MENTAL HEALTH IN
PRADER-WILLI SYNDROME

IPWSO Mental Health ECHO®
Clinical challenge

When Services Fail
The prevention of avoidable deaths

IPWSO is a charity registered in England and Wales, charity number 1182873

Summary histories

Information publically available, some personal details changed

Mr X aged 30 years

- Placement breakdown due to his behaviour
- Severely obese 177Kg, BMI 73Kg/m^2
- Moves back home
- Accepts the idea of a PWS placement but funding not agreed, later changes his mind
- Weight increases
- Respite care offered in a second floor room of a hostel for people with ID
- Orders in food, increasing weight, physical complaints
- Feels unwell seen at hospital but discharged same day (no cellulitis or DVT)
- Refuses to attend out-patient appointments – diabetes and sleep apnoea
- Has a fall
- Two days later died in his sleep
- Cause of death cardio-respiratory arrest

Mr Y aged 13

- Diagnosed as having PWS shortly after birth
- As a child generally doing well but started having outbursts
- Mother and Y together with three younger siblings move house
- Weight increase on-going behaviour problems
- Home tuition whilst looking for school (disagreements)
- Settled period after starting school
- Behaviours leading to police being called - behaviour deteriorating
- Very limited support from Child and Adolescent Mental Health Services
- Covid lockdown
- Outpatient child psychiatric appointment
- Repeated referrals to Children’s Disability Team turned down
- Family receiving 2 hours support daily
- Following a serious incident at home involving the police, died later that day as a consequence of an accident

Shared and individual issues

- People with PWS become trapped in what appears to be a pathways of inevitable decline
- A failure to appreciate the seriousness of the situation and the impact on others
- Lack of understanding by health and social care of the complexity, severity and particular needs of someone with PWS
- A failure to either engage with or be offered meaningful support or expertise
- No comprehensive formulation or response to or strategy to manage problematic behaviours
- Expertise available at a distance but what is needed is local services
- Failure to manage crises, police become the ‘crisis service’
- Missed opportunities – e.g. admission to hospital
- Importance of informed social care and prompt access to education for children

Making sense of and learning from such failures

There are excellent services available and the lives of people with PWS can be fulfilling BUT

- How do we understand such failures? What are some the key moments in the life-trajectory when things might have been different?
- What are the lessons and how do we reduce the risk of further avoidable deaths?
- Can we identify and share ‘near misses’ where someone’s life is turned around and learn from these?
- Do you have similar experiences?