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PRADER-WILLI SYNDROME

RESIDENTIAL SERVICES: CHARACTERISTICS ENSURING SUCCESS

In my experience in managing and assessing residential services for adults with PWS, I have found certain characteristics to be most essential in ensuring a successful program (i.e., optimal health and a high degree of satisfaction with services provided experienced by residents, families and staff).

Leadership

- Experienced management in providing residential services and utilization of PWS resources, such as conferences, written materials, videos, and consultation with experts.
- Develops and implements program systems and routines which provides clarity of roles and responsibilities
- Establishes a rapport with families and ancillary services, including health care professionals and vocational providers/employers
- Represents program needs to agency management

Physical Facility

- Individual bedrooms with locks
- Adequate space for in-house exercise and a variety of exercise equipment
- Secure kitchen and/or food storage areas
- Secure area for staff belongings, medications, and resident records

Program Size

- Program size of six or less. More residents means there must be adequate staffing and program design to provide “programs within programs” or subsets of residents since whole group activities are not feasible

Communication

- Regular opportunities for the staff : direct service, clinical, and management to communicate, plan, and problem-solve
- Routine, formalized opportunities to communicate with families
- Regular resident meetings (with and without direct service staff; facilitated by someone skilled in group work)
- Agreed upon resident rules and responsibilities
- Agreed upon channels of communication for families
- Formalized in-house communication system for staff
- Means to give and receive information from clinicians when not on-site

Staffing

- Adequate number of direct service staff (1:2 ratio of staff to residents)
- Staff with expertise in meal preparation
- Staff with expertise in exercise and fitness

Community Resources

- Small group and individual recreation and leisure activities
- Utilization of community resources for routine needs (pharmacy, personal shopping, hair care, banking, etc)

Clinical Supports

- Appropriate clinical staff serving group (rather than different clinicians for different residents): minimally; nurse, dietician, psychologist or behavior specialist with hours appropriate to resident needs.

Training

- PWS specific training (initial and on-going)
- Training in strategies for crisis intervention and prevention
- Training in nutrition, meal preparation, and dietary exchanges
- Training in behavior management strategies
- Training in health and medical concerns of individuals with PWS

Exercise/Fitness Program

- Developed according to individual needs, abilities, and interests
- Provides variety and incentives
- Occurs on a routine basis (5-6x per week for 45-60 minutes)
- Includes direct staff involvement as participants, not observers

These program characteristics are interactive in that they all serve to empower and enhance the quality of life for all parties involved. Each of these characteristics calls for a much deeper discussion than provided in this outline. This list can serve as a starting point for revising, revitalizing, and renewing your residential program.

At the top of the list is *leadership*. This means that there must be someone close to the program with management responsibilities who has chosen to become expert in PWS as well as residential services. The agency must support this person in developing that expertise. High turnover at the house manager level accounts for much of the dissatisfaction experienced by the families. Direct service staff feels strongly the lack of leadership and support. I know that most agencies recognize this problem and seek to fill these positions. But filling the position is not enough. Agencies must invest in the person as a PWS expert. Anyone who has managed both a residence for people with developmental disabilities and those with PWS can attest to the fact that managing a program for people with PWS is significantly more complex, stressful, and demanding.

Communication among staff members and with families needs to be a high priority. (It is common practice for staff meetings to occur 1x per month—often in the late evening to allow for the greatest level of attendance. A great deal of time is spent on management concerns, rather than staff or resident needs). While informal communication is unquestionably valuable; regular, formalized opportunities are essential. Without this type of communication, individual staff members are rarely equally familiar with a number of important facets in serving the residents and are inconsistent in their management approaches. Families need to know that they will have regular opportunities to share their ideas and concerns (compliments too!) both as a group and as separate families. The annual team meeting may not be the appropriate time or place, so set up quarterly group family meetings (minimally) and monthly (or more) phone calls and/or meeting opportunities with individual families.

Clinical supports are essential to ensure that the unique needs of individuals with PWS are addressed. Without such, the residence is designed as a generic community residence for individuals with mild to moderate mental retardation. Individuals with PWS require that appropriate attention paid to those very unique symptoms and characteristics that drive us to establish homogeneous residences to begin with. Given the life threatening nature of the hyperphagia, a dietician is essential. Nursing is necessary in order to monitor health conditions related to weight, medications, and skin-picking among the many other health related issues related to PWS. A behavior specialist with expertise in PWS and behavior management (or willing to acquire such expertise) is mandatory to address the many and wide ranging behavior issues presented by individuals with PWS. It would not be unusual to also require the services of an OT, PT, or Recreation Therapist.

Prader-Willi syndrome specific training is another essential program component. Both staff and parents alike, in every program I have visited, consider this a problem area. While a new staff person may receive some initial training; they most likely are not engaged in on-going training opportunities or even routine opportunities to share questions and concerns. The additional issue of staff turnover--at all levels—further contributes to discontinuity among staff knowledge and responses to the residents.

Finally, in a conversation with a residential director serving adults with and without Prader-Willi syndrome, she proudly noted that the agency's two residences for adults with PWS had the lowest turnover rate as compared to their other residential programs (MH and MR). When asked how she accounted for that, she did not hesitate to reply that there was strong leadership in each of the sites, established routines and responsibilities, a strong clinical presence, and weekly meetings involving staff and clinicians.

Many residential programs are weak in these areas. I suspect that, in designing and funding programs initially, it was thought that these “high functioning” individuals would not need the level of service that they, indeed, do require. You must make a case and advocate for the resources necessary to enable your program to provide all that the individuals (and you) need and deserve to live as safely and fully as possible.