

A Resource for parents and providers created by Barbara J. Goff

PROVIDERS: SOME DO'S AND DON'TS FOR IMPROVING PARENT/PROVIDER RELATIONSHIPS

DO

- ...say positive things to the parents about their child—they've heard plenty of negatives over the years. Make routine phone calls with good news.
- ...arrange the individual's team meetings at a time and place convenient for the family and allow a realistic amount of time for meaningful discussion
- ...work with families in coordinating home visits so that you can plan house activities accordingly. Remember, a special family occasion trumps any policy on visitation.
- ...provide the family with the program's policies and procedures in writing and discuss them up front. Make sure to provide a good rationale for your policies.
- ...take the initiative to contact families about any unusual happenings involving their child. You can be sure they are going to hear about it in any case!
- ...communicate thoroughly and regularly with your supervisor about any issues you are experiencing or foresee with parents and families. You may need guidance in order to be proactive, not reactive
- ...ask the parents questions about their child. They possess a wealth of information and would love nothing more than to share it with those who need it most—you.
- ...be sensitive to parent concerns over restrictions regarding calling and visiting. While such policies serve an important function for the program; they can alienate some parents, especially those with children who are unable to articulate their experiences.
- ...tell the truth and take responsibility for your mistakes. (You will make a few.)
- ...work together to establish balanced and realistic expectations

DON'T

- ...be disrespectful or lose your temper with family members no matter how upset you may be. Instead, respectfully end the conversation.
- ...discuss internal agency or personnel issues with family members. It only serves to confuse and create ill will.
- ...discuss confidential matters pertaining to other program participants or discuss the family member in front of other program participants
- ...contradict a parent's decision in front of their family member
- ...believe everything an individual reports about their latest home visit...like the apple pie and quart of ice cream their mom let them eat.
- ...say you are going to do something and then not do it. Parents count on you to follow through.
- ...be afraid to ask for help...Whether it's a new approach to managing a behavior or needing a new treadmill...most parents will do whatever it takes to support their child's program
- ...make assumptions

Finally...

Don't expect that parents are going to understand all the complications and intricacies in managing a program for several people. That's not their job. Do recognize that most families are very grateful for your support and care of their family member, even if they don't always show it.

PARENTS: SOME DO'S AND DON'TS FOR IMPROVING PARENT/PROVIDER RELATIONSHIPS

DO

- ...say positive things to the staff—your support means more than you can imagine
- ...attend your child's planning meetings
- ...coordinate your child's home visits with the staff so they can plan house activities accordingly
- ...ask for the program's policies and procedures in writing and discuss any questions or concerns up front
- ...follow-up with staff when your child tells you about something terrible that happened to him or her at the program
- ...follow the communication chain—creates good faith with the staff (and doesn't preclude you from going straight to the top when you really need to)
- ...ask questions
- ...adhere to program guidelines regarding calling and visiting
- ...work together to establish balanced and realistic expectations

DON'T

- ...blame, threaten, or yell at direct service staff—bring your concerns to the appropriate supervisor
- ...question a decision made by a staff person in front of your child or other program participants
- ...do your child's household chores for him/her
- ...forgo his diet plan entirely during home visits
- ...believe that absolutely every behavior issue that arises is a result of PWS and isn't subject to change (after all-do we really know for sure?)
- ...believe everything you hear from a staff person about an incident-check it out with a supervisor who usually has the bigger and more complete picture
- ...give cash or credit cards directly to your child (and worse yet, neglect to tell staff about it!)
- ...make assumptions

FINALLY...

Don't expect that any program can provide all that you provide as a loving parent, but do acknowledge what your child gains by being in a work or residential program. There are trade-offs and most are very worthwhile.

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FOR PROVIDERS: SOME THOUGHTS ON IMPROVING PARENT/PROVIDER RELATIONSHIPS

Parents report concerns in two major areas of residential programs: communication and staff training. Below are some ideas you might want to consider in addressing those broad concerns which, most likely, you share.

COMMUNICATION

- Develop communication protocols for parents, so they know who to talk to about what and when (e.g., calling the residence during peak program time to talk with direct support staff is not a good idea. Calling or meeting with the manager when they can have an uninterrupted, private conversation is a much better idea).
- Establish program routines, schedules, paperwork, and accountability systems prior to opening the program and review periodically.
- Develop clear program policies and procedures and review with parents prior to admission. Include policies on phone calls, visitation, searches, weight management, behavior management, and anything else that guides your residential programming.
- For new (or troubled) programs, hold monthly parent meetings (if enough family members live within the area). Have an agenda; include as many staff as possible and invite the dietician, behavior specialist, nursing staff, and any other involved clinicians to share their work and answer questions. Provide families with their child's monthly weight record, report on planned recreational and social events, discuss any changes or issues that have arisen since the last meeting, and solicit ideas for improvement. Keep it structured and upbeat with opportunities for everyone to contribute, without it becoming a gripe session. You will find that parents will ask to reduce the frequency of meetings over time as they come to know (or come to know you anew) and trust you. (If a meeting isn't feasible send out monthly weight charts and activity schedules to families).
- Establish "traditions" in which families contribute; such as the annual summer barbeque, the holiday party, the anniversary of residency for the individuals, birthday celebrations, agency events...
- Establish a schedule of parent contact via phone or email, especially for those families who do not have frequent on-site contact. Let them know what their son/daughter has been doing. Share a story or two. Fill them in on planned events. Don't wait for a crisis to pick up the phone. Sharing the positives builds trust and respect and a belief that you truly care about their child
- Be honest with families. Tell them what is going on and ask for help when you need it. If you messed up-*admit it-apologize-institute corrective action-and move on*. The more we acknowledge that caring for an individual with PWS is not an exact science and that we are all simply human and doing our best, the stronger the bond will be. ***Put your energy into progress not patchwork.***

- Respond promptly (within the day-no more than 24 hours) to parent concerns/requests even if your response is “I don’t know yet.” It’s disturbing to think that the folks who care for your child don’t take you or your concerns seriously.
- Enlist the parents to support you in working out conflicts with your monitoring and funding agencies. They can be extremely effective advocates on issues you all care about. Parents want the program to succeed just as much as you do.

TRAINING

- Identify and support someone in your agency (director, manager, clinician-someone who will be around for awhile) to become expert in PWS.
- Develop a training program specific to Prader-Willi syndrome. Utilize experts in the field and parents. Invite your funding and licensing agencies such as the State Department of Mental Retardation and Developmental Disabilities (or your state equivalent) so they can learn about the uniqueness of PWS and the need for specially designed services so that they have a stake in your program.
- Develop an in-house handbook of essential information, including a personal profile of each resident (nothing too clinical—likes, dislikes, idiosyncrasies). Involve the family in this and update at least annually.
- Establish a routine and on-going schedule of PWS training for “old” and new staff. Contact PWSA/USA for a list of resources, including educational DVD’s, books, newsletters, research articles...Create a training program and handbook with these materials to be reviewed with new staff by your agency PWS expert. Become a member of PWSA/USA and when you receive your copy of *The Gathered View* newsletter-distribute it and discuss at your next staff meeting. Reading an article or viewing a video is not nearly as effective a learning experience as reading, watching, and discussing!
- Join your local or regional Prader-Willi Association. Go to conferences. Bring back the information and share at staff meetings. Meet and stay in touch with other providers.
- Consider a one day annual retreat to assess progress, brainstorm strategies, review and revise existing routines and practices, and establish new goals for the next year. Remember, the individuals are changing-so be sure to keep up with them and keep your services fresh and interesting. Make your home a place where people want to be or they may take it upon themselves to change things in a way that you aren’t prepared for.
- Establish a mentoring program for new staff, so that they are paired with someone more experienced for a specified period of time.
- Give your direct support staff responsibilities that are meaningful and challenging and train them in those responsibilities.
- Remember, well prepared staff members who are treated as professionals are much more likely to stay within the program and do a good job than those who are thrown into” the residence to sink or swim.

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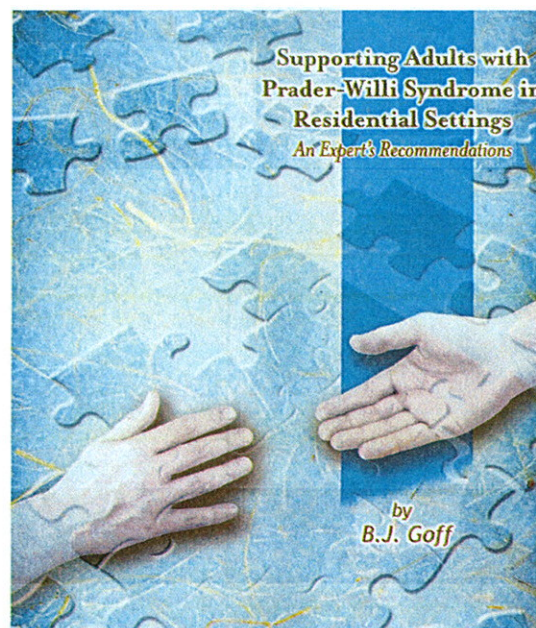
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