



IPWGO  
6th International IPWSO Conference  
Cluj-Napoca 21.06.07 - 24.06.07  
"Coming here, you will discover yourself, discovering others"  
Romanian Prader-Willi Association

ASOCIACIÓN MADRILEÑA  
PARA EL SÍNDROME DE  
PRADER-WILLI



## AN ETHNOGRAPHY OF RESIDENTIAL SERVICES FOR ADULTS WITH PRADER-WILLI SYNDROME: THE ROLE OF THE BEHAVIOURAL PHENOTYPE IN STAFF MEMBERS' INTERPRETATIONS OF RESIDENTS' BEHAVIOURS.

Rebecca Hawkins, Tony Holland, Marcus Redley.

The Learning Disabilities Research Group, Section of Developmental Psychiatry, University of Cambridge, UK.

The behavioural phenotype associated with Prader-Willi syndrome (PWS) has been largely accepted by those involved in the provision of services. This presentation will explore the role of the behavioural phenotype in the care practices adopted by specialist residential homes that provide services for adults diagnosed with PWS.

The staff members' understanding of the behavioural phenotype, in particular the idea that the eating behaviour and challenging behaviours are genetically determined, was central to the design of the residential settings (e.g. locks on kitchen doors), the daily routines (e.g. strict mealtimes) and the training provided for new support workers (e.g. teaching of restraint techniques). In this talk particular attention will be paid to support workers' and managers' interpretations of residents' behaviours and the role that their understanding of the behavioural phenotype played in the support they offered residents. The data discussed in this presentation is taken from a qualitative ethnographic study, which involved ten months of observation in two specialist residential homes, interviews with staff members and residents and the analysis of institutional documents.

The support workers and managers used the concept of the behavioural phenotype to make sense of residents' eating behaviour and challenging behaviours however, when used alone this interpretation was not sufficient. They also understood these behaviours as being both learnt, from previous care placements, and self determined. At different points in time therefore, the same behaviour could be understood as being genetically determined, learnt and self determined. To view these apparently contradictory interpretations as being due to support workers' and managers' misunderstanding of the behavioural phenotype however, would fail to take into account the role these interpretations played in the provision of services. The ability to make flexible interpretations of residents' behaviours facilitated support workers in managing residents' dependencies and behaviours. For instance, constructing a resident's challenging behaviour as being self determined allowed support workers to encourage the resident to take responsibility for their actions and lessened the need for physical restraint. Furthermore, these interpretations enabled both support workers and managers to (re)produce care relationships between support workers and residents. For instance, perceiving a resident's past violent behaviour as being genetically determined or learnt meant support workers did not blame the resident for their behaviour. The complex and flexible constructions of residents' behaviours made by support workers and managers therefore enabled them to carry out subtle work that resulted in the provision of good care.