Co-designing mental health and social services for PWS in Ireland

IPWSO Project Echo

DECLARATION OF DISCLOSURE

- Speakers name: Dr. Louise Gallagher

- Relationships with commercial interests:
- Provided non compensated scientific advice in relation to clinical drug development for autism in 2022: Kingdom Therapeutics

Learning objectives

At the end of the presentation, participants should:

1. Understand how to conduct a gaps analysis of service provision with stakeholders through co-design and co-creation
2. Understand the behavioural, emotional and psychiatric needs of children and youth with PWS
3. Learn about the development of an integrated approach to care delivery involving psychiatry

Introduction:

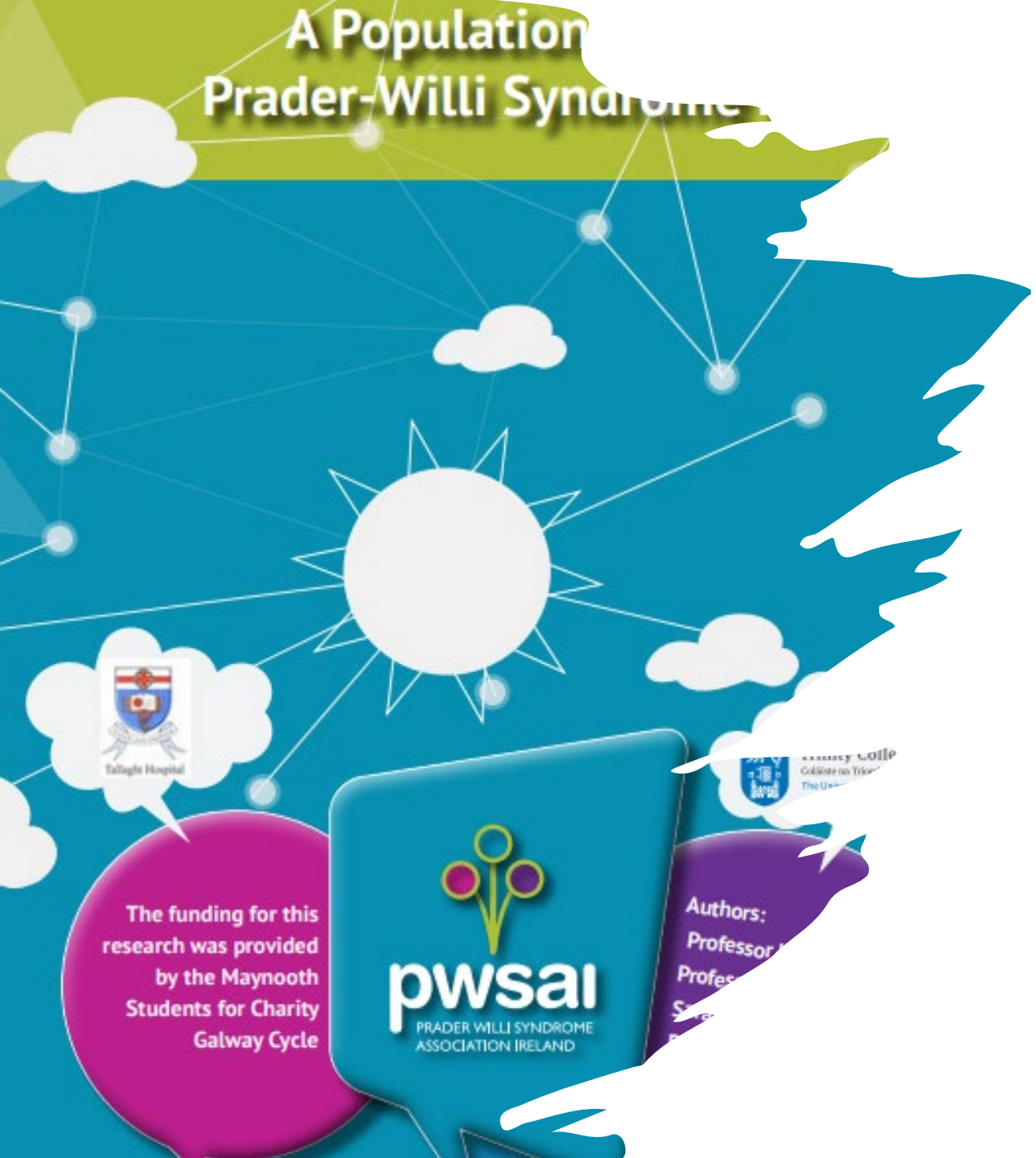
- National caregiver survey
- Collaboration PWSAI, TCD Autism and Neurodevelopmental Prof. Edna Roche, Professor of Paediatrics at TCD and Tallaght Hospital
- PWS is a complex genetic disorder with developmental and psychological symptoms.
- Goal to assess and characterize the needs of individuals with PWS and their families in Ireland to inform service development

Survey design and scope

- Cross sectional survey
- Co-design with key stakeholders

Focus:

1. Early life and development,
2. Physical health,
3. Mental health and behaviour,
4. Education and employment,
5. Respite and social supports and finally
6. Impact on the family and individual.



Our Participants

- 61 participants
- 37 children and 24 adults
- Age range: 11 months – 52 years
- 58% female and 42% male
- 43% deletion subtype, 26% mUPD, 28% unsure and 3% imprinting centre defect

Early life:

- Early life challenges were prominent
- Mean stay of 26 days in the neonatal intensive care unit
- 57% needed nasogastric feeding
- Time to diagnosis improved in younger individuals indicating improved recognition and genetic diagnosis.

Multidisciplinary needs

Infants:

Developmental and adaptive functioning needs:

Mental Health Diagnoses: >12 years

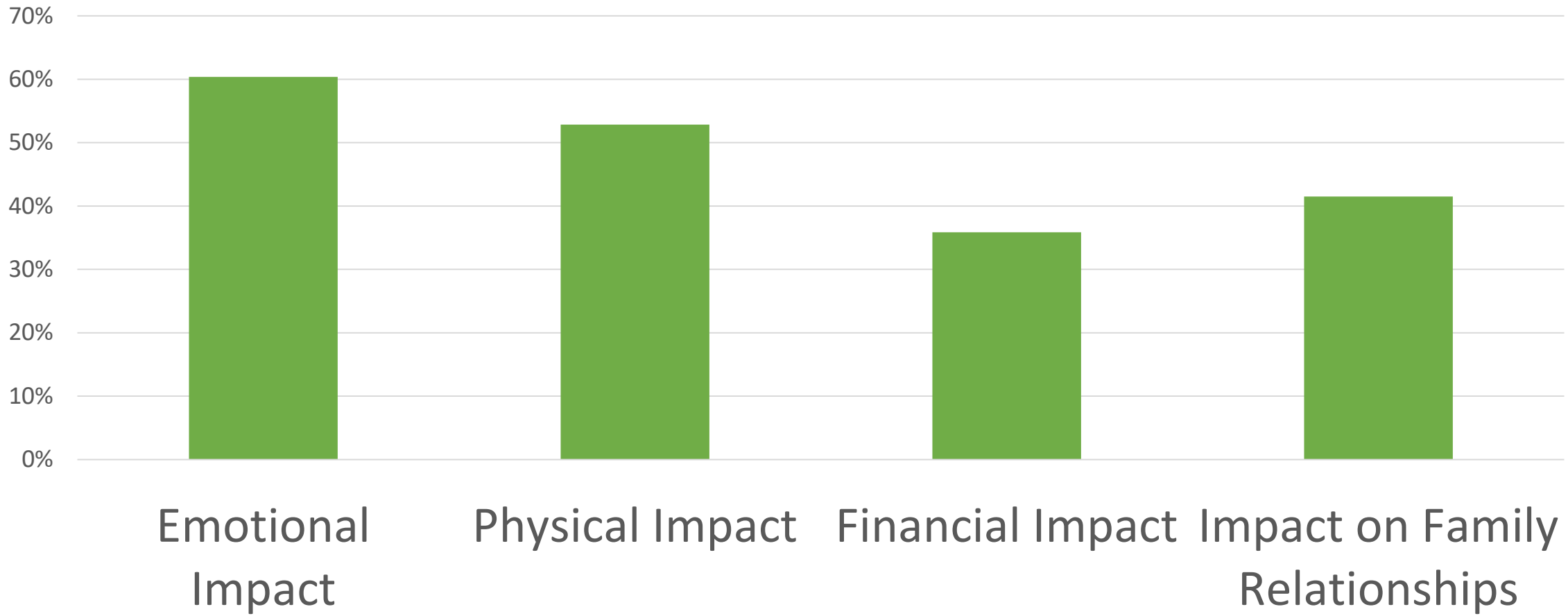
	Total (N=38)	Del (N=17)	mUPD (N=5)	ID (N=2)	Unknown (N=14)
Any Diagnosis	19 (50%)	7 (41%)	5 (100%)	2 (100%)	5 (36%)
Depression	9 (24%)	3 (18%)	1 (20%)	2 (100%)	3 (21%)
Anxiety Disorder	14 (37%)	5 (29%)	4 (80%)	2 (100%)	3 (21%)
OCD	6 (16%)	1 (6%)	1 (20%)	2 (100%)	2 (14%)
Autism	2 (5%)	1 (6%)	1(20%)	0 (0%)	0 (0%)
Psychosis	6 (16%)	3 (18%)	0 (0%)	2 (100%)	1 (7%)
Bipolar	3 (8%)	1 (6)	1 (20%)	1 (505)	0 (0%)

Table 5. CBCL DSM orientated scales

	PWS		Control group	
DSM orientated scales	Mean T score	SD	Mean T score	SD
Affective problems	66.22	8.516	60.06*	6.829
Anxiety problems	60.37	6.334	60.88	8.027
Somatic problems	63.05	8.334	52.00*	6.497
Attention deficit/hyperactivity problems	63.53	7.259	63.13	8.582
Oppositional defiant problems	61.58	5.846	58.58	7.625
Conduct problems	62.50	7.372	63.17	6.829

*$P < 0.05$

Skokauskas et al, 2012


70%
60%
50%
40%
30%
20%
10%
0%
Emotional Impact
Physical Impact
Financial Impact
Impact on Family Relationships

Education and Employment

- 63% were in mainstream primary school, remainder were in special educational settings.
- Majority accessed special school placements in secondary school.
- A high proportion of adults in the survey left education without any educational qualification.
  - 13 (56%) had no education qualification,
  - 2 (13%) completed Leaving Certificate Applied (LCA) and
  - 3 (9%) had completed some part of the Junior Certificate program and
  - 5 (22%) were still in education.

Only one adult with PWS who completed education had paid employment

Residential, Respite and social supports

Impact on families

Financial, emotional, physical and impact on siblings

50% of cases - one caregiver had given up or reduced working hours

Significant emotional and physical toll on family and carers – Negative impact on family relationships,

Negative impact on the mental health and social life of siblings – E.g. emotionally, physically and time spent with siblings -

Summary and conclusions

- Comprehensive and representative survey
- Positive advances have been made in the medical care – less morbidity
- Obesity rates remain high, particularly in adults still living at home with elderly carers
- Critical Gaps in access to physical health services
  - access sleep studies,
  - progressing to GHT and other specialist services was limited
- Mental health and behavioural concerns continue to progress across the life-course
- Educational attainments are not reflected in paid employment
- Significant carer burden and negative impact on family functioning

Key recommendations for specialist MDT care for PWS

- Specialist multidisciplinary supports with expertise in dietary management and behaviour support
- Specialist mental health teams for adults and children/ adolescents with expertise in rare syndromes, including PWS
- PWS specific residential care and respite care
- Co-design and person-centred services