients (N=41)

- Other specialist paediatrician
- Paediatric Endocrinologist
- Community Paediatrician

- Mean paediatric specialties: 2.41

- Most common
  - Spinal: 10
  - Respiratory: 10
Families also receiving support from PWSA-UK

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

CAMHS History at Assessment
- Active intervention/involvement: 19
- Opened but no active involvement: 10
- Referred but not accepted: 3
- Never referredseen previously: 9

AHP Contact Locally Whilst Under Our Care
- Physiotherapy
- Occupational Therapy
- Speech and Language Therapy

Highest level of social care involvement
- Not recorded: 2, 5%
- No clear support: 13, 32%
- Receiving Short Breaks: 8, 19%
- Child In Need: 10, 24%
- Child Protection: 8, 20%
Audit findings: Services involved for our clients (Education)

EHCP (N=41)
Referral: 38  Discharge: 40

First School attended (N=39)
- Mainstream Primary: 27, 69%
- Specialist all-through: 9
- Specialist Primary: 4
- Don't know: 3, 8%

Out of education at some point: 7

Average no. of schools: 2.7

Final School placement (N=37)
- Specialist residential (52 weeks): 6
- Specialist residential (38 weeks): 4
- Specialist all-through: 14
- Specialist Primary or Secondary: 4
How we work

Multiple clinical concerns and risks

Inconsistent support

Risk of placement breakdown

High need cohort

Risks

Behaviour

Food security

Mental Health

PWS specific expertise

Developmental needs

Complex PBS

MDT Formulation

Children and Families Act

Education

Social Care

Health

Third Sector

Children’s Act

Child Protection Plan

Child In Need Plan

Education, Health and Care Plan
Training for family and professionals
Sessions now include
• Understanding PWS
• Individualised advice
• Relationship building within network
• Joint safety planning

Audit findings: Our multiagency work (Psychoeducation)

Representation in sessions (/25)

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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)
- Statutory:
  - Invited to: 15
  - We set up: 2
  - Both: 8
- Non Statutory:
  - Invited to: 10
  - We set up: 3
  - Both: 2
How we work...

- Behaviour concerns
- Decreased food security
- Increased restrictions
- Fewer opportunities and positive experiences
- Lower wellbeing
- Higher need and risk
- Reduced access to supports
- Isolation and burnout
- Shame, despair, negativity

How we work...
How we work...

Meet Needs
Improve wellbeing

- Confidence and Optimism
- Reduce Behaviour
- Increase psychological food security
- Increase food limits
- Reduce additional restrictions
- Increase opportunity
- Increase positive experiences

- Increase family support
- Increase proactive support
- Increase food limits
- Reduce additional restrictions
- Increase opportunity
- Increase positive experiences
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 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?"

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

- Understanding whole child
- Multi-agency working
- PWS expertise
- Increase support and security
- Decreased restrictions!
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