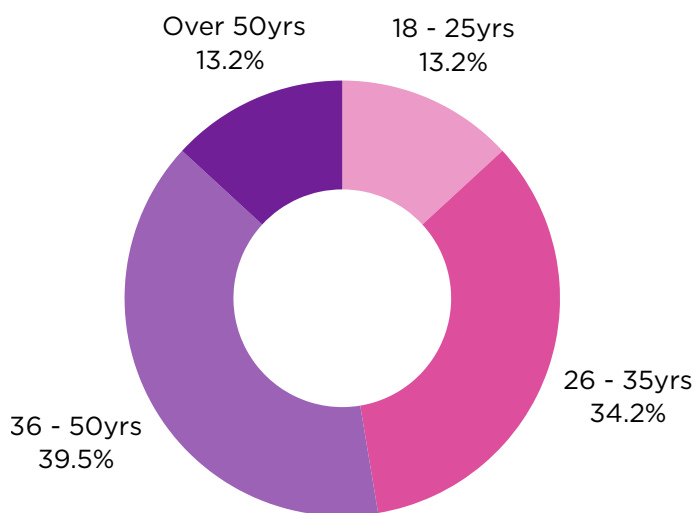


Parent/family survey of the UK's PWS Provider Market

The Prader-Willi Syndrome Association UK (PWSA UK) is dedicated to understanding and improving the quality of care in settings that support individuals with Prader-Willi syndrome (PWS). To gather insight, we conducted a survey with parents and family members of people with PWS living in residential settings. A total of 38 responses were received, although some questions were skipped by certain participants. This short report provides a summary of the key findings.

Demographics

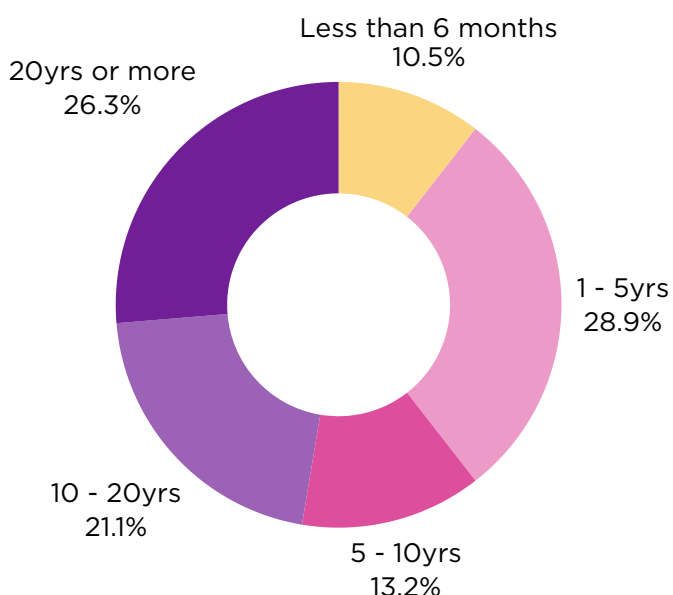
Age of individuals supported:



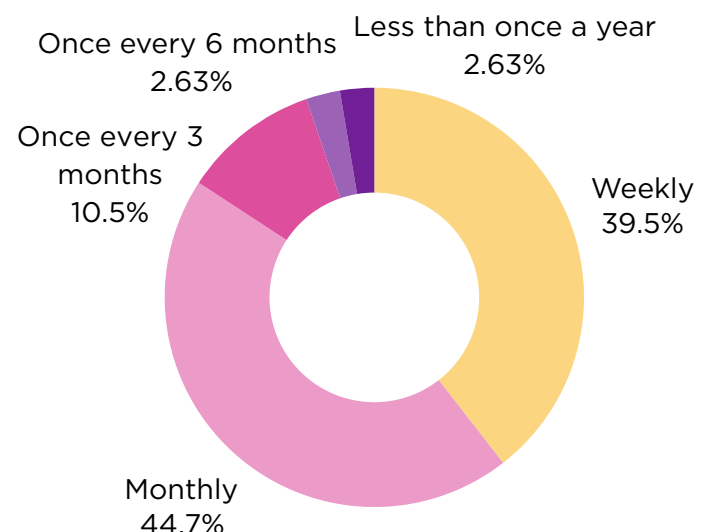
Care Providers Represented:

Other	17
Consensus Support Services	13
Priory Adult Care	5
Home Farm Trust	2
Voyage Care	1

Length of Time in Care Settings:



Visitation Frequency and Distance: *Wide variation from as little as 4 miles to as far as 178 miles.*

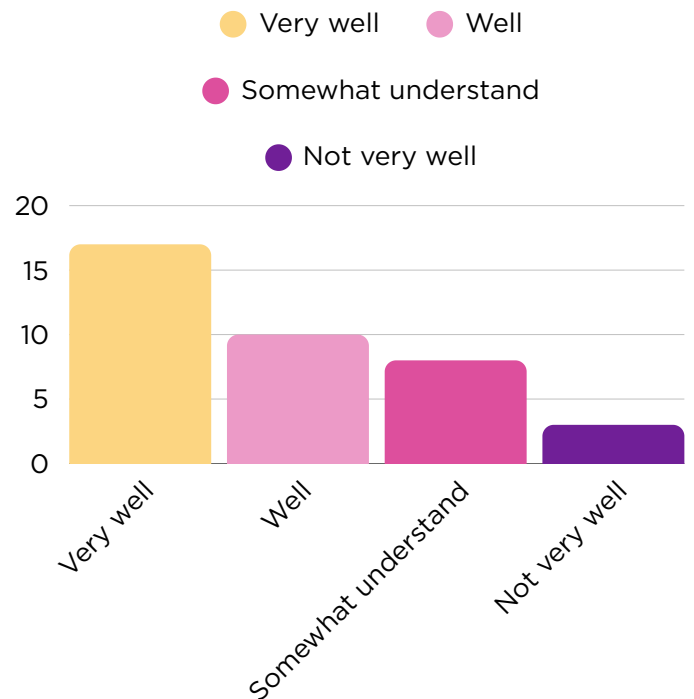


Care received

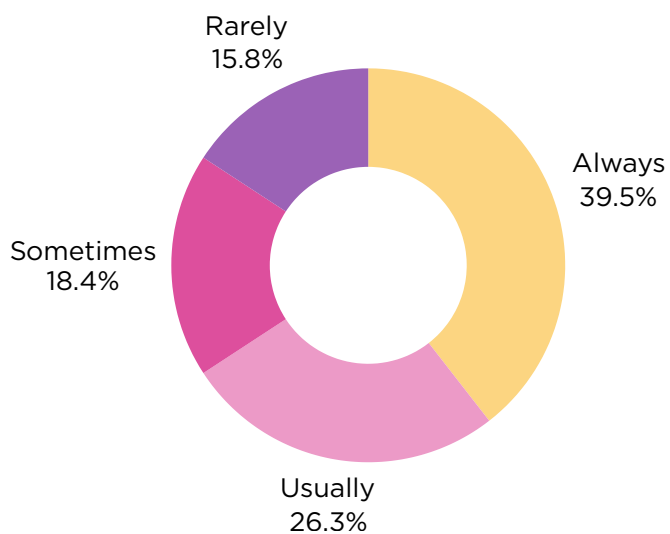
When asked 'How would you rate the overall quality of care provided?'



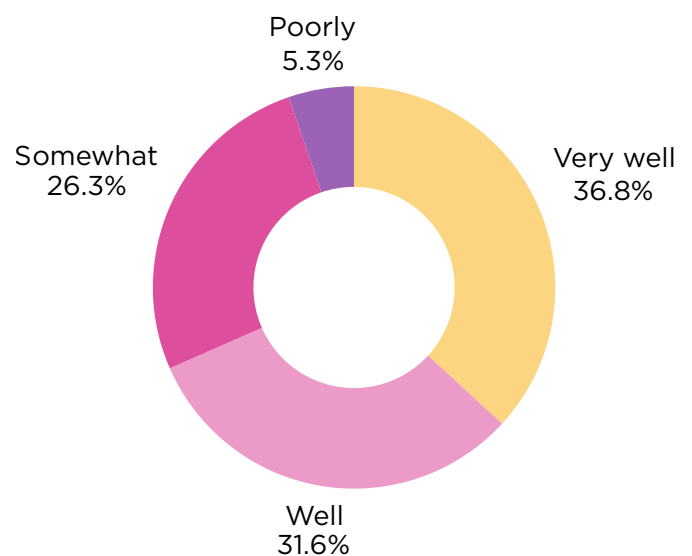
Staff understanding of needs:



65.8% feel their concerns or suggestions are always or usually taken seriously by the care & support staff.



68.4% feel the care home handle behavioural challenges associated with PWS very well or well.



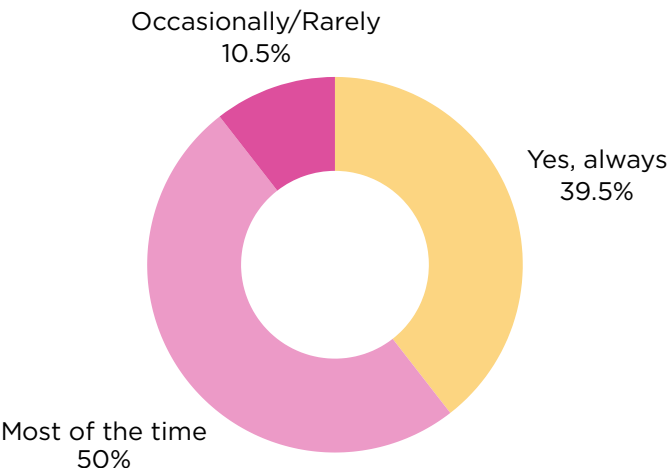
Responsiveness, Nutritional Needs, Communication, and Overall Satisfaction

Medical Responsiveness



Nutritional Needs

89.5% of respondents feel that their relative's nutritional needs are always met or met most of the time.

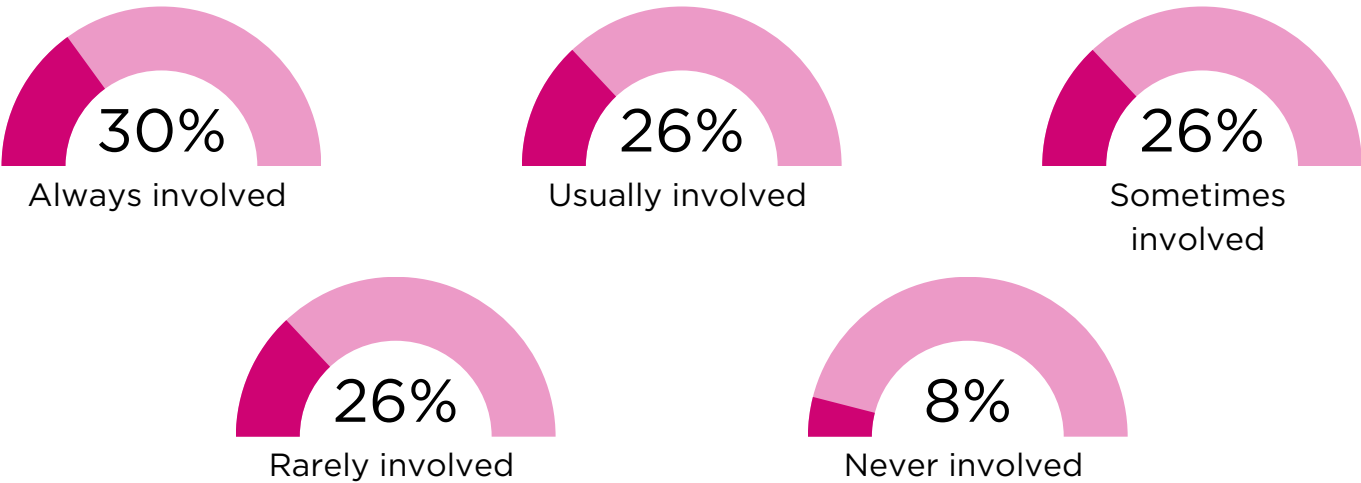


Communication with Care Staff

Respondents rated communication between support staff and families with an average of 3.6 out of 5. Nine respondents gave 5 stars, while one respondent rated communication 1 star.



Involvement in Care & Support Planning



Suitability, Satisfaction, and Recommendations

Suitability of Care Setting



Feel the care setting suitable for the needs of people with PWS.

Social and Recreational Opportunities

<40%

Less than 40% feel that there are adequate opportunities for their relative to engage with social and recreational activities.

Overall

3.8

average rating



When asked 'Overall, how satisfied are you with your relative's care setting?'

Recommendation to Other Families

55%

Would recommend the care home their relative lives in to other families.

32%

Would recommend but with reservations and advice

13%

Would not recommend the home to other families.

Additional Comments

Family members provided in-depth comments on the positives as well as where improvements could be made to the care provided for their family member.

Areas for improvement

- The most common concerns were around staffing both the levels and lack of specialist PWS training.
- Many families referred to a reduction in social and meaningful activities, especially in the community.
- Families were also frustrated with poor communication between them and the home.
- Care for personal items and refurbishment of homes were commonly cited as an area of concern.
- Management of food was an area for improvement, but this was with a relatively small number of respondents.

“

Training through PWSA and not just in house.

He is bored and sits playing on his iPad all day. There is never enough staff on to go out and do things.

There always seems to be an issue with staffing which can impact on planned activities, or the inability to do activities.

Keeping me informed, attempting to prevent me from attending appointment, generally communication is very difficult.

It's not all about FOOD!!!! PWS once food is organised, agreed and supported, need social and mental stimulation. Opportunities to engage.

”

Where things are going well

- Families commented on positive management of food, diet and weight.
- Where care is tailored to the needs of the individual with appropriate social activities.
- Where behaviours were well managed by staff who cared and were well trained and supported.
- Low staff turnover, staff who are well trained and supported.

“

Provides an excellent service for people with pws by always putting their needs first, medically, nutrition, exercise, socially and promotes independence as much as possible.

Well looked after. Diet is maintained well.

Provides a beautiful home and house, which is spotlessly clean. Provides a beautiful garden where residents can keep their own pets. Residents can grow their own vegetables etc in the garden. Activities and menus and are very suitable to PWS residents and are varied.

”