

Transition Planning and Resource Guide

for Parents and Guardians of Young Adults
(ages 15 and up) with Prader-Willi Syndrome



Alex, age 21



Hana, age 27



Tony, age 22

Compiled by
Kate Beaver, M.S.W. and Barb Dorn, R.N., B.S.N.

USA
PRADER-WILLI SYNDROME ASSOCIATION
Still hungry for a cure.

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General Information

Compiled by Kate Beaver, M.S.W., and Barb Dorn, R.N., B.S.N.

The topic of transition planning encompasses many areas. All parents/guardians of teens with a disability should begin transition planning when their son/daughter reaches 14-16 years of age. According to the Individuals with Disability Education Act (IDEA) 2004, transition planning is required in the IEP for students by the age of 16 years. It is a time to investigate and prepare the young adult with PWS for their future.

We have attempted to gather information, provide resources, and address questions that frequently arise when parents or guardians begin the process of looking at their son or daughter moving into the world of adult services. Connecting with resources in **your** state and **your** local area will be very important. States may organize things or call things by different names. If confused – you are not alone, but don't be afraid to ask questions.

We have organized this information using a Question and Answer format. We hope that this format will make it easier for you to find information as well as for us to add information.

The following topics will be covered in this resource:

1. General Information – Why and how to plan for transition services.
2. Education – This includes planning and training for academic and practical experiences to prepare the person with PWS for post-high school graduation adult living and/or further education.
3. Vocational Evaluation and Transition from School to Work for the Student with Prader-Willi Syndrome - Information shared includes the participation in assessment and development of job skills so that the person with PWS can become gainfully employed in a job after graduation.
4. Residential Living Options/Considerations and Services – Topics include how to investigate what supported living options are available in the community of the young adult with PWS.
5. Transportation Issues – What needs to be done to secure transportation services for service-based situations as well as medical appointments?
6. Important Legal and Financial Issues – Areas covered include how to apply for programs that will support the economic needs for long term care and services as well as health insurance coverage for the person with PWS. The topic of guardianship is also addressed.
7. Personal Health Education, Transitioning To the Adult Health Care System, Educating Health Care Professionals and Health Insurance Coverage – Includes many health related topics for the young adult with PWS including transitioning from the pediatric to the adult health care world, as well as some information on health insurance.

WHY PLAN FOR TRANSITION SERVICES?

Transitioning into the adult world can present challenges for all young people. The process of transitioning is more difficult for many youth with disabilities and requires unique strategies to enable each student to achieve the maximum possible independence in working, living and participating in the community as adults. Because of many unique challenges and the need for constant food security, transition planning can be more challenging for the young adult with PWS.

WHAT DOES TRANSITION PLANNING INCLUDE?

The Individuals with Disability Education Act defines transition services as a coordinated set of activities which are designed to prepare the student for outcomes that are envisioned for the student in adult life.

Transition Planning and Resources for Parents/Guardians of Young Adults with Prader-Willi Syndrome

Transition planning includes outcomes related to:

- Pursuing academic and educational opportunities including postsecondary education and adult education.
- Involvement in community experiences.
- Building employment skills and work experiences.
- Investigating post school adult living opportunities as well as advancing daily living skills
- Determining what steps need to be taken for the individual to access financial support in their adult years.
- Evaluating whether the person with PWS can make informed decisions or if guardianship needs to be pursued.

The set of transition activities for each student needs to be based on the student's individual needs, preferences, and interests. The activities must include instruction, community experiences, and development of employment or other post-school adult living objectives. Students with PWS will require special attention to food security as well as emotional, behavioral considerations.

IS TRANSITION PLANNING THE SAME FOR ALL YOUNG ADULTS WITH PWS?

No, transition planning is different for each person with PWS. Planning will depend on the person's strengths, abilities and needs. It will be a combination of a person's goals, desires and wishes of their parents. It will also be affected by what resources and options are available in their area.

ARE SERVICES THE SAME IN ALL STATES AND AREAS?

No, states vary on how services for persons with disabilities are organized, delivered and funded. Most have long waiting lists for many services. Accessing the human service system to get on these waiting lists becomes a critical step in this process.

ARE FEDERAL AND STATE REQUIREMENTS FOR TRANSITION SERVICES THE SAME?

Federal and state requirements defining transition services for students with disabilities are consistent. However, some states have minor differences including what age transition services are initiated. For example, in the state of New York, transition services are required to be provided by age 15 rather than 16, as federal law provides.

WHAT AND WHEN SHOULD TRANSITION ACTIVITIES BEGIN?

You may want to utilize some or all of the handouts and/or references included at the end of this chapter. They provide information on suggested activities and timing to start preparing and planning. A questionnaire has also been included to help plan for the student with PWS.

- Transition Planning Timeline (Reference Guide New York State Education Department)
- Transition Questionnaire for Students with PWS (adapted from O'Leary & Paulson, 1991)

WHERE CAN I GET HELP AND INFORMATION ON VARIOUS TRANSITION TOPICS AND RESOURCES IN MY STATE?

Parent Training and Information Centers (PTIs) or Community Parent Resource Centers (CPRCs) are a great resource for parents/guardians. They have various handouts, trainings and other information to assist parents/guardians of children and young adults with disabilities about many topics that will assist them in transition planning as well as resources in their state. Since they are state specific, they should be able to help you navigate this complex process.

Resource: To locate a PTI or CPRC in your state go to: <http://www.parentcenterhub.org/find-your-center>

TRANSITION PLANNING TIMELINE

From an individual student perspective, the following is a series of events that may need to be considered during the student's transition process. All items will not be applicable to all students. The list is provided to serve as an optional planning tool.

| | <u>Action</u> | <u>Suggested Age</u> |
|-------|--|----------------------|
| _____ | Administer initial vocational assessment | 12 |
| _____ | Discuss the following curriculum areas at IEP meetings: <ul style="list-style-type: none"> • Academic • Social • Language/communication • Occupational • Self-help skills • Self-advocacy skills | 12-15 |
| _____ | Develop and implement strategies to increase responsibilities and independence at home | 12-15 |
| _____ | Complete periodic vocational evaluations | 12-21 |
| _____ | Introduce & discuss transition services | 14 |
| _____ | Notify parents that transition services will be incorporated into the IEP beginning at age 15 | 14 |
| _____ | Assure that copies of work-related documents are available: <ul style="list-style-type: none"> • Social security card • Birth certificate • Obtain working papers (if appropriate) | 14-16 |
| _____ | Obtain parental consent so that the appropriate adult agency representative can be involved | 14-16 |
| _____ | Develop transition component of IEP and annually thereafter | 15+ |
| _____ | Discuss adult transition with CSE | 15-21 |
| _____ | Consider summer employment/ volunteer experience | 15-20 |
| _____ | Explore community leisure activities | 15-21 |
| _____ | Consider the need for residential opportunities, including completing applications, as appropriate | 15-21 |
| _____ | Obtain personal ID card | 16-18 |
| _____ | Obtain driver's training & license (if appropriate) | 16-18 |
| _____ | Investigate SSDI/SSI/Medicaid programs | 16-18 |
| _____ | Consider guardianship or emancipation | 16-18 |

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| | <u>Action</u> | Suggested Age |
|-------|---|----------------------|
| _____ | Develop Transportation/Mobility Strategies: <ul style="list-style-type: none"> • Independent Travel Skills Training • Public or Paratransit Transportation • Needs for Travel Attendant | 16-21 |
| _____ | Develop & update employment plans | 16-21 |
| _____ | Involve State Department of Vocational Rehabilitation as appropriate, within 2 years of school exit | 16-21 |
| _____ | Research possible adult living situations | 16-18 |
| _____ | Investigate post-school opportunities (further educational vocational training, college, military, etc.) | 16-18 |
| _____ | Seek legal guardianship | 18 |
| _____ | Apply for post-school college & other training programs | 17-21 |
| _____ | Male students register for the draft (No exceptions) | 18 |
| _____ | Register to vote | 18 |
| _____ | Review health insurance coverage: inform insurance company of son/daughter disability & investigate rider of continued eligibility | 18 |
| _____ | Complete transition to employment, further education or training, and community living, affirming arrangements are in place for the following: <ol style="list-style-type: none"> 1. Post-Secondary/Continuing Education 2. Employment 3. Legal/Advocacy 4. Personal Independence/Residential 5. Recreation/Leisure 6. Medical/Health 7. Counseling 8. Financial/Income 9. Transportation/Independent Travel Skills 10. Other: | 18-21 |

Reference: Transition Services: A Planning and Implementation Guide. New York State Education Department
<http://www.p12.nysed.gov/specialed/publications/transition/guide.htm>

TRANSITION QUESTIONNAIRE: A TOOL FOR TRANSITION PLANNING FOR THE STUDENT WITH PRADER-WILLI SYNDROME

As the student, family, school and other agencies begin working together to prepare for transitioning the student with Prader-Willi syndrome (PWS) to enter the world of work, further education, and/or community living, the following information will help guide the process. Students with PWS have varying strengths and levels in their needs for support. Sharing this completed questionnaire with the other team members is one way to help them better understand the student's plans and ideas for the future, as well as identify the necessary supports which will be needed for this individual to remain safe and be successful.

Student Name _____ Date _____

Birthdate _____ Current Telephone Number _____

Current Address: _____

City: _____ State: _____ Zip: _____

Expected Date of Graduation/School Completion _____

Parent's Name _____

I. Vocational Needs

1. After graduation from school, what career path would you like the student to follow?

- | | |
|--|--|
| _____ Competitive Part-Time Employment | _____ Vocational School/Training |
| _____ Competitive FullTime Employment | _____ Adult and Continuing Education Program |
| _____ Supported Employment | _____ 2 Year College |
| _____ Sheltered Employment | _____ 4 Year College |

Other: _____

2. What kind of jobs seem most interesting to the student?

3. What kinds of jobs does he or she most dislike?

4. What vocational training programs do you prefer for the student?

5. What are the jobs that you do not want the student to do?

6. What medical concerns do you have about the student's vocational placement, if any?
7. What skills does the student need to develop to reach career goals?
8. What vocational education classes would you like the student to enroll in?
9. What job do you foresee the student doing after school is completed?
10. What supports are needed for the student to be safe and successful in the work environment?

_____ 1:1 supervision for monitoring of food security

_____ Environmental assessment of workplace food practices – break rooms, handling social celebrations, access to vending machines etc.

_____ Work site behavior plan – motivators and/or incentives

_____ Handling changes and/or frustration

_____ Plan for unplanned food situations/celebrations

_____ Supervised transportation

_____ On-site job coach

_____ Short work assignments/strategies to deal with sleepiness and/or fatigue

_____ Modified communication of work instructions and expectations (often need more time to process new information and tasks). May be slow to respond to questions or feedback.

_____ Communication with co-workers and/or supervisors

_____ Other _____

11. Has the student had an evaluation by your state Department of Vocational Rehabilitation or other entity who can assess vocational abilities and skills?

12. Do you know what vocational agencies are available and utilized in supporting adults when they transition to adult services? Do you need to do anything to obtain these services?

II. Further education

Please answer the following if the student is considering the idea of attending college, business or trade school; if not, skip to section III.

1. What further education beyond high school would you like your son or daughter to obtain?

_____ Adult and Continuing Education

_____ Business School

_____ 2-year College Study

_____ Trade School

_____ 4-year College Study

_____ Apprenticeship

2. What career(s) would further education prepare the student to enter, or would the student need assistance to decide on a specific career?

3. What does the student like best about doing school assignments? What accommodations have helped him/her to be successful?

- | | |
|-----------------------------------|---|
| _____ Additional time to complete | _____ Modified amount to be completed |
| _____ Tutoring assistance | _____ Curriculum modification |
| _____ Assistance with note taking | _____ Assistance with computer (online) assignments |
| _____ Other _____ | |

4. What does the student like least about doing school assignments?

5. What skills does the student need to develop in order to be a good student?

6. What living arrangements do you foresee for the student while going on to further education or training -- living at home and commuting or living away from home in some other living arrangement?

8. What kinds of help on campus will the student need to get the most out of classes?

9. What kinds of financial aid will be needed to pay for the training?

III. Personal Management/Living Arrangements

1. What chores or responsibilities does the student presently have at home?

- | | |
|------------------------------------|-----------------------|
| _____ Makes bed | _____ Laundry |
| _____ Cleans room – dusts, vacuums | _____ Empties garbage |
| _____ Other _____ | |

2. What other tasks would you like the student to be able to do at home?

3. After graduation from school, what do you think the student's living situation will be?

- _____ At home _____ Foster home _____ Group home _____ Apartment with support
- _____ Other: _____

4. In which of the following independent living areas does the student need instruction?

- | | |
|---|---|
| <input type="checkbox"/> Clothing care | <input type="checkbox"/> Sex education |
| <input type="checkbox"/> Meal preparation & nutrition | <input type="checkbox"/> Household management |
| <input type="checkbox"/> Hygiene/grooming | <input type="checkbox"/> Health/first aid |
| <input type="checkbox"/> Transportation/Mobility Skills | <input type="checkbox"/> Consumer skills |
| <input type="checkbox"/> Parenting/child development | <input type="checkbox"/> Community awareness |
| <input type="checkbox"/> Measurement | <input type="checkbox"/> Time management/organization |
| <input type="checkbox"/> Safety | <input type="checkbox"/> Self-advocacy |
| <input type="checkbox"/> Interpersonal Skills | <input type="checkbox"/> Other: _____ |

Do you know what agencies or resources to contact to explore future residential care and services for the student?

IV. Leisure & Recreation Needs

- 1. In what organized leisure or recreational activities does the student participate (i.e. Special Olympics, camps, scheduled social outings)?**
- 2. In what leisure or recreational activities does the student participate with your family?**
- 3. In what leisure or recreational activities does the student participate with friends?**
- 4. In what other leisure or recreational activities would you like to see the student participate?**
- 5. In what leisure or recreational activities would you not want the student to participate?**
- 6. Does the student have social skills deficits? What classes or activities do you recommend for the student's participation in order to develop more leisure interests and skills?**
- 7. What supports are needed for the student to successfully participate in social activities?**

- Planning and 1:1 supervision around all food sources, meals and snacks (Food security)
- Social coaching – appropriate things to say and do in various social situations
- Planning for handling situations where he/she may become frustrated and/or upset
- How to handle changes

V. Financial

1. As an adult, what financial support will the student have (check all that apply)?

- | | |
|------------------------------------|---------------------------------|
| _____ earned income | _____ unearned income |
| _____ insurance | _____ general public assistance |
| _____ food stamps | _____ trust/will |
| _____ Supplemental Security Income | _____ Medicaid |
| _____ other support _____ | |

2. What are the financial needs you think the student will have as an adult?

3. Is the student able to manage his own finances or will he/she require oversight?

VI. Legal

1. Will the student need a legal guardian to assist in making financial and health care decisions?

2. Do you need information and resources on what steps need to be taken to become the student's legal guardian?

VII. General

1. When transitions have been made in the past, such as from one school to another, were problems encountered; and, if so, what were they and what helped the student to transition?

2. What are other agencies that currently provide services for the student or are expected to do so after graduation?

3. What would you like the school district to do to assist you in planning for the student's living, working, and educational needs after completing high school?

The two greatest challenges that many students with Prader-Willi syndrome face as they enter the adult services world are noted below. It is important that these areas are evaluated and considered in all aspects of planning.

- 1:1 assistance to manage and secure food security
- Behavior management in helping them deal with change, frustration and emotional control

This form was adapted from O'Leary & Paulson, 1991/B Dorn 2015

Education

Important Information on High School Graduation Diploma vs. Post Graduate Special Education

Compiled by Kate Beaver, MSW, and Barb Dorn, BSN

One of the major questions Crisis Counselors at PWSA (USA) receive from parents is about their children graduating from high school at 18 with either a certificate or diploma or continuing an educational program until age 21 or 22 (varies by state). This is a question that each family needs to consider carefully at the start of the student's high school program, not in 11th or, worse yet, 12th grade.

Generally, the right to special education ends when the student "ages out" **or** when the student meets the exit criteria for high school and graduates with a regular diploma. Aging out refers to the upper age limit set by the states whereby a student may continue to receive special education services; typically 21-22. However, some states have passed laws allowing their special education students to continue receiving services until the age of 25. Federal law under *IDEA* mandates that students be allowed to remain in school until they turn 21. States may extend the age but they cannot make it less than what federal law stipulates. Be sure to ask your school district what their age limit is for continuing education.

The purpose of allowing additional time in high school is so those students who learn differently or at a slower rate have the time to complete the demands of a high school curriculum, whether modified or not. Another reason is to afford students the opportunity to work on relevant vocational and independent living skills that they will need to be successful in their adult lives.

Special education services may stop the moment your child receives a signed high school diploma, even if your student has not made adequate yearly progress on his or her post-secondary goals as described in his or her IEP. Many districts believe that once the student has met the exit criteria, he or she, like typical students, is to be awarded a diploma and is officially finished with K-12 public education. Continuing for an additional year or two is simply not an option. As parents, you may want to have your child remain in school to accomplish specific vocational and independent living goals, but will your district agree to that? You need to ask for your district's policy on how long a student with disabilities and receiving special education can remain a student, **with or without earning a diploma**, as well as what specific services would be available to him should he remain.

With so many of our children falling within a wide spectrum of ability, this issue must be resolved in order to adequately plan for your child's future. For children who have successfully completed the high school graduation requirements, they may choose to graduate with their classmates. Just bear in mind that once graduated, many schools will no longer provide any services at all. But that may be just fine for those students who have the ability to go on to a college or vocational training program. Something to consider, should this be your option, is to be sure the post-high school program or services has accepted your child into their program. It is not unusual to be on a long waiting list for services in the adult system.

On the other hand, if you decide that your child would benefit from the services available within or through the educational system, you may have many options, a couple, or even none that are appropriate for your child. For example, there may be several community-based opportunities, whereby your child attends vocational classes within the school and then is transported into the community for supervised work experiences. There are increasingly more college opportunities for students with disabilities where they use their home school as a base and then attend a credit or non-credit college course with supervision and, ideally, participate in typical college activities and enjoy the many campus resources. (There is evidence that participants in these college programs have a greater employment rate).

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But don't be surprised if your district says that they don't have an extended school program for students with disabilities who are electing to remain in school. There are school districts that are so small that developing their own school-based program is cost-prohibitive. Instead, they might fund a student to participate in a community-based program until they age out. You just need to hope that the program is one that provides your child with what he or she needs. If not, you need to fight very hard to get something developed. You need to work on this when your child enters high school, not at the end.

Delaying and Opposing Graduation

For most families, the opportunity for their child to remain in school as a "post graduate" provides that extra time for the student to mature, try out various vocational options, be taught how to prepare for and interact during an interview, what to do when there is conflict in the workplace, and more. If this is what you want for your child, here's what you need to do:

- Check the anticipated graduation date on your child's IEP. Most likely it reflects your child's class year rather than an extended date allowable by law or according to realistic completion of IEP goals.
- Request that your child's IEP reflect an exit date that includes the additional time allowed by state law. (Remember, it can't be less than age 21, which is stipulated in federal law).
- If the school argues that your child is well on the way to achieve the necessary academic requirements for graduation, you need to identify goals that your child needs to master in order to enter the adult world (e.g., exposure to various jobs that are appropriate for a child with PWS, social skills, problem-solving skills, interview skills, anger management skills, transportation skills, budgeting skills...). While many typical graduating teens lack these skills, they do not require special education to acquire them. Your child does!
- Do not accept the graduation date if it does not reflect your desires. Write a statement regarding the reason for your refusal and incorporate it in the IEP. You can still sign off on all the other programs and services identified in the IEP.
- Your child is entitled to a transition plan no later than the IEP year in which he or she turns 16 (Federal law/IDEA). For example, if your child will turn 16 in the winter of the following school year and your IEP meeting is held the previous spring when he or she is still 15, the IEP should include a transition plan. But first, find out if your state mandates a transition plan prior to age 16. Many do and it's usually ages 14 or 15. Hold them to it
- There is a specific form used for the transition plan, which becomes part of the IEP. You can get it from your school or go on-line to your State Department of Education, under Special Education, *IEP Forms and Documents...or words to that effect*)
- If your transition plan is mandated at age 14 or 15, the focus will be on the child's high school program as pertains to graduation requirements and preparedness for transition to the adult world
- If your school initiates transition planning at age 16, the plan should most definitely establish goals that incorporate community and vocational skills, as well as social and behavioral skills as needed.
- Don't wait until your child's junior or senior year when they may well have met the bulk of their graduation requirements. It will weaken your case to keep your child in school beyond his scheduled date.

Persuading the school that your student may not be ready to graduate can be difficult. The school has a mandate to provide every student with access to the general education curriculum (meaning, they must follow the state required educational curriculum). So it's not enough to say you don't care if he learns geometry and biology and you'd much rather he be in the woodworking and computer classes learning skills he will actually use! You accept that he must be involved in the general education curriculum requirements, but you continue to make it clear that

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these other “electives” need to be provided to him prior to exiting the school program. This is the beginning of building your case for continuation beyond graduation.

Assemble and maintain a binder of assessments, progress reports, and other materials that indicate skills that your child needs to develop prior to exiting school. These do not all need to be formal reports. Record your own knowledge of your child’s abilities. Many parents are quite shocked to learn that their child has a passing grade in an algebra class when, at home, he can’t seem to complete simple addition, tell time, or count money! This kind of disconnect is worth noting. And if your child receives assistance from a paraprofessional, the work he or she produces in the classroom may reflect a less than independently created document.

Participating in Graduation Ceremonies without Receiving a Diploma

This is a common practice in high schools and colleges everywhere. A student has met almost all graduation requirements and is on board to complete them, but simply wants to participate in the graduation ceremonies with his or her classmates. If your child is going to continue on in school, he should be allowed this opportunity. It’s called “social” graduation or “walking” with the class. No one but your child and the family knows that he is not officially graduating and that there is no diploma in the folder he receives. If the school advises against it or seeks to prevent it, ask them to put in writing their reasons and pursue it. Here again, you can’t wait until the last minute. Get this resolved well before the end of your child’s senior year. (Sometimes a school might want to prohibit the child from participating because of a history of behavior issues that are seen as disruptive. And you may decide that the length and pomp and circumstance is just too much for your child, but establish some kind of agreement with the school). Nowadays, with so many states mandating that certain tests be passed in order to graduate, more and more students seek to have the experience of graduating with their friends and sharing in all the festivities, even though they haven’t passed the required assessments. It’s simply the right thing to do.

Finally, here are some questions to ask your school (sooner than later)

- What is the age at which my child has a transition plan?
- What is the age whereby my child is no longer eligible for educational services?
- What kind of transition programs and services do you provide (or arrange to be provided) for students who remain in school beyond their senior year?
- If my child is not eligible for a general education diploma at the time of graduation, but instead continues on in an educational/vocational program through the school, can he continue to work on those unmet diploma requirements? (Or receive help toward GED?)
- What exactly does a certificate represent? Completion of IEP goals? Attendance?

Remember, once your child exits the school system, you are NOT greeted by someone from the adult system who offers you all kinds of options. Indeed, while your child may be *eligible* for various programs and services, he or she is not *entitled* to much of anything. It’s all on you to seek out options, get assessments, visit programs, get on waiting lists, fill out paperwork for the adult service system and whatever else is required.

So, unless you have dealt with your child’s next step during his school years, you may find him or her sitting at home...waiting. Insist on transition plans that deal not just with goals, but also with services and supports. And Good Luck to you all! PWSA (USA) is here if you need us.

Daily Living Activities – Skill Development

Teaching and reinforcing the skills of daily living is a cooperative task between parents/guardians and educators. According to federal law, ***“goals must be based on age appropriate transition assessments related to training, education, employment and independent living skills where appropriate. The IEP must also contain a statement of needed transition services for the student that focus on the student’s courses of study (such as participation in advanced-placement courses or a vocational education program). In addition, the IEP must contain, when appropriate, a statement of the interagency responsibilities.” [20 United States Code (U.S.C.) Sec. 1414(d)(1)(A); 34 Code of Federal Regulations (C.F.R.) Sec. 300.320(b) & 300.321(b)(3).]***

The more the young adult can do for him/herself, the less reliant he/she will be on others, which also can improve their quality of life and assist in preventing errors. Skill development also instills a sense of responsibility and pride that all adults should experience.

There are varying abilities in teens with PWS. Some require a great deal of assistance in mastering daily living skills, while others can become very independent in many (if not most) areas, especially with the use of visual and/or verbal prompts. Because of issues involving food security as well as other safety and behavior concerns, many areas require one-on-one oversight.

Learning and mastering daily living activities oftentimes allows students to remain in high school beyond the age of 18 years. If you are looking for ways to keep the young adult in high school, don’t be in a hurry to have them learn and become proficient at these skills quickly. **Include these skills in the transition IEP.**

The following is a very comprehensive daily living skills checklist that parents/guardians and educators may find helpful in assessing the student’s current level of skills as well as planning for future goals and service needs. This can easily be adapted to the student’s individual capabilities and needs.

Daily Living Skills Checklist for the Young Adult with PWS

| Rating Scale | | | | |
|--|---|---|---|------------------------------------|
| 0 = Unable to verbalize or demonstrate. Requires total assistance. | 1 = Needs a great deal of visual/verbal prompts and hands-on physical assistance. | 2 = Able to verbalize and/or perform with minimal visual/verbal prompts and hands-on physical assistance. | 3= Able to verbalize and/or perform with minimal visual/verbal prompts and no hands-on physical assistance. | 4 = Able to perform independently. |
| PHYSICAL HEALTH CARE SKILLS | | Initial Score | Current Score | Comments |
| Can identify symptoms of illnesses. | | | | |
| Can identify home treatment of illness. | | | | |
| Can use basic first aid & medicine appropriately. | | | | |
| Can identify when he/she should be seen by a health care professional. | | | | |
| Can seek medical care from a clinic (make appointment). | | | | |
| Can identify when emergency care is needed. | | | | |
| Can seek help for emergency medical care (911). | | | | |
| Can read a thermometer and identify a fever. | | | | |
| Can care for personal appliances (glasses, retainer, CPAP supplies). | | | | |
| Participates in a daily exercise activity/program. | | | | |
| Can perform a daily weight check and state target weight goal range. | | | | |
| Can identify when falls and/or injuries should be reported to staff or a responsible adult. | | | | |
| Voices an understanding of reporting accessing food or binge eating to staff or a responsible adult. | | | | |
| Can identify the importance of applying sun-screen and is able to demonstrate skill. | | | | |
| (If applicable) can use a glucometer and identify out-of-range readings (too high or too low). | | | | |
| Can dispose of hazardous materials safely. | | | | |
| Can identify what steps must be done if blood sugar readings are too high or too low. | | | | |
| MEDICATION MANAGEMENT SKILLS | | Initial Score | Current Score | Comments |
| Can self-administer medications. Can open container or break open bubble pack of medication. | | | | |
| Can correctly name all of his/her medications. | | | | |
| Knows time that medications are to be taken. | | | | |
| Understands why the medications are prescribed. | | | | |
| Can list at least 2 side effects for each medication. | | | | |
| Knows what steps need to be taken to re-order medication. | | | | |

Transition Planning and Resources for Parents/Guardians of Young Adults with Prader-Willi Syndrome

| HYGIENE SKILLS | Initial Score | Current Score | Comments |
|---|----------------------|----------------------|-----------------|
| Can shower / uses soap. | | | |
| Can complete shower within 20 minutes. | | | |
| Can wash hair. | | | |
| Can brush/comb hair. | | | |
| Can brush teeth. | | | |
| Can floss teeth. | | | |
| Uses deodorant daily. | | | |
| Can dress self. | | | |
| Can shave. | | | |
| Washes hands after using toilet. | | | |
| Can care for feminine needs during menstruation. | | | |
| Wears clean clothes daily. | | | |
| Wears clothing in good condition. | | | |
| Wears clothing appropriate for weather and conditions. | | | |
| LAUNDRY SKILLS | Initial Score | Current Score | Comments |
| Can sort laundry/clothing (lights/darks/colors). | | | |
| Can wash clothing per instructions on label. | | | |
| Can appropriately measure the amount of detergent/softener. | | | |
| Can operate washing machine using appropriate settings. | | | |
| Can load appropriate amount of clothes in washer. | | | |
| Can operate the dryer using appropriate settings. | | | |
| Can clean lint tramp on dryer after each use. | | | |
| Can fold laundry. | | | |
| Can hang up clothing. | | | |
| Can put away laundry in dresser or closet. | | | |
| Can iron clothing as needed. | | | |
| Can mend clothing as needed. | | | |
| Can communicate to staff or a responsible adult when new clothing items are needed. | | | |
| HEMOCARE and HOME SAFETY SKILLS | Initial Score | Current Score | Comments |
| Understands not using electrical devices near water. | | | |
| Can safely plug and unplug a vacuum. | | | |
| Can vacuum. | | | |
| Can sweep and use a dust pan. | | | |
| Can mop a floor. | | | |
| Can dust. | | | |
| Can wash a window/mirror. | | | |
| Uses cleaning supplies as indicated and safely. | | | |
| Uses protective items (gloves) when indicated. | | | |
| Can clean a bathroom sink, shower & toilet. | | | |

Transition Planning and Resources for Parents/Guardians of Young Adults with Prader-Willi Syndrome

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| HEMOCARE and HOME SAFETY SKILLS cont. | | Initial Score | Current Score | Comments |
| Can clean countertops and appliances. | | | | |
| Can empty trash (without exhibiting food seeking behavior). | | | | |
| Can separate recyclable trash. | | | | |
| Puts away cleaning supplies after use. | | | | |
| Complete household chores in timely manner. | | | | |
| Voices understanding of importance of keeping walkways clear. | | | | |
| Voices understanding of locking doors and windows. | | | | |
| Voices understanding of not opening doors to strangers. | | | | |
| Voices understanding of when police should be called. | | | | |
| Responds to in-home fire alarms and plan. | | | | |
| Responds to severe weather broadcasts/warnings. | | | | |
| Keeps room clean and in order. (Persons with PWS often exhibit hoarding behavior which requires oversight to prevent unsafe living conditions). | | | | |
| Keeps items off floor to permit safe evacuation. | | | | |
| Can make bed. | | | | |
| Can change sheets/bedding regularly. | | | | |
| Uses a laundry basket/hamper properly. (Keeps clean and dirty clothes separate). | | | | |
| Keeps appropriate amount of items in dresser. | | | | |
| Keeps closet organized (door opens and closes easily). | | | | |
| Keeps personal property in good condition. | | | | |
| TABLE MANNERS SKILLS | | Initial Score | Current Score | Comments |
| Takes appropriate size bites. | | | | |
| Uses utensils when appropriate (not fingers). | | | | |
| Uses napkin to wipe mouth. | | | | |
| Takes time between bites. | | | | |
| Chews with mouth closed. | | | | |
| Refrains from talking with food in mouth. | | | | |
| Verbalizes reason for using proper manners especially related to speed in eating and quantity of food. (Prevent choking). | | | | |

Transition Planning and Resources for Parents/Guardians of Young Adults with Prader-Willi Syndrome

| KITCHEN SKILLS (NOTE: There are many young adults with PWS who cannot safely participate in most aspects of food preparation tasks) | Initial Score | Current Score | Comments |
|--|----------------------|----------------------|-----------------|
| Can set a table. | | | |
| Uses proper sanitary practices before engaging in activities in the kitchen or food preparation. | | | |
| Can wash and dry dishes. | | | |
| Can load a dishwasher. | | | |
| Uses appropriate amount of dishwasher soap. | | | |
| Can operate a dishwasher. | | | |
| Can put away dishes/pans/utensils. | | | |
| Can operate kitchen appliances safely. | | | |
| Can plan a balanced meal. | | | |
| Can follow a recipe. | | | |
| Can measure out food portions. | | | |
| Can prepare a meal (with supervision). | | | |
| INTERPERSONAL & SOCIAL SKILLS | Initial Score | Current Score | Comments |
| Can verbally communicate. | | | |
| Uses complete sentences when conversing. | | | |
| Uses expressive voice tones with proper volume. | | | |
| Uses appropriate expressive body language. | | | |
| Appears to be able to read social cues & body language. | | | |
| Shows respect for other's personal property. (Does not take items from others without their consent.) | | | |
| Exhibits appropriate personal boundaries. | | | |
| Participates in group discussions. | | | |
| Participates in one-on-one discussions. | | | |
| Initiates conversations. | | | |
| Uses eye contact when conversing. | | | |
| Makes requests politely (please, thank you) | | | |
| Interrupts a conversation appropriately. Waits for others as needed. | | | |
| Interacts with peers appropriately. | | | |
| Shows respect for other's opinion, which differ from his/her own. | | | |
| Interacts appropriately with teachers, staff and others who work with him/her. | | | |
| Interacts appropriately with people in the community (store clerks, librarians, church personnel...) | | | |
| Can answer close-ended (yes or no) questions. | | | |
| Can answer open-ended questions. | | | |
| Can communicate thoughts in writing. | | | |
| Can follow multi-step directions. | | | |

Transition Planning and Resources for Parents/Guardians of Young Adults with Prader-Willi Syndrome

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| INTERPERSONAL & SOCIAL SKILLS cont. | | Initial Score | Current Score | Comments |
| Can comprehend written material at a functional level. | | | | |
| Demonstrates appropriate "dating behavior" including appropriate consent, touch and intimate contact. | | | | |
| Uses social media sites utilizing appropriate postings and communication. (Strongly recommend close supervision) | | | | |
| TELEPHONE SKILLS | | Initial Score | Current Score | Comments |
| Can dial and use a telephone and/or cell phone. | | | | |
| Can use a calling card. | | | | |
| Can make a long distance phone call. | | | | |
| Can use proper phone etiquette (greeting & closing). | | | | |
| Knows home phone number. | | | | |
| Knows phone numbers of other family members (or where to locate them). | | | | |
| Knows emergency phone numbers (or how to locate them). | | | | |
| Is able to demonstrate steps to locate phone numbers (phone book, computer, ...) | | | | |
| Verbalizes and demonstrates appropriate amount of time talking on phone and/or frequency in contacting another person. | | | | |
| Can send a simple text message. | | | | |
| SELF DIRECTION SKILLS | | Initial Score | Current Score | Comments |
| Appears to be able to make decisions for self. | | | | |
| Relies on others to make decisions. | | | | |
| Is able to communicate needs. | | | | |
| Knows the difference between needs and wants. | | | | |
| Expresses personal feeling and opinions. | | | | |
| Can manage time in completing tasks. | | | | |
| Is able to transition to new activity and/or task with no prompts. | | | | |
| Participates in leisure activities without suggestions of others. | | | | |
| Engages in leisure activities with peers. | | | | |
| COMMUNITY INTEGRATION SKILLS | | Initial Score | Current Score | Comments |
| Locates community resources in phone book. | | | | |
| Locates community resources using newspaper. | | | | |
| Can schedule appointments. | | | | |
| Can use public transportation. | | | | |

Transition Planning and Resources for Parents/Guardians of Young Adults with Prader-Willi Syndrome

| COMMUNITY INTEGRATION SKILLS cont. | Initial Score | Current Score | Comments |
|--|----------------------|----------------------|-----------------|
| Can locate community resources using the internet (with supervision). | | | |
| Is respectful of "rules" of community resources – returns library materials and/or videos on time. | | | |
| Uses public restrooms appropriately – takes turns, washes hands... | | | |
| Engages in appropriate conversations and eye contact with strangers. | | | |
| COMMUNITY SAFETY SKILLS | Initial Score | Current Score | Comments |
| Understands road signs and traffic lights. | | | |
| Uses pedestrian crosswalk signals appropriately. | | | |
| Uses pedestrian crosswalks when available. | | | |
| Walks/ bikes on the correct side of the road. | | | |
| Uses protective gear when biking/skating. | | | |
| Wears seat belt consistently while riding in a vehicle. | | | |
| Remains seated while riding on a bus. | | | |
| Looks both ways when crossing a street. | | | |
| Uses caution and identifies potential risks when walking in a parking lot. | | | |
| Does not approach strangers in the community. | | | |
| Uses appropriate eye contact and length of time when encountering people in the community. | | | |
| Knows what to do if a stranger approaches. | | | |
| Knows what to do if lost. | | | |
| Knows his/her home address. | | | |
| FINANCIAL MANAGEMENT SKILLS | Initial Score | Current Score | Comments |
| Understands currency values. | | | |
| Can prepare a shopping list. | | | |
| Can estimate the cost of items. | | | |
| Sets priorities for purchases. (Needs vs. Wants) | | | |
| Can purchase items at checkout; give correct amount for purchase; & confirm correct change. | | | |
| Can write a check and use a checkbook. | | | |
| Can determine account balances. | | | |
| QUANTITATIVE SKILLS | Initial Score | Current Score | Comments |
| Can read the face of a clock/watch. | | | |
| Can read a scale and state his/her weight. | | | |
| Can read a thermometer. | | | |
| Can measure liquids and solids. | | | |
| Can add one digit numbers. | | | |
| Can add two digit numbers. | | | |
| Can subtract one digit numbers. | | | |
| Can subtract two digit numbers. | | | |
| Can multiply single digit numbers. | | | |
| Can accurately use a calculator. | | | |

Social Skills Deficits and Development

(Much of the content of this section was taken from of the “Management of Prader-Willi Syndrome”, 3rd Edition, Chapter 13, Educational and Social Issues for Adolescents with Prader-Willi Syndrome by Barbara J. Goff)

Young adults with PWS want to have friends and be accepted by their peers. Even those who have a higher IQ often lack age-appropriate social skills and their social gap often becomes more evident the older they become. It is an area of need that can and should be addressed in the transition IEP. It is an ongoing area of need that remains long after they graduate from high school.

WHAT SORT OF BEHAVIORS ARE COMMONLY SEEN IN PERSONS WITH PWS THAT MAY INTERFERE WITH SOCIAL MATURITY?

Some behaviors that are very common in young adults with PWS often interfere with them being able to make and keep friends. Immaturity, rigidity and behavior outbursts can result in distancing by other students. Students with PWS may not understand this withdrawal, and may try even harder to be a friend and innocently “stalk” their peers. This in turn adds to more alienation and isolation. The need for constant food security can also impact their ability to be included in many social opportunities without close oversight. Unfortunately, teasing and bullying may also take place.

ARE FORMAL SOCIAL SKILLS CLASSES OR TRAINING APPROPRIATE?

Many educators feel that taking advantage of teachable moments are the primary ways to provide social skills development. However, many young adults with PWS require a more formal approach. It has been shown that the most effective social skills training occurs in small groups that meet (at least) weekly throughout the school year. The group can learn, practice and review many practical skills in a safe environment. Some skills included are listening, using good manners, asking someone out on a date, and solving a variety of problems. Phone skills as well as prevention of sexual abuse can also be addressed. The use of role playing as well as videotaping may be practical, fun ways to approach these topics. These sort of social groups are often utilized by residential providers once these young people leave the school environment.

IS IT IMPORTANT FOR THE STUDENT WITH PWS TO DRESS IN AN AGE-APPROPRIATE WAY?

Young people with PWS (as well as other disabilities) may stand out in the crowd for many reasons. It is important for family members, educators and others to assist these young people in buying and wearing clothes that are in style for their age and peer group. Soliciting the help of siblings or other willing friends and peers may also be useful. Young ladies should learn how to use make up and how to style their hair. Men may also need to learn what is in fashion and how to cut their hair. The more that can be done to make them look and feel a part of their peer group, the greater the chance that they will be more accepted.

WHAT OTHER AREAS OF “AGE-APPROPRIATENESS” SHOULD BE ADDRESSED?

Finding topics and interests that are shared with others their own age should be pursued. Not everyone is an athlete or an actor, but finding ways that young people can relate to others with similar interests should be investigated. Learning what topics to talk about as well as who are popular musical groups may provide a means to talk with their peers in a less awkward manner. Some teens with PWS have had positions as an athletic trainer even though they cannot actually play a sport. Others have assisted in the production of school plays. Finding a coach or chaperone to provide oversight and social coaching has allowed some individuals with PWS to become more active and involved in school activities. It is also important for these young people to learn the current “jargon” in communicating with peers.

DATING AND SOCIAL ENCOUNTERS

Young people with PWS want what most teens want – friends and a relationship with another person. Learning appropriate ways to pursue this is very important. Oftentimes, young adults with PWS can take their interest and desire to date to an unhealthy level by becoming obsessed and “over-pursuing” communications with a person they would like to date. With the expanding ways that young people can communicate, coaching and oversight of phone calls, text messaging as well as the use of social media must take place. It is important to be quite frank as to what is and what is NOT allowed when communicating with others. Unfortunately, there have been far too many young adults with PWS who have gotten in trouble by saying and demonstrating inappropriate sexual behavior. It is also important to discuss guidelines for appropriate dating behaviors. When is it ok to hold hands, kiss and show other public displays of affection? Some have utilized “dating contracts” to outline in writing (visually) these behaviors. It should be noted that all need repeated instruction on asking for permission and that “no means no” – even for holding hands.

SEXUALITY AND PERSONAL DEVELOPMENT

During the teen years, young people transform in many different ways. Physically, young men may have facial hair growth, see changes in their voice tone, as well as have a significant growth in height. Young women may have breast development as well as begin menstruation. Both may have fluctuations in emotions. Because of varying hormone levels and treatments, young people with PWS may or may not experience these changes. However, some may become aware of these changes in others and question why these changes are not occurring in their own bodies. It is important for young people with PWS to receive accurate information about these changes in a health class with individual explanations to help them understand their differences. It is also important for there to be collaboration between home and school. (Educators oftentimes do not know specific hormone and health related information about young people with PWS).

The high school environment of today is very different than the environment was for many parents. There is more acceptance of differences and these differences are openly talked about and shared. Many students are more open about their sexual orientation and there are now groups that meet, oftentimes during school hours, to share and discuss their concerns and issues. The point is, young people with PWS may have more exposure to topics and situations that parents need to be prepared to discuss.

UNWANTED AND WANTED SEXUAL ENCOUNTERS

Persons with disabilities are at greater risk of experiencing an unwanted sexual encounter than the general population. Because many persons with PWS often lack good judgement and some want very much to have or experience a sexual encounter, they can be at greater risk for this. It is important to discuss and plan for this. In the case of an unwanted sexual encounter, it is important that young adults receive instruction and have a plan of what to do if this were to occur. Many school districts utilize the “No-Go-Tell” program to help with this instruction.

Transition Planning and Resources for Parents/Guardians of Young Adults with Prader-Willi Syndrome

“No-Go-Tell” – A Personal Protective Approach is a personal protective strategy utilized by many schools and programs around the world that help educate children about unsafe situations that could result in abuse. This approach attempts to provide them with a simple way to develop skills to manage bullying and other socially threatening situations. It is often used with younger students as well as disabled students including ones as young as age 3 years. The No-Go-Tell approach provides students with a simple tool to help them identify, alert and remove themselves from unsafe situations.

- **NO/STOP:** Use words to communicate your feelings
- **GO/THINK:** Walk away from the situation.
- **TELL/DO:** Tell a teacher or someone in your safety network to help you with the situation and keep you safe.

On-line Resources:

www.curriculumsupport.education.nsw.gov.au/primary/pdhpe/assets/pdf/child_prot_k6/cpe_s1_theme_3.pdf
www.stanfield.com/products/family-life-relationships/other-family-ed-programs/no-go-tell/

Young adults with PWS often see and hear of many sexual experiences and encounters – from peers, from the media and from music (just to name a few). Many teens with PWS are very open about sharing their desire to become a parent and are very curious about “having sex”. It is very important to keep the lines of communication open. It is a personal decision about how much information is to be shared; however, it is imperative that if there is any chance of a person with PWS becoming sexually active, appropriate measures should be taken to prevent sexually transmitted infections and pregnancy. Even though pregnancy in women with PWS has been rare, it has occurred and steps should be considered to prevent it.

THE DANGERS OF SOCIAL MEDIA

I am sure there are probably a few young adults with PWS who have utilized social media (Facebook, Twitter ...) without incident with appropriate supervision and oversight. However, there has been a growing number of reports in which individuals with PWS have gotten in trouble with law enforcement with its misuse. Some have been “removed” from Facebook because of inappropriate postings, including sexual harassment types of complaints. Some have been solicited and enticed by people they do not know. If a person with PWS is allowed to use this form of communication, it is strongly recommended that oversight, guidance and time limitations be included with this privilege.

WHAT CAN BE DONE TO KEEP THE PERSON WITH PWS SOCIALLY INVOLVED AFTER GRADUATION?

Once persons with PWS graduate from high school, their social opportunities may also slow down or stop. They are dependent upon their parents or caregivers to assist in scheduling and providing social opportunities. For many of us, work can provide another environment where we meet and socialize with others. In most cases, people with PWS are limited in who, when and where they are able to communicate while working. It is almost always not a place to socialize unless they are in a work environment where they may also be provided with a social component. Even if this is the case, they must then coordinate with others to arrange a time when they can talk or invite this person for a social encounter.

Parents, guardians and caregivers must make a concerted effort to offer these sorts of opportunities. Take and/or enroll them in other social opportunities including Special Olympics, church groups and/or other local social opportunities. Encourage them to call others and maintain friendships. If possible, arrange for outings that include other friends.

What the Laws Say about Transition Services: The Code of Federal Regulations

DOES THE SCHOOL DISTRICT HAVE TO HELP STUDENTS WITH DISABILITIES MAKE THE TRANSITION FROM HIGH SCHOOL TO ADULT LIFE?

Yes. Federal special education law requires that there be transitional planning services for students with disabilities regardless of which agencies provide support or educational services to the student. Beginning no later than the first Individualized Education Program (IEP) held after a student turns 16 (or younger if determined appropriate by the IEP team) and updated annually, the IEP must contain a statement of appropriate measurable postsecondary goals. The goals must be based on age appropriate transition assessments related to training, education, employment and independent living skills where appropriate. The IEP must also contain a statement of needed transition services for the student that focus on the student's courses of study (such as participation in advanced-placement courses or a vocational education program). In addition, the IEP must contain, when appropriate, a statement of the interagency responsibilities. [20 United States Code (U.S.C.) Sec. 1414(d)(1)(A); 34 Code of Federal Regulations (C.F.R.) Secs. 300.320(b) & 300.321(b)(3)]

The statement of needed transition services in each IEP must include, where applicable, a statement of the responsibilities of other participating agencies. However, remember that the district remains ultimately responsible for ensuring that these services are provided. Therefore, if a participating agency stops providing an agreed-upon service, the district must fulfill that obligation or responsibility, either directly or through contract or other arrangement. [20 U.S.C. Sec. 1412(a)(12)(B)] The district must also have another IEP meeting to find a different way to meet the transition objectives in the IEP. [34 C.F.R. Sec. 300.324(c)]

WHAT IS AN INDIVIDUAL TRANSITION PLAN (ITP)?

The Individual Transition Plan (ITP) is a written plan designed to help prepare students for passage from school to post-school life. [20 U.S.C. Sec. 1401(34); Cal. Ed. Code Secs. 56462 & 56345.1] The ITP must be based on the student's needs, preferences and interests and reflect the student's own goals. Objectives, timeliness, and people responsible for meeting the objectives should be written into the ITP (and made part of the IEP). It is important to understand that transition planning and development of the ITP are part of the IEP process.

WHEN SHOULD TRANSITION PLANNING OCCUR?

Transition planning must begin by the first IEP held after the student reaches age 16 or earlier if appropriate for the student. [20 U.S.C. Sec. 1414(d)(1)(A)(i)(VII); 34 C.F.R. Sec. 300.320(b)] It is important to begin the transition process when students are younger than 16 to ensure enough time to plan for and receive effective services. It is particularly important for students with significant disabilities, those at risk of dropping out, and those on a specific academic track.

Transition planning can occur at a combined Individualized Education Program (IEP) and Individualized Transition Plan (ITP) meeting, or it can occur in a separate meeting. A separate transition planning meeting can be beneficial because it allows more time to focus on the student's desires and preferences. Then, the ITP can be made part of the IEP.

When a combined ITP/IEP meeting is held, ideally, transition planning should occur first. No matter which method of planning is used, transition objectives, goals and activities should be identified and included in the student's IEP or a separate ITP can be attached to the IEP form. All of the IEP procedural guidelines must be followed.

HOW DO I INITIATE A TRANSITION PLANNING MEETING?

You can initiate a transition planning meeting by making a written request to your child's teacher, the principal, or special education administrative office. The letter should clearly say that the purpose of the meeting is transition planning.

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Whether you or the district have initiated the transition planning process, the district must send out a meeting notice that:

- (1) Indicates that the purpose of the meeting will be to discuss transition;
- (2) Indicates that the student will be invited; and
- (3) Identifies any other agency that will be invited to send a representative. [34 C.F.R. Sec. 300.322(b)]

HOW SHOULD TRANSITION SERVICES BE WRITTEN INTO THE IEP?

The transition IEP should be “outcome oriented.” This means that the coordinated set of transition activities developed by the IEP team includes goals that prepare your child for as independent a life as possible. For example, the outcome for a student might be employment in a retail store. The services for that student should focus on seeking and maintaining a position with the necessary supports, solidifying basic work habits, punctuality and grooming, and developing supported and/or independent living skills.

HOW DOES THE IEP TEAM DETERMINE MY CHILD’S TRANSITION NEEDS AND THE SERVICES THAT SHOULD BE PROVIDED?

The five main components of transition are: instruction, related services, community experience, daily living skills and the development of employment and other post-school adult living objectives. [34 C.F.R. Sec. 300.43] The district must conduct appropriate assessments in the above areas to determine your child’s transition needs and the services that address those needs. The assessment process should be followed as it is for any other area of need. [34 C.F.R. Sec. 300.304(b)]

HOW CAN STUDENTS BE INVOLVED IN DEVELOPING THEIR OWN TRANSITION PLANS?

Students must be invited to attend any ITP meeting. The meeting should be person-centered so that its focus is the student and their needs and desires for the future. Goals and objectives in the student’s ITP should emphasize the student’s preferences, and include all life areas, such as home, work, community, social, etc. During the meeting, it may be useful to list the strengths, needs, dreams, fears, and wishes of an individual student and family.

The meeting should be conducted in a manner that enables the student to understand the planning process and to participate fully. [34 C.F.R. Sec. 300.321(b)(1)] If the student does not attend the IEP meeting, the school district must take other steps to ensure that the student’s preferences and interests are considered. [34 C.F.R. Sec. 300.321(b)(2)]

WHO SHOULD PARTICIPATE IN A TRANSITION PLANNING MEETING?

In addition to the required IEP participants, and with the consent of the parents or a student who has reached the age of 18, the district is required to invite a representative of any agency that is likely to provide transition services to the IEP meeting. This should include representatives from the vocational rehabilitation agency, the regional center, community mental health, community college, and traditional private rehabilitation agencies, as appropriate. [34 C.F.R. Secs. 300.321(b)(3) & 300.324(c)] If a representative does not attend, the district should take steps to obtain the agency’s participation in the planning of any transition services.

WHAT IF A PARTICIPATING AGENCY FAILS TO PROVIDE AGREED-UPON TRANSITION SERVICES THAT ARE LISTED IN THE IEP?

If a participating agency agrees to provide transition services and then fails to do so, the school district must hold a meeting of the IEP team as soon as possible to identify alternative strategies for meeting the ITP goals. The district is ultimately responsible for ensuring that transition services are provided. However, this does not relieve any participating agency (including a state vocational rehabilitation agency) of the responsibility to provide or pay for any services the agency would otherwise provide to students with disabilities who meet that agency’s eligibility criteria. [20 U.S.C. Sec. 1412(a)(12)(B); 34 C.F.R. Sec. 300.324(c); Cal. Ed. Code Sec. 56345.1(c)]

WHAT IS THE RELATIONSHIP BETWEEN TRANSITION SERVICES AND VOCATIONAL EDUCATION?

Vocational education is broadly defined in the overall definition of special education as “organized educational programs that are directly related to the preparation of individuals for paid or unpaid employment, or for additional preparation for a career not requiring a baccalaureate or advanced degree.” [34 C.F.R. Sec. 300.39(b)(5)] In addition, vocational training is included within the definition of transition services. [34 C.F.R. Sec. 300.43] Since vocational education and training may be a crucial part of a student’s transition services, they should also be a major part of the ITP planning process.

WHEN SHOULD I REQUEST A VOCATIONAL ASSESSMENT AND WHAT SHOULD IT INCLUDE?

A “functional vocational evaluation” may be conducted before your child enrolls in vocational education. [34 C.F.R. Sec. 300.343(a)(20(5))] The assessment process should determine vocational interests, aptitudes, achievement, and potential. A variety of assessment procedures have been developed to measure your child’s level of performance in relation to selected careers and occupations such as work samples, on-the-job observation, simulated work stations, manual dexterity tests, career interest inventories, and aptitude tests. Vocational interests can be determined through the use of career interest inventories and interviews with students, parents, and previous teachers. Prior experiences, hobbies, and career exploration activities are helpful in determining the student’s interest in particular career fields.

For students with more significant disabilities, for whom traditional vocational tests are not valid or who are unable to communicate, functional assessments may be more appropriate.

Vocational aptitudes (such as manual dexterity, eye/hand coordination, fine motor skills, and general intelligence) are examined in order to blend a student’s career interest and vocational strengths and limitations.

WHAT CAN I DO LEGALLY IF THE SCHOOL DISTRICT IS NOT PROVIDING THE NECESSARY PLANNING AND EVALUATING FOR TRANSITION SERVICES?

It can be very frustrating and challenging if your child’s school district is not providing the necessary planning and evaluating for transition services. First of all, it is important to share these facts and your requests in writing. Start with the student’s case manager; if no response – go up the chain of command – principal, special education director and even the superintendent. Many times, one of these individuals will do what is needed to get evaluations and planning underway.

If you still meet resistance, there are some resources you can contact for assistance. Each state however has different contacts and resources. The following is a list of organizations and Web sites that may be helpful.

RESOURCES:

1. Parent Training and Information Centers (PTIs) or Community Parent Resource Centers (CPRCs)

Parent Training and Information Centers (PTIs) or Community Parent Resource Centers (CPRCs) are a great resource for parents. Not only do they have various handouts, trainings and other information to assist parents of children and young adults with disabilities about many topics that will assist them in transition planning, as well as resources in their state, since they are state specific, they should be able to help you navigate this complex process.

Website: <http://www.parentcenterhub.org/find-your-center>

2. National Disability Rights Network:

Every state is required to have a state advocacy organization for persons with disabilities. Depending on the issue, they may or may not take on your case. However, it can be a starting point in investigating and problem solving your issue or concern.

820 1st Street NE, Suite 740

Washington, DC 20002

Phone: 202-408-9514

TTY: 220-408-9521

Website: <http://www.ndrn.org/index.php>

You can click on your state and be connected to your state's organization. They also have an on-line form you can complete to share your issue and/or concern.

3. The ARC

This organization supports persons with developmental disabilities in many topic areas. Depending on the issues and situation, they may be a great resource and/or may be able to connect you with legal resources in your area.

Website: <http://thearc.org/find-a-chapter>

4. Wright's Law:

This website does not provide actual legal assistance but it is a great resource in gathering information to help you prepare and possibly avoid an actual legal hearing or action.

Website: <http://www.wrightslaw.com/>

Post-High School Education

HOW TO DECIDE AND PLAN:

Young adults with PWS have varying cognitive abilities. Some may be academically able to pursue post-high school learning opportunities. However, careful planning and decision-making must take place early. This can and should be a part of the student's IEP as he/she enters high school in order for him/her to complete all necessary course work and assessment testing. The following are a few areas to consider in your planning. More information on these topics follows.

- High school graduation requirements and assessments – what needs to be completed?
- Student with PWS – what are their support, supervision and accommodation needs?
- College or Training programs – which option is best for the student with PWS?

HIGH SCHOOL GRADUATION REQUIREMENTS AND ASSESSMENTS

In the world we live in today, more and more states have implemented high school graduation policies and requirements that include either state or local testing as well as exit exams to make sure students are ready for college or employment opportunities. Many states are adopting “college and career ready standards” which are a set of high expectations for all students – including students with disabilities.

If it is determined that the student with PWS is interested and capable of pursuing post-high school educational opportunities, it is important for his/her IEP to include access to standards-based instruction. IEPs should also include participation in state assessments and procedures for monitoring the student's progress throughout the school year in relation to the standards. The student will be expected to show competency in these standards. In addition to these standards and assessments, each state and/or local school district may have certain requirements for course work that must be completed in order for the student to officially graduate and receive a standard diploma. These requirements may vary by state, area or school district and should be investigated for each student. A plan for taking these courses and meeting these requirements should be addressed in every IEP.

DOES THE STUDENT WITH PWS HAVE TO COMPLETE ALL OF THESE REQUIREMENTS IN 4 YEARS?

The simple answer is “no”. It is the responsibility of the IEP team to ensure that a student's course of study is consistent with their post-secondary goals and that the student is involved in the planning and implementation of these goals. All instruction and testing accommodations should be explored and outlined in the IEP to document their knowledge and skills. Many students with disabilities need extra time to complete these requirements. According to IDEA 2004 (Individuals with Disabilities Education Act) a student is eligible for special education until he/she graduates from high school with a *regular high school diploma* or ages out at age 22. For some students, they need this extra time to complete course work and pass all of the assessment tests. It is very important, however, that this is all included and planned for in the IEP.

WILL THE STUDENT WITH PWS HAVE AN IEP IN THEIR POST-HIGH SCHOOL EDUCATION AND RECEIVE THE SAME LEVEL OF SUPPORT AND ACCOMODATIONS AS HE/SHE DID IN HIGH SCHOOL?

Students with PWS who are pursuing education beyond high school in either a college or training program are no longer eligible for services under IDEA 2004 (Individuals with Disabilities Education Act). They no longer will have an IEP and will no longer be provided with extra support or services. However, college students with disabilities are protected from discrimination under Section 504 of the Rehabilitation Act of 1973. This may be a very big change from the level of support and accommodation the student with PWS had been receiving in high school. Some colleges and other academic settings may be willing to provide some educational accommodations. This will vary from school to school. This must be investigated prior to making a choice in placement. There will be several considerations when making this decision and plan.

WHAT ARE THE GREATEST CHALLENGES FOR THE STUDENT WITH PWS IN PURSUING POST-HIGH SCHOOL EDUCATION AND TRAINING?

Students with PWS face several challenges when pursuing post-high school education and training. In many cases, the information and learning are the least of these challenges – their need for 1:1 supervision and food security is the greatest. This need for constant supervision, especially in the area of food security, now becomes the responsibility of the parent/guardian. The presence and visibility of food expands and is often overwhelming. Students can and do bring more food items with them into classes. Vending machines and snack areas are more prevalent. And there are also many fund raising and charity events that include the selling and/or the collection of food items. It becomes increasingly challenging to make sure the student with PWS does not face food situations which not only present a health concern but often result in stealing or escalations in behavior.

Another area of need that has been noted is the need for the student to use appropriate communication with educators and other students. Many students with PWS can become argumentative and openly disruptive when things change or they are not able to do things the way they have always been done. Immediate expulsion has been seen in students who have pushed or touched their professor due to their frustration and/or anger. There can also be inappropriate behavior demonstrated that may alienate the student from his/her peers.

An additional yet very important challenge is the change from the educational system providing supervision and support to the parent/guardian providing these services. Those students with PWS who have been successful in post-high school education have done so because of the hard work and dedication of parents/guardians. A lot of work goes in to working with educators to make sure they have a good understanding of PWS as well as any special accommodations that may be needed in instruction and/or testing. Successful learning outcomes have also relied on parents/guardians either providing the 1:1 support that is needed or hiring staff to accompany the student in the learning environment.

The ultimate challenge once the student completes their course of study is to then find a job that is willing and able to support their vocational needs. It is suggested that parents/guardians stay in touch with their state Department of Vocational Rehabilitation who can also help in connecting with a vocational support agency. All of this will be dependent upon the local funding support for these services.

CAN THE STUDENT WITH PWS TAKE COURSES IN HIGH SCHOOL THAT WILL HELP HIM/HER PREPARE AND KNOW WHAT TO EXPECT IN CLASSES OR PROGRAMS AFTER HIGH SCHOOL?

You may want to include the opportunity to explore and prepare for college and training programs in the student's IEP prior to graduation. The student with PWS may be able to enroll in an on-line class that will prepare him/her for the academic requirements he/she will be expected to complete. The special education teacher may be able to work with the post-secondary institution to see if special accommodations can be made. This also allows a trial in a setting, which more safely allows the student to experience the higher expectations, as well as provides a safe environment for them to learn. Some school districts have also assisted and allowed students with PWS to attend a local junior college or training program prior to the student graduating from high school. In these situations, students, parents and educators learned what environmental barriers (especially the presence and access to food) needed to be addressed.

Some students with PWS have also been able to experience volunteer positions and/or internships in their area of interest while still in high school. Many of these experiences helped vocational planning staff to once again see what sort of help or assistance these students required. It also provided the student with hands on experience to help them know if this was an area of study they wanted to pursue.

If the student with PWS is planning to pursue post-high school educational opportunities they will also want to gain more experience in writing and math skills while still in high school or work with a tutor or family member to help them prepare.

HOW CAN I LEARN WHAT POST-HIGH SCHOOL EDUCATION OR TRAINING PROGRAMS ARE AVAILABLE IN THE AREA IN WHICH THE STUDENT WITH PWS LIVES?

Ask the student with PWS' special education teacher/case manager. He/she should be able to provide you with the names of colleges or training programs in the area and be able to tell you which ones are willing to work with students with learning challenges who may need accommodations. You can also search the Internet and make inquiries to those you feel best meet the needs and interests of the student with PWS.

| Examples of Post-high School Educational Programs | |
|--|--|
| Type of Program | General Information |
| Certificate Program | <ul style="list-style-type: none"> • Usually take less than 1-2 years to complete. • May be the 1st step towards a future degree. • Examples: carpenter, childcare assistant, nursing assistant, veterinarian assistant. |
| Technical School or Community College | <ul style="list-style-type: none"> • Have varying admissions requirements. • Typically open to any student with a high school diploma or GED (general education development) diploma • Offer a wide assortment of classes and career courses. |
| Colleges or Universities | <ul style="list-style-type: none"> • Have higher admission requirements – typically need a high grade point average and high scores on ACT/SAT testing. • Many require volunteer work and a personal essay or interview. |
| <p>Many post-high school educational programs have departments that help students with disabilities. It is an important resource to utilize when considering which program is right for the student.</p> | |

WHAT TYPES OF ACCOMMODATIONS ARE TYPICALLY PROVIDED TO STUDENTS WITH DISABILITIES?

The following are some examples of accommodations that may be provided to students with disabilities. The key will be to identify which accommodations help the student with PWS be successful. Make sure they are being utilized in the high school setting so the student can pursue future options. And then investigate if the post-high school educational program is willing to also provide these accommodations. They are not legally obligated to do so.

| Examples of Accommodations in Instruction | Examples of Accommodations in Testing & Assessment |
|---|---|
| <ul style="list-style-type: none"> • Alternative or fewer assignments • Substitution materials with lower reading levels • Decreased length of assignments • Copied pages so students can mark on them • Early syllabus • Tape-recorded versions of printed material • Information presented in multiple formats • Use of listening devices • Use of student partners when reading and writing is required | <ul style="list-style-type: none"> • Separate room • Extended time, frequent breaks, unlimited time • Repeated directions, sign language, magnifying device • Word processing writing example, use of reference materials (e.g dictionary) • Special test preparation techniques • Use of equipment or manipulatives - calculator |
| <p>Resource: Graduation Requirements and Diploma Options for Students with Disabilities: What Families Need to Know. National Collaborative On Workforce and Disability. InfoBrief: May 2009 – Issue 22</p> | |

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The following shares the story of a young man with PWS and his struggles in pursuing a higher education.

Studying To Be a Computer Animator – Strategies Tried and Lessons Learned

(This article was written by Gary, Martha and Katherine Girdaukas. It has been edited by Barb Dorn – a consultant and advocate who was fortunate to have worked with this family and their son and brother, Michael. The following article points to the creativity and perseverance that Michael and his family utilized as they planned and prepared for Michael’s transition from high school into adulthood. The article shares many strategies, successes, as well as frustrations he has encountered on this journey.)

Michael is a very bright young man with PWS who was able to meet his high school graduation requirements at age 18. He was able to remain in high school because Michael had not met all of his IEP goals – an important step that allowed this to take place. *(Editor’s note: Many school districts are very resistant in allowing students to remain in school once they have met these requirements.)* Michael and his parents (along with his IEP team) then developed goals and a plan to utilize this opportunity. Michael also desired to participate in his class graduation ceremony and “walk” with his classmates, even though he remained enrolled in high school for an additional three years. He was able to do so as long as his diploma was unsigned.

Michael’s goal has always been to become a computer animator. He developed strong computer skills and was quite advanced in this area. Since he had met his high school requirements, finding classes and opportunities within the walls of his high school became challenging. The request to continue computer classes at his high school was denied. Michael then presented a detailed plan to his IEP team for continuing his education and eventually pursuing his dream job as an animator. He requested help and assistance to attend a local technical college to receive training in 3D animation, and pursue his goals in animation. Although Michael was articulate and thorough, his initial request was denied. Michael’s team wanted him to focus his “post graduate education” on developing vocational skills and to focus his efforts on finding a job. Due to his strong food seeking and other behavioral challenges, each job Michael tried was self-limiting.

| Jobs Attempted | Reason for Leaving | Comments |
|--|---|---------------------------------|
| “Cage Cleaner” – Veterinary Hospital | Behavior issue – was not allowed to complete job task and became upset. | Lasted one shift. |
| Sound Editing Assistant for a company that develops products for special education, including assistive technology, educational curricula, software, videos and hands-on training materials. | Behavior issue – disagreement with job coach escalated and resulted in termination. | Was successful for over 1 year. |
| **In all of these vocational experiences, Michael had a 1:1 job coach. | | |

During this time, the job market was terrible. By his post-high school second year there were no realistic vocational options. Michael’s parents hired his sister (Katherine) to accompany him to a nearby technical college. Katherine started this experience in the summer by taking Michael to one class. Prior to him stepping foot on the campus, Katherine toured the campus to look at layout, food access and other logistics with “PWS eyes”. Detailed planning and discussions took place with Michael to make sure things were carefully planned out and agreements were made before attending any classes. They also made contact with a counselor to assist with making requests for academic adaptations and modifications that Michael needed to succeed. Even though post-high school education institutions are not mandated to provide special education services, many do offer assistance to students with disabilities. Michael’s instructor was also educated about PWS and his special education needs. After the summer and a successful experience, Michael’s 1:1 support transitioned to an educational assistant

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from his high school (with extra training from Katherine). The educational aide accompanied Michael to his classes. Success continued, so after the age of 21 years, Michael was able to receive funding from his county to hire staff that accompanied him to some additional classes. There were a few behavior and food security bumps in the road but because of Katherine's expertise at pre-screening areas for potential complications, Michael had only a few problematic incidents.

Michael did well in the first three semesters. He got good grades (B+ average). He did require a lot of help at home to stay organized and ensure that assignments were turned in on time. This included regular prompts and structured time and support for his homework. He also required an aide to sit with him in class to provide guidance and help him manage his behavior and frustration.

Michael worked on completing his prerequisites while being placed on a waiting list for the animation program. Eventually, Michael was accepted. During the first semester in animation studies, he acquired Influenza H1N1, became very ill and nearly died. His recuperation took several weeks and he missed a great deal of class time. It was too difficult to keep up with the intense demands of his studies and he had to drop out of school. Instead of waiting a year to retake the missed courses, Michael applied to and was accepted into an animation program at a private school. Because of his disability, he qualified for a Pell Grant. This grant helped with the cost of his animation studies program, especially since this private school was far more costly than the previous program.



Because he was unable to borrow money, his parents loaned him additional money for tuition. He was able to pay off the loan over several years while living at home, mowing lawns, snow-blowing the driveway and doing other jobs. Michael enjoyed taking classes, and for the first time had a strong incentive to practice reining in his temper so that he could stay in class. Many of the same support strategies were utilized on this new campus with new instructors. Unfortunately, although his frustration self-control improved, dealing with the inevitable frustrations of computer software crashes, Michael continued to experience behavior outbursts. In the end, these outbursts were incompatible with continuing education at this college and his education ended after two semesters.

Michael was heartbroken. Animation had always been his dream, and to see it shut down was devastating. He sunk into a deep depression. His anger and weight spiraled out of control. His health began to decline. As a result of the weight gain, he was diagnosed as pre-diabetic and his health deteriorated. Michael was hospitalized at The Children's Institute (TCI). Upon discharge, he moved into a group home about one hour from his parent's home. After the move, he continued to lose weight and his health improved. He became more mature and more circumspect about his situation.

Unfortunately, with the move, his ability to continue his education stopped. Despite Michael having the computer equipment and software needed to continue his education via on-line classes, there have been many barriers. He currently works in a sheltered work environment, which is low paying and does not meet his personal vocational goals. His vocational provider has offered limited opportunities to help him pursue his vocational aspiration. His residential provider has been unwilling to provide Internet access with a fire-wall to limit access to approved sites. Funding for additional services like these have been cost prohibitive.

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Sometimes Michael feels that his advocacy team has forgotten him and feels sad because he realizes that he cannot do it all alone. He wants to be an active participant in goal setting and in living life to the fullest. We are not sure what the future holds for Michael, but he has a thirst for learning and personal growth that drives him. He is learning to advocate for himself, including dealing with the frustrations and the long wait that such advocacy entails. He has received a lot of support from his family and many opportunities as he continues his quest to become an animator.

Planning, support and personal advocacy has allowed Michael to experience many educational opportunities that many young adults with PWS (as well as others) dream of. The behavior challenges that accompany PWS have been hurdles that have prevented him from achieving his dream – so far. The need for specialized services and continued education has been another challenge in his adult world. Hopefully with continued advocacy and perseverance, Michael may someday be able to achieve his dream to become a computer animator.

Vocational Evaluation and Transition from School to Work for the Student with Prader-Willi Syndrome

Vocational Evaluation is an educational process in which a client obtains greater self and work knowledge through participation in work activities designed to evaluate vocational skills, interests, and abilities. Clients learn about the functional impact of their disability in relation to their career options. They also learn about assistive technology and the devices and accommodations needed to remove barriers to employment. The evaluation process encourages personal involvement in career planning and development and empowers clients by increasing their self-confidence in career decision-making.

WHAT ARE SOME IMPORTANT THINGS TO CONSIDER WHEN EVALUATING INDIVIDUALS WITH PRADER-WILLI SYNDROME?

Many individuals with PWS exhibit difficulty in concentrating while sitting for long periods of time. Distractibility and, at times, sleepiness may have a negative effect on test results. Selecting tests that are not lengthy may provide more reliable results. Also, limiting distractions in the evaluation area is extremely helpful. Allowing the individual to stand for short periods of time while being tested may prevent sleepiness. It is important to caution evaluators that very obese persons may have swelling in their lower extremities that will require them to elevate their legs while seated.

Individuals with PWS may present unique expressive and receptive language skills. It is common that expressive skills are much higher than receptive language skills. This means that a person with PWS may say what he/she understood about an instruction but, in actuality, may have missed some of the details or misinterpreted the instruction. This can often lead to argumentativeness or excessive questions. There are some useful techniques to minimize potential problems in this area. Limiting the amount of information presented at one time and giving the person with PWS time to process each step, asking the person to repeat the information, clarifying any discrepancies before the person begins testing, and maintaining a supportive, positive interaction style will ensure a successful evaluation.

Motivators or behavioral intervention techniques that have been successful with the individual should be shared with the evaluator before testing and a plan developed on how the testing will be conducted should also be discussed before testing.

ASSESSMENT ACTIVITIES

This process should include effective practices and the gathering of helpful planning information. To collect all needed data, assessment activities should include observations, interviews, record reviews, and testing/performance activities.

Observation is the process of watching or listening to an individual's behavior and performance and recording relevant information. This process can be structured or unstructured, formal or informal, obtrusive or unobtrusive. Observation has elements of the objective and the subjective, but objectivity should be emphasized. Also, because different observers may come to different conclusions, it may be important to have more than one observer.

Interviews are structured or unstructured conversations intended to gather information from an individual through a verbal question-and-answer format. Like observations, interviews can also be formal or informal. An interviewer can quickly gather key information about an individual, while at the same time build trust and a shared vision for the career planning process.

Record Reviews incorporate prior assessment results and should include records from schools and care providers, as available. A review of records can provide background information about academic achievement and performance, previous career planning and goals, and family involvement and support systems. Care should be

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taken that the information is up-to-date and from sources that have properly gathered the data. Legally obtained releases of information are usually required, and confidentiality is essential when reviewing any assessment data or other protected records.

Testing and Performance Reviews account for a large share of the most common assessment activities of youth in transition. Testing “consists of administering a particular set of questions to an individual...to obtain a score” (Salvia & Ysseldyke, 2004, p. 6). Typically, scores are intended to be used for quite specific purposes. This type of data collection is generally more formal and structured and frequently requires specially trained persons to administer and/or score the test. It is important to note that accommodations are of particular concern when using criterion-referenced or norm-referenced instruments. The goal should be to change the way that a test is taken without changing the validity of the test results.

Performance reviews are activities that look at a whole spectrum of what has been learned and are more subjective, holistic, and qualitative in nature (Salvia & Ysseldyke, 2004, p. 252). Work experiences and related activities often are best evaluated using performance reviews. It is very helpful to have some written, objective standards for individuals to use in measuring behaviors.

Formal Testing:

Youth service professionals must choose tests that fulfill the specific needs of the individual. After reviewing available records and conducting informal interviews, planning should determine some short-term, and possibly longer-term, goals. Eligibility assessment can be conducted at this point along with diagnostic or achievement testing to determine where an individual may belong in classes or in training programs. Here, more formal assessments may be used to answer some questions. For our purposes, formal assessments are defined as published instruments with specified administration procedures.

Formal testing is used to assess seven areas related to career planning:

1. Academic Performance or Achievement
2. Cognitive Abilities
3. Behavior, Social, and Emotional Issues
4. Vocational Interests
5. Vocational Aptitudes
6. Certification of Occupational Competencies
7. Physical and Functional Capacities

Individual youth may need assessment in a few or several of these areas.

Vocational Evaluation Checklist for an Individual with Prader-Willi Syndrome

Student: _____ Work Setting: _____

Evaluator: _____ Date: _____

| COMMUNICATION | Agree | Disagree | COMMENTS: (please indicate if student requires assistance – verbal prompts, visual reminders or other aids/ assistance) |
|---|--------------|-----------------|--|
| Understands verbal language. | | | |
| Needs time processing ideas and questions. | | | |
| Responds verbally to questions and interactions. | | | |
| Uses pictures / gestures to communicate. | | | |
| Expresses questions and concerns to co-workers and supervisors appropriately in proper tone and volume. | | | |
| Able to read at a basic level. | | | |
| Utilizes strategies when introduced to new work tasks or responsibilities. (schedule, checklist, simple written directions) | | | |
| Communicates appropriately when needing help, assistance or additional work. | | | |
| Uses appropriate non-verbal communication. | | | |
| WORK BEHAVIORS | Agree | Disagree | COMMENTS: (please indicate if student requires assistance – verbal prompts, visual reminders or other aids/ assistance) |
| Understands and completes work-related tasks appropriately. | | | |
| Performs 2-3 step sequencing activities. | | | |
| Conducts multi-step tasks with accuracy. | | | |
| Works at appropriate rate. | | | |
| Needs additional time to complete tasks. | | | |
| Stays attentive and alert. | | | |
| Requires breaks and/or utilizes strategies to stay alert and awake. | | | |
| Follows rules and directives. | | | |
| Completes job with accuracy and quality. | | | |
| Requires demonstration and practicing of new skills. | | | |
| Stays in approved work areas as designated by staff. | | | |
| Handles changes in work assignments using appropriate strategies. | | | |
| Uses appropriate strategies to manage negative feelings or emotions. | | | |

Vocational Evaluation Checklist for an Individual with Prader-Willi Syndrome

| WORK BEHAVIORS cont. | Agree | Disagree | COMMENTS: (please indicate if student requires assistance – verbal prompts, visual reminders or other aids/ assistance) |
|---|--------------|-----------------|--|
| Has a difficulty managing emotions when faced with new tasks or expectations. | | | |
| Requires additional incentives to complete work tasks. | | | |
| SOCIAL SKILLS | Agree | Disagree | COMMENTS: (please indicate if student requires assistance – verbal prompts, visual reminders or other aids/ assistance) |
| Initiates conversations at the correct time and context of situation. | | | |
| Responds appropriately to social interactions. | | | |
| Shares with peers. | | | |
| Waits and/or takes turns with peers. | | | |
| Requires extra supervision around money and personal belongings of others. | | | |
| Needs coaching and/or modeling from others for some social situations. | | | |
| Verbalizes and demonstrates an understanding of appropriate workplace social behavior and conversations. | | | |
| Dresses with appropriate clothing for the weather and temperature. | | | |
| Wears clean clothes, combs hair and uses good hygiene. | | | |
| FOOD SECURITY AND OTHER HEALTH AND SAFETY ISSUES | Agree | Disagree | COMMENTS: (please indicate if student requires assistance – verbal prompts, visual reminders or other aids/ assistance) |
| Requires and receives supervision around all food sources to ensure food security (break rooms, vending areas, special food collection drives). | | | |
| Requires supervision and strategies to prevent skin picking. | | | |
| Uses bathroom facilities independently. Uses proper hygiene. | | | |
| Reports any falls and/or injuries to an identified staff person. | | | |
| Requires the administration of medication in the work setting. | | | |
| Requires special transportation to/from work. | | | |

Work Skill Development for Employers of Employees with PWS

- Workers who have PWS can learn simple tasks and multiple-step procedures.
- Directions should be presented a few at a time in simple terms, since many have difficulty understanding complex concepts.
- Additional time and repetitions may be required to learn new tasks. One training session may not be enough.
- Visual models are more effective than verbal directions. Demonstrating and hands-on examples are effective learning tools.
- Close monitoring during the learning process helps to insure that instructions are followed.
- People who have PWS respond well to positive reinforcement and positive behavior support plans.
- Look for signs of anxiety and be proactive in reducing their anxiety.

Adults with PWS can present unique challenges for staff within a work program. **Trained staff is essential for a successful work program.** Below are suggestions to help staff understand the worker who has PWS.

- Persons with PWS are generally concrete thinkers. Terms like, “Hop to it!” may not be understood to mean “Begin the task immediately” and may cause confusion, anxiety, and result in an unwanted behavior.
- Persons with PWS have a delay in processing the information you give them. Most people who have PWS will take between 3-5 seconds to understand what you say. If too many instructions are given or the instructions are generalized, they can miss the middle part of what you said and misunderstandings occur. Instead of saying “here’s your job,” try breaking the process down into steps; “It’s time to take out your bin.” Then wait 3-5 seconds before repeating the request. If after the second request they do not comply, do the task with them before asking that they do the next step.
- Problem-solving skills are often impaired. This is in part due to the processing delay and not being able to put things in order of how they should be done, which also creates anxiety. People who have PWS become frustrated and anxious trying to do what you want them to without being able to know or remember the steps. Visual directions can be helpful.
- Short-term memory can be poor, but long-term memory is usually excellent; so once something is learned, they will remember it.
- If a task has too many steps or is above the ability of the person with PWS, they can become frustrated and then anxious. This is also true in that if the task are too far below the abilities of the person with PWS, they will become frustrated. People who have PWS are already anxious; so if you can reduce or eliminate the source of the anxiety, it can reduce behavior problems.
- Contact PWSA (USA) at 800-926-4797 for handouts for staff and training materials.

Food Security – Creating a Safe Work Environment

- Restrict access to all food. Persons who have PWS will go to extremes to acquire food. Supervision in the work environment is necessary as well as during lunchtime, in break areas, and during trips to the bathroom.
- Have workers who have PWS bring lunches and snacks pre-packed. They may need to eat with just a few people to avoid focusing on other people’s food. Store food in secure (locked) location.

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- Look for food in all locations – candy dishes, vending machines, break rooms, coffee machines, and “special treats”.
- Make sure money and purses are kept out of sight and secured. Remember – money buys food!

Helping to Ensure Positive Behaviors

- Be generous with verbal praise for work accomplished and appropriate behavior
- Identify rewarding work incentives, as in assisting a supervisor with a special task, spending break time with a specific co-worker or receiving points/tokens to be used later that day for a reward.
- Define off-limit areas. Select monitors to direct the person back to an appropriate area.
- When there will be a change in jobs or schedules, inform the individual who has PWS of the changes in advance. Some people require a longer time period to adjust to change and others a shorter time period. Know the person who has PWS and what is best for them.
- Daily written or picture work schedules may be helpful. Go over the schedule when they arrive at work. Some people with PWS do better going over the morning schedule when they arrive and then going over the afternoon schedule after lunchtime.
- Remember, positive support plans work best. People who have PWS need frequent positive reinforcement.

Suggestions for Managing Challenging Behaviors if They Occur

Management of the behaviors requires consistency and teamwork on the part of the staff. Again, trained staff is the key to success.

- Speak in a calm, quiet voice.
- As you are walking toward the person, walk slowly; don't run or react in an excited manner. Have another staff remove items that could be used to harm or be destroyed.
- If someone's behavior does escalate, have a designated staff person move in and control the situation while the rest of the staff maintains a sense of normalcy within the work area.
- Have a cool down area available where the person can go to calm down.
- Once the person is calm, allow them the choice of going back out to the work area or remaining in the cool-down area to work. They may show signs of being very tired. This also helps them to have the expectation of continuing to work.
- After an outburst occurs and the person has calmed down, they are usually sorry for their actions. It's okay to acknowledge that the person is having a tough day. Review what happened, why it happened, and what can be done to help avoid the same situation again.

Finding a Job for the Young Adult with PWS – Things to Keep in Mind

There are many things that need to be considered in looking for a job environment that will be safe and successful for the person with PWS. The person who is researching job possibilities should put on “Prader-Willi glasses” to be able to identify areas of concern. The following are some things to keep in mind.

ENVIRONMENTAL CONSIDERATIONS

FOOD RELATED ISSUES

- The work environment must be evaluated for food sources and it must be determined how it is impacted by food.
 1. Is food an integral part of the company’s culture?
 2. Is staff able to eat at their work site?
 3. Is food left out and to what degree?
 4. Will the employer be willing to be supportive of the needs of the person with PWS?
 5. Where is the break room in relation to the worker’s job site?
 6. What are the smells?

TRANSPORTATION

- The success within the work setting can often be dependent on what happens before the person even arrives at work. Transportation issues must never be overlooked.
 1. What form of transportation is available?
 2. Is it reliable?
 3. Is there a consistent driver – are they aware of the special dietary needs?
 4. Are people eating on the trip to work?
- Oftentimes there are safety considerations that need to be addressed with transporting the person with PWS to the workplace. Some people with PWS have problems with impulse control and may jump out of a moving vehicle. A vehicle with child locks on the doors or a safety belt cover may be used along with behavior incentives.

WORKPLACE ENVIRONMENT

- Behavior challenges often interfere with the ability of the person with PWS to adhere to prompt time schedules. It needs to be clearly identified what areas may be negotiable with the employer:
 1. Can time frames for arrival and departure be flexible?
 2. Can the employee make up lost time?
 3. Can the worker take a longer break?
- There also needs to be an acceptance of the environmental (food) monitoring and behavior supports.
- Most persons with PWS are sensitive to over-stimulation, loud noises and frequent distractions. These can often cause irritability and/or low productivity. The need for “break time” is necessary when the employee is becoming overstimulated.

ON-SITE WORK SUPERVISION CONSIDERATIONS

VOCATIONAL SUPPORT – JOB COACH

- Persons with PWS need constant supervision and support at a work site. This must be done to ensure the safety and well-being of the person with PWS. Proactive measures to prevent food seeking, stealing and behavior escalations must be monitored and supported at all times.
- It is important for the vocational support staff to receive training and/or information about PWS. They must have a very good understanding of the unique needs of the person with PWS so that thoughtful planning and appropriate interventions can take place.

LOCATING AND FUNDING VOCATIONAL SERVICES

HOW DO YOU LOCATE A VOCATIONAL AGENCY TO SUPPORT THE YOUNG ADULT WITH PWS?

- **It is important to start this process while the person with PWS is still in high school.** The transition period – these final years in high school - provides an opportunity to identify jobs that the person with PWS can perform and what is needed to create and maintain a successful work experience.
- The education case manager can assist in identifying local resources that provide vocational support. This individual can also assist in providing information in making referrals to human service agencies who are typically the ones who provide funding for vocational services.
- You can contact your State Division of Vocational (Rehabilitation) Services. This should also be done while the student is in high school; however, this can be done after graduation, if it was not done while in high school. Oftentimes, this agency will not become involved until the student is within 1 year of graduating. This may vary by state, so discuss this with your education case manager or contact the agency directly. Each state may have different criteria for vocational evaluations; however, they can provide this information and give additional assistance. The state vocational agency may be able to connect you with appropriate agencies to provide direct vocational services; however, the key will be obtaining funding to support these services. Remember to start the discussion and research early – it takes time to get funding and services arranged.

WHO PROVIDES FUNDING FOR VOCATIONAL SUPPORT SERVICES?

- Funding for vocational support comes from federal, state and/or local funding. This is typically approved and provided by a local human service agency. Ask the education case manager who is responsible for this in your area and what needs to be done to access these resources.

Employer Responsibilities and Employment

Many parents of children who have PWS ask about the Americans with Disabilities Act and what are the responsibilities of the employers in hiring and making accommodations. The information below is a summary from the U.S. Equal Employment Opportunity Commission of the ADA and the responsibilities the ADA places on employers. For more information go to: <http://www.eeoc.gov/eeoc/publications/ada17.cfm>

The Americans with Disabilities Act (ADA) Amendments Act of 2008

On September 25, 2008, the President signed the Americans with Disabilities Act Amendments Act of 2008 ("ADA Amendments Act" or "Act"). The Act emphasizes that the definition of disability should be construed in favor of broad coverage of individuals to the maximum extent permitted by the terms of the ADA and generally shall not require extensive analysis.

The Act makes important changes to the definition of the term "disability" by rejecting the holdings in several Supreme Court decisions and portions of EEOC's ADA regulations. The effect of these changes is to make it easier for an individual seeking protection under the ADA to establish that he or she has a disability within the meaning of the ADA.

The Act retains the ADA's basic definition of "disability" as an impairment that substantially limits one or more major life activities, a record of such an impairment, or being regarded as having such an impairment. However, it changes the way that these statutory terms should be interpreted in several ways. Most significantly, the Act:

- Directs EEOC to revise that portion of its regulations defining the term "substantially limits";
- Expands the definition of "major life activities" by including two non-exhaustive lists:
 - the first list includes many activities that the EEOC has recognized (e.g., walking) as well as activities that EEOC has not specifically recognized (e.g., reading, bending, and communicating);
 - the second list includes major bodily functions (e.g., "functions of the immune system, normal cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine, and reproductive functions");
- States that mitigating measures other than "ordinary eyeglasses or contact lenses" shall not be considered in assessing whether an individual has a disability;
- Clarifies that an impairment that is episodic or in remission is a disability if it would substantially limit a major life activity when active;
- Changes the definition of "regarded as" so that it no longer requires a showing that the employer perceived the individual to be substantially limited in a major life activity, and instead says that an applicant or employee is "regarded as" disabled if he or she is subject to an action prohibited by the ADA (e.g., failure to hire or termination) based on an impairment that is not transitory and minor;
- Provides that individuals covered only under the "regarded as" prong are not entitled to reasonable accommodation.

WHAT DOES THIS MEAN FOR THE EMPLOYER?

The Americans with Disabilities Act of 1990 (ADA) makes it unlawful to discriminate in employment against a qualified individual with a disability. The ADA also outlaws discrimination against individuals with disabilities in state and local government services, public accommodations, transportation and telecommunications.

Title I of the ADA protects qualified individuals with disabilities from employment discrimination. Under the ADA, a person has a disability if he has a physical or mental impairment that substantially limits a major life activity. The ADA also protects individuals who have a record of a substantially limiting impairment, and people who are regarded as having a substantially limiting impairment.

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To be protected under the ADA, an individual must have, have a record of, or be regarded as having a substantial, as opposed to a minor, impairment. A substantial impairment is one that significantly limits or restricts a major life activity such as hearing, seeing, speaking, breathing, walking, learning, working, performing manual tasks, and caring for oneself.

An individual with a disability must also be qualified to perform the essential functions of the job with or without reasonable accommodation, in order to be protected by the ADA. This means that the applicant or employee must:

- Satisfy your job requirements for educational background, employment experience, skills, licenses, and any other qualification standards that are job related; and
- Be able to perform those tasks that are essential to the job, with or without reasonable accommodation.

The ADA does not interfere with your right to hire the best qualified applicant. Nor does the ADA impose any affirmative action obligations. The ADA simply prohibits you from discriminating against a qualified applicant or employee because of her disability.

HOW ARE ESSENTIAL FUNCTIONS DETERMINED?

Essential functions are the basic job duties that an employee must be able to perform, with or without reasonable accommodation. You should carefully examine each job to determine which functions or tasks are essential to performance. (This is particularly important before taking an employment action such as recruiting, advertising, hiring, promoting or firing).

Factors to consider in determining if a function is essential include:

- Whether the reason the position exists is to perform that function,
- The number of other employees available to perform the function or among whom the performance of the function can be distributed, and
- The degree of expertise or skill required to perform the function.

Your judgment as to which functions are essential, and a written job description prepared before advertising or interviewing for a job, will be considered by EEOC as evidence of essential functions. Other kinds of evidence that EEOC will consider include:

- the actual work experience of present or past employees in the job,
- the time spent performing a function,
- the consequences of not requiring that an employee perform a function, and
- the terms of a collective bargaining agreement.

WHAT ARE THE OBLIGATIONS AS AN EMPLOYER TO PROVIDE REASONABLE ACCOMMODATIONS?

A reasonable accommodation is any change or adjustment to a job or work environment that permits a qualified applicant or employee with a disability to participate in the job application process; to perform the essential functions of a job; or to enjoy benefits and privileges of employment equal to those enjoyed by employees without disabilities. For example, reasonable accommodation may include:

- acquiring or modifying equipment or devices,
- job restructuring,
- part-time or modified work schedules,
- reassignment to a vacant position,
- adjusting or modifying examinations, training materials or policies,
- providing readers and interpreters, and
- making the workplace readily accessible to and usable by people with disabilities.

Reasonable accommodation also must be made to enable an individual with a disability to participate in the application process, and to enjoy benefits and privileges of employment equal to those available to other to fail to

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provide reasonable accommodation to the known physical or mental limitations of a qualified individual with a disability, unless to do so would impose an undue hardship on the operation of your business. Undue hardship means that the accommodation would require significant difficulty or hardship.

WHAT IS THE BEST WAY TO IDENTIFY A REASONABLE ACCOMMODATION?

Frequently, when a qualified individual with a disability requests a reasonable accommodation, the appropriate accommodation is obvious. The individual may suggest a reasonable accommodation based upon her own life or work experience. However, when the appropriate accommodation is not readily apparent, you must make a reasonable effort to identify one. The best way to do this is to consult informally with the applicant or employee about potential accommodations that would enable the individual to participate in the application process or perform the essential functions of the job. If this consultation does not identify an appropriate accommodation, you may contact the EEOC, State or local vocational rehabilitation agencies, or state or local organizations representing or providing services to individuals with disabilities. Another resource is the Job Accommodation Network (JAN). JAN is a free consultant service that helps employers make individualized accommodations. The telephone number is 1-800-526-7234.

WHEN DOES A REASONABLE ACCOMMODATION BECOME AN UNDUE HARDSHIP?

It is not necessary to provide a reasonable accommodation if doing so would cause an undue hardship. Undue hardship means that an accommodation would be unduly costly, extensive, substantial or disruptive, or would fundamentally alter the nature or operation of the business. Among the factors to be considered in determining whether an accommodation is an undue hardship are the cost of the accommodation, the employer's size, financial resources and the nature and structure of its operation.

If a particular accommodation would be an undue hardship, you must try to identify another accommodation that will not pose such a hardship. If cost causes the undue hardship, you must also consider whether funding for an accommodation is available from an outside source, such as a vocational rehabilitation agency, and if the cost of providing the accommodation can be offset by state or federal tax credits or deductions. You must also give the applicant or employee with a disability the opportunity to provide the accommodation or pay for the portion of the accommodation that constitutes an undue hardship.

HOW WILL THE ADA BE ENFORCED AND WHAT ARE THE AVAILABLE REMEDIES?

The provisions of the ADA which prohibit job discrimination will be enforced by the U.S. Equal Employment Opportunity Commission. After July 26, 1992, individuals who believe they have been discriminated against on the basis of their disability can file a charge with the Commission at any of its offices located throughout the United States. A charge of discrimination must be filed within 180 days of the discrimination, unless there is a state or local law that also provides relief for discrimination on the basis of disability. In those cases, the complainant has 300 days to file a charge.

The Commission will investigate and initially attempt to resolve the charge through conciliation, following the same procedures used to handle charges of discrimination filed under Title VII of the Civil Rights Act of 1964. The ADA also incorporates the remedies contained in Title VII. These remedies include hiring, promotion, reinstatement, back pay, and attorney's fees. Reasonable accommodation is also available as a remedy under the ADA.

HOW WILL EEOC HELP EMPLOYERS WHO WANT TO COMPLY WITH THE ADA?

The Commission believes that employers want to comply with the ADA, and that if they are given sufficient information on how to comply, they will do so voluntarily.

Accordingly, the Commission conducts an active technical assistance program to promote voluntary compliance with the ADA. This program is designed to help employers understand their responsibilities and assist people with disabilities to understand their rights and the law.

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In January 1992, EEOC published a Technical Assistance Manual, providing practical application of legal requirements to specific employment activities, with a directory of resources to aid compliance. EEOC publishes other educational materials, provides training on the law for employers and for people with disabilities, and participates in meetings and training programs of other organizations. EEOC staff also will respond to individual requests for information and assistance. The Commission's technical assistance program is separate and distinct from its enforcement responsibilities. Employers who seek information or assistance from the Commission will not be subject to any enforcement action because of such inquiries.

The Commission also recognizes that differences and disputes about the ADA requirements may arise between employers and people with disabilities as a result of misunderstandings. Such disputes frequently can be resolved more effectively through informal negotiation or mediation procedures, rather than through the formal enforcement process of the ADA. Accordingly, EEOC will encourage efforts to settle such differences through alternative dispute resolution, providing that such efforts do not deprive any individual of legal rights provided by the statute.

SO WHAT DOES THIS MEAN FOR THE PERSON WITH PWS?

What accommodations employers will make and how much is needed will be based on the individual needs of the student with PWS. Some students are able to manage their food drive and emotions with minimal accommodations. No matter, all students with PWS require oversight and supervision in the area of food security. They cannot "learn to manage" this on their own. Another consideration is the job itself and the work environment. There are some jobs and some work environments that have little food involved in the workplace or in their job tasks. When this is accompanied with job responsibilities that are predictable and consistent, the employee with PWS may only require little, if any, accommodations (other than supervision and oversight). In reality, there are also some employers who are more welcoming and accepting of persons with disabilities and they will easily make the necessary changes as long as they do not negatively impact other workers. If a person with PWS has a strong food drive and/or many challenging behaviors, the employer may feel the necessary supports create a hardship for other employees. The vocational agency that will be providing services, will need to evaluate the student's needs as well as the employer's willingness to make the necessary changes to make the work environment safe and successful for the student with PWS.

Successful and “Not-So Successful” Job Options for the Young Adult with Prader-Willi Syndrome

WHAT ARE COMMON FACTORS THAT HELP CONTRIBUTE TO A SUCCESSFUL JOB PLACEMENT?

Many educators, vocational professionals and parents often ask, “What jobs and work environments are the most successful for young adults with PWS?” There is no simple answer to this question. A lot depends on the individual strengths of the person with PWS as well as what resources and supports are available for him/her. However, there are some common concerns and some common environments that have been found to be more successful than others.

| COMMON FACTORS THAT OFTEN CONTRIBUTE TO MORE SUCCESS IN A JOB PLACEMENT | COMMON FACTORS THAT MAY CONTRIBUTE TO LESS SUCCESS and DISMISSAL FROM A JOB PLACEMENT |
|--|---|
| <ul style="list-style-type: none"> • Employment in family or friend businesses where food security, access to money and flexibility in behavior management is accepted, understood and implemented. | <ul style="list-style-type: none"> • Food security is not maintained and the employee is found accessing and/or stealing food or money. • Food oriented work environment that becomes overwhelming and too stressful. |
| <ul style="list-style-type: none"> • Close supervision and support by a job coach where issues and concerns can be anticipated, prevented or quickly managed. | <ul style="list-style-type: none"> • Behavior escalations that are disruptive to the work environment. |
| <ul style="list-style-type: none"> • Shortened work day. Persons who work 3-4 hours per day are often more successful. | <ul style="list-style-type: none"> • Too many changes in work tasks with little or no warning or predictability. |
| <ul style="list-style-type: none"> • Shortened work week. Persons who work at one job site 2-3 days per week (possibly alternating with another job site) are often more successful. | <ul style="list-style-type: none"> • Behaviors that result in assault or property destruction. • Attendance problems. Low productivity. |
| <ul style="list-style-type: none"> • Clear expectation of job tasks – often communicated in a written or visual format. | <ul style="list-style-type: none"> • Poor hygiene. |

WHAT TYPES OF JOBS HAVE PERSONS WITH PWS BEEN MORE SUCCESSFUL IN?

The following are examples of some of the jobs that have been reported to have more successes, along with jobs that resulted in some “not-so successful” experiences. Most successful job experiences have been reported in situations where the person with PWS received close supervision in food security and an understanding and acceptance in doing what was needed to address challenging behaviors.

| EXAMPLES OF MORE SUCCESSFUL JOB OPPORTUNITIES | EXAMPLES OF “NOT-SO-SUCCESSFUL” JOB OPPORTUNITIES |
|---|--|
| <ul style="list-style-type: none"> • Sheltered work environment where food security is maintained and job security is not in jeopardy when negative behaviors occur. • Manufacturing jobs – small groups with other employees that required close supervision. • Floral Shop / business • Computer jobs – data entry • Library • Laundry services • Mail delivery / clerical jobs • Veterinary Aide | <ul style="list-style-type: none"> • Restaurant or other food service jobs. • Grocery Store • Housekeeping positions that expose employees to trash that contain discarded food. • Jobs that require responsibility with money. (Stealing often occurs). • Childcare • Veterinary Aide – IF the person with PWS is known to be cruel to animals or eat pet food. |

Day Programs – Another Option for Consideration

Some persons with PWS cannot and do not find a successful vocational experience. Many are starting to age, and they are not able to keep up with the demands of working. Participation in a day program (or a day training and habilitation program) may provide another option for consideration. There are many different types of day programs around the country – some offer many worthwhile services and some do not. It is important to visit and see exactly what activities participants are provided and if this is a good fit for the person with PWS.

WHAT TYPES OF SERVICES AND OPPORTUNITIES MAY BE OFFERED IN A DAY PROGRAM?

Day program services should build and support meaningful community, leisure and work experiences. They should not just be an adult “babysitting experience”. They should offer activities and experiences that attempt to stimulate mental, emotional and social growth. Most of the time is typically spent in a non-work environment.

During this time, they may be involved in:

- Planned therapeutic services (Recreation or Art therapy)
- Community activities
- Continuing education

Examples of some of the activities that may be included:

- Personal grooming/housekeeping
- Communication growth
- Social integration / recreational opportunities
- Behavior management
- Exercise
- Basic work skills and/or volunteer opportunities

HOW DO I LEARN IF THESE PROGRAMS ARE AVAILABLE WHERE WE LIVE?

Ask your son/daughter’s educational case manager and/or their county case manager about what options are available in your area. Referrals to these programs often require approval from a funding source and there may be a waiting list. You can also try doing a search on the Internet to see what may be available. Many organizations like Goodwill Industries, Easter Seals (just to name a few) have these programs.

Day RISE Program – A Big Success

By Barb Dorn

Over several years, my son, Tony, experienced a roller coaster ride of varying job experiences. While in high school, he was successful for a time, working in a grocery store (in the paper product area) and volunteering in a day care. Because of his often unpredictable behavior changes, these jobs were self-limiting. When he moved into residential care, he was very motivated and productive in a group, sheltered work environment. He was so successful that he was able to transition into the community and worked in a manufacturing company. However, the pressure of this position became too great and Tony requested to return to the group workshop. The next few years were filled with many challenges. Tony worked fewer and fewer hours. His “paychecks” were almost nothing and he spent a great deal of time in the back room – sleeping. Several incentive programs were tried and failed. Tony was then offered admission into a newly created **Day RISE** program (**R**esponsible, **I**maginative, **S**uccessful, and **E**xtraordinary) where he is learning new information and skills. He exercises daily – being provided with a wide range of different exercise options. He does art therapy; is involved in a book club and earns points toward outings out in the community. Most important – he is happy and receiving cognitive and social stimulation. At first I was afraid we were “giving up” on Tony working. However, it was becoming increasingly challenging to have him stay engaged and be productive in his work environment. Today, Tony is very happy and he can’t stop talking about all he is learning and doing. For him, this move was a big success!

What Shall We Do About a Job for Lauren? By Debbie Lange

With each year that passes, this objective brings a new challenge. My daughter with PWS, Lauren, is now 33 years old. But the struggle began long ago.

Becoming Aware

The first sign of this impending issue came with high school. Even with Special Education, the issue of “transition” applies. First we tried technical school. What a nightmare. The first job she was offered was in the cafeteria at a prestigious catholic school in Atlanta. Can you imagine a kid with PWS being responsible for clearing and cleaning the lunch tables? At our objectives, they said, “She can scoop out the cookie dough to be baked. It’s frozen so she won’t eat it.” (Ha Ha –run away... very fast ...) This opportunity was never considered viable.

Next came the job at Holiday Inn. Ironing sheets...hmmm....sounds possible... She got a 2nd degree burn and was fired on the first day. *Bingo*.

This wasn’t going well. Our options were becoming more and more limited. Bagger at a grocery store? Yea... right... fast food restaurant... nooooooo!

Finally it became obvious that the technical school was aligned with, mainly, food service jobs (unless we wanted to consider a skilled labor job. (Heavy machinery and my daughter? I think not).

Option #2

These limitations, and failures, meant we were going back into the school setting to find another option. In our state, the transition process offers a state funded vocational rehabilitation/training program. The training occurs at a job site with a job coach. OK... Let’s try this. It looked ok at first glance.

But, then we learned the rules. Within a six-month period, all participants had to be capable of performing duties in a competitive work setting, without supervision. The six months was intended to be a training period, where the work hours increased while the supervision reduced. We just didn’t believe she could handle this.

Re-Evaluating

It was time to go back to the drawing board. What was it Lauren wanted to do? She actually had a dream! She wanted to be a cashier in a clothing store! Well, there’s no food there, is there? She was certainly capable of running a cash register. But, would anyone give her the chance to handle money. Turns out they won’t. I can’t blame them for their concerns. If only they knew how savvy she was on the internet and how talented she was at math... OK... think some more...

What about checking out books at the library? That’s sort of like a cash register, right? Months later, we were forced to accept that jobs at the library were hard to get. Not to mention the fact that you had to pass a test to prove you could arrange books via the Dewey Decimal System to even get in. Most of the paying jobs went to retired persons or apprenticeships. The volunteer jobs were very few and filled long before they would consider a person like... Lauren.

This was the hardest hurdle of all. How could I break it to Lauren that her dream was beyond reach? Her dream remains the same to this day! At 33 years old, Lauren’s dream is still to run a cash register.

The Search Continues

So, what kind of employers would hire a person with developmental delays? Wait a minute... why does it have to be a paying job? Especially since Lauren was receiving SSI (at the time) and living at home. Ahhh Hahh! A whole new thought process began. Let’s look into volunteering! The first opportunity came through the school system at a local business called Angel Flight. They agreed to give her a chance to help out while being supervised by a ParaPro from school. At the time this opportunity arrived, Lauren was in 11th grade. She still had four more

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years of school, until age 22. It was a wonderful arrangement! She loved it and they loved her. Finally, we had some success. She worked there for almost four years, until we learned that the program was for individuals still in school, **only in school**. After graduation she would have to leave. Woe is me... back to square one.

Progress

Then, Eureka! A new idea! Lauren's best friend (also DD) was working at a local Children's Hospital in the Volunteer Department. After contacting the manager and conferring with the school, it looked like the only problem was transportation. OK, I could live with that! Between family and friends and blessings from above, we could manage the transportation. We were promised that she would have an escort to make sure there were no detours to the cafeteria. And so... it began. Year one, total bliss... Everything was working. She was being escorted to and from lunch to minimize the access to food. The tasks she was doing seemed to satisfy her: she was pushing the media cart from room to room; delivering mail and flowers; and several other tasks. In year two, things changed a bit. Things got a little lax about the cafeteria. I noticed that several rolls of quarters were missing from home, even though well hidden. Obviously the vending machines were too much of a challenge. Time to make a change....

We stayed at the same location but refocused to a different job. There was a new program using workers with developmental disabilities to prepare surgical packages for the Emergency Room and Operating Rooms. (I was assured that our participation would not jeopardize a patient's well-being.) This repetitive, important task was received enthusiastically. The tasks were accomplished in a "clean room" meaning she got to wear "hospital clothes" and she felt very important. The group was isolated together with their support staff and brought their own lunches.

Of course, none of this would have been possible if not for the caring oversight of the Volunteer Services Manager at the hospital. She truly cared that Lauren succeeded in developing some autonomy and self-esteem. But then, nothing stays the same forever.

In year three, we were blessed with a new opportunity to move to another city. The area we were moving to was not in a major city and we weren't sure about what opportunities would be there for Lauren, but we had to go. They threw a big "going away" party for Lauren at the hospital and away we went.

In our new location, we were unable to find employment for Lauren and decided to try a residential placement for her. After 3 different living situations, we accepted that this wasn't the right time for residential service. But that's another article.

Our only other option was to utilize a new program in our state called "participant directed services". Without going into too much detail, this allowed us to hire staff for Lauren and direct all her service activities, ourselves, by directing the funds for her waiver. It took a year to put in place but today she is very happy.

Her caregiver has been with her for four years now and has become a part of our family. We still haven't found a paying job for Lauren, but her volunteer/supported employment activities are better than ever. She goes someplace different every day dividing her time between working at the County Humane Service Thrift Store and another non-profit thrift store in our town. These placements have been particularly effective because of the laid back atmosphere! There is very little pressure and lots of staff working together toward common goals. One of these thrift stores actually has a grant to do work for UPS and Merck Labs to process piece work, one day a week. She loves it and is usually the top producer at the task. Her caregiver goes with her everywhere, constantly monitoring the environment for emotional barriers and to make sure there is food security. Some of her other activities include a personal trainer at the gym who works with her three days a week and Equine therapy once a week.

This is working for us now. But, someday, when we aren't here anymore... but that's another article too!

Residential Living Options/Considerations and Services

DO PARENTS/GUARDIANS HAVE TO PLACE THEIR SON/DAUGHTER IN A SUPPORTED LIVING SITUATION?

No, no one is forced to place their son/daughter in a supported living arrangement outside of their family home. This is a personal decision made by a family. Most parents however find the constant need for structure and food security 24/7 to become more challenging as they age. They also realize that they will not live forever and want peace of mind knowing their son/daughter is being cared for by caring, knowledgeable staff. Also, the adult with PWS often wants to live as others his/her own age. He/she wants to go to work, be involved in the community, and engage in social activities in the least restrictive environment possible.

WHAT TYPES OF SERVICES OR HELP CAN PARENTS/GUARDIANS RECEIVE FOR THEIR SON/DAUGHTER WHILE THEY LIVE IN THEIR HOME?

Adults who live in their parents' home can receive other support services. Most qualify for transportation services as well as vocational (job) support. These services are covered by the person's school district until the time of graduation. Depending on the individual's abilities and needs, some may qualify for personal care assistance. Many parents/guardians may also be able to receive respite services. Exact services and the requirements to receive services will vary by community and state.

HOW DO PARENTS/GUARDIANS LEARN WHAT SERVICES ARE AVAILABLE IN THEIR COMMUNITY AND HOW CAN THEIR SON/DAUGHTER ACCESS THEM?

Exactly what services are available and how to access them is going to vary from state to state and possibly from each county, region or parish. Many families may be connected to services when their child is younger. However, if this is not the case, this can and should be done as part of the transition planning.

The student's special education case manager/teacher is a very good resource person in connecting parents to services within their community. Parents can also contact their **local or state human service agency** while their son/daughter is in their early teens. Many states have different names for the human service agency that helps the disabled. It is never too late to inquire and/or investigate services.

To locate the name and contact information for the Department of Human Services in your state –
Go to: <http://www.medicare.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/community-living/downloads/state-by-state-poc-list.pdf>

SUGGESTED INFORMATION TO OBTAIN FROM EDUCATIONAL STAFF AS PART OF THE TRANSITION IEP INCLUDE THE FOLLOWING AREAS:

- Contact information for human service agency in their community
- Contact information to learn more about accessing residential services in their community
- Contact information to learn more about transportation services in their community
- Contact information about other services available for disabled teens/adults in their community – respite, case management ...

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WHAT ARE THE DIFFERENT SUPPORTED LIVING MODELS?

The following chart was taken (and edited) from “*Management of Prader-Willi Syndrome*”, 3rd Edition, by Merlin Butler, MD, Phillip Lee, MD and Barbara Whitman, PhD, 2006 p. 360

Living Options from Most Restrictive to Least Restrictive Environments

| Term | Description | Comments |
|---|---|---|
| State Hospitals or Developmental Centers | Serve individuals who need 24-hour supervision in a structured health facility where they receive programming, training, care and treatment on site. | Today, the adult with PWS is rarely residing in these locations unless he/she is temporarily placed there until a less restrictive placement is secured or as a temporary measure if he/she has exhibited extreme challenging behaviors and safety is a concern. |
| Intermediate Care Facilities (ICF) <i>(for the Mentally Retarded-ICFMR)</i> | Offer 24-hour service to 4 to 16 individuals with disabilities. These facilities serve individuals with developmental disabilities who have a primary need for developmental services as well as some needs for skilled nursing services. | We are starting to see a few more older adults with PWS residing in these facilities when they are requiring skilled nursing care. |
| Group Homes or Community Care Facilities (CCF) | Offer 24-hour non-medical residential care to individuals with developmental disabilities who may need personal services, supervision, and/or assistance crucial for self-protection or sustaining the activities of daily living. These residential models are popular because of their integration into the community. | Group homes are one of the most popular models used in supporting the adult with PWS. Sizes vary – some have 3-4 adults while others may be as large as 12-15. Some only support persons with PWS; while others may be “mixed” and support adults with other disabilities. Parents/guardians should validate that food security is in place and maintained as well as confirm that staff is educated on the behavioral and health needs of adults with PWS. |
| Supported Living | The individual with the disability has support systems, typically nondisabled roommates who are trained to help or outside agencies that teach independent living skills. In most situations the person is monitored and supervised because he/she may not yet have mastered basic financial, shopping and self-care skills. They learn to manage these duties while living either alone or with roommates in apartments or condominiums. | Supported living homes are another popular service delivery model. You may see 2-4 persons with disabilities living together in an apartment or other living environment. These tend to be most successful if all roommates have PWS and/or require food security. Parents/guardians must make sure food security is in place and maintained as well as confirm that staff is educated on the behavioral and health needs of adults with PWS. |
| Independent Living | The individual with the disability may choose to live alone in a home that they own or lease in the community. They may have hired staff that aid in some daily living activities but they do not need supervised care and training in basic life skills. | This model is rarely used in supporting the adult with PWS. In situations where it has been tried, it often results in extraordinary weight gain and the demonstration of other unsafe behaviors/situations. |

HOW DO PARENTS/GUARDIANS LEARN WHICH RESIDENTIAL PROVIDERS HAVE KNOWLEDGE AND EXPERIENCE IN CARING FOR ADULTS WITH PWS IN THEIR STATE OR AREA?

It is best to start locating the names of residential agencies who have experience in working with adults with PWS by contacting your state chapter. Because leadership in many chapters changes often, it is best to go to the PWSA (USA) website to obtain the most recent contact information. Some states are fortunate to have paid staff that can provide this information. If there is not a state or local chapter in the area, it will be more challenging to find a residential agency that has the knowledge and understanding to support a person with PWS. If a parent/guardian does not have access to the Internet or if assistance is needed to locate a residential agency, they should contact the staff at PWSA (USA) and they will do their best to provide this information, if available.

PWSA (USA) Chapter Contact Information:

Website <http://pwsausa.org/find-a-chapter/>

Toll Free Phone Number: 1-800-926-4797 (9:00 am – 5:00 pm eastern standard time)

WHAT CAN A PARENT/GUARDIAN DO IF THERE ARE NO RESIDENTIAL OPTIONS IN THEIR STATE?

If there are no residential options in a state, parents/guardians will basically have two options.

#1 Advocate for the Development of Supported Living within their State:

Parents/guardians can also help to educate and advocate for the development of a home in their state or local vicinity for their son/daughter. It is often more successful if parents within a state or area unite and “pool their efforts” to do this.

#2 Investigate Options Outside of their State:

Some human service agencies may be willing to look at options outside of their state. Most agencies however, do not like to fund residential care across state lines. Parents/guardians should expect that this process of investigating, advocating and educating for the specialized needs and care for their son/daughter with PWS will take hard work and often times a great deal of time. Looking at services that are not in close proximity can be a hard decision for parents to make. It may be reassuring to know that there are many adults with PWS who reside outside of their home state in order to get the specialized care and services they need to help them live safely with their disability.

CAN PWSA (USA) HELP IN EDUCATING AND ADVOCATING FOR SPECIALIZED RESIDENTIAL SERVICES?

PWSA (USA) can help by providing information as well as consultation services to providers to help them gain an understanding of the special needs and issues that are needed for a successful and safe living environment for a person with PWS. The staff at PWSA (USA) can also share contact information of other residential providers who successfully support adults with PWS. PWSA (USA) hosts an annual meeting and conference for residential providers that can assist in this process as well. There are many more resources and educational materials to help a residential provider gain this knowledge and understanding.

WHAT CAN A PARENT/GUARDIAN DO IF THEY ARE TOLD THEY HAVE TO WAIT FOR SERVICES?

Unfortunately, frequently there are long waiting lists for services for adults with disabilities. In some states, this wait is several years. Some human service agencies have made a funding priority to providing services for young adults during the daytime when they leave high school. However, this is not the case in all localities. It is advisable for the parent/guardian to write letters, make phone calls, get placed on waiting lists and maintain a constant voice in advocating for necessary services. Get and stay connected with a human service agency and/or case manager in the young adult’s area.

(NOTE: It is strongly advised that parents/guardians research what services their son/daughter will receive before agreeing to have their son/daughter graduate prior to the age of 21 years (or older depending on the state).

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Once the student with a disability receives a diploma, a school district no longer has any obligation to provide services. The longer the student with PWS can gain support, education, training and preparation from their local school system, the better. Unfortunately, we often see young people with PWS graduate early and then have no vocational or other daytime services resulting in added stress for the parent/guardian.)

WHO PAYS FOR RESIDENTIAL LIVING SERVICES?

Who or how services get paid for will once again vary within each state and/or locality. Most services are paid for by a variety of resources – local, state and federal. People with PWS will need to meet eligibility requirements and prove that they qualify for services. Typically this is easily proved by reports from schools, physicians as well as other professionals in their lives. Planning and assistance for arranging some of these services often begins in the final years of high school. The young adult with PWS will also need to use his/her Supplemental Security Income checks to help pay for their support services. However, the amount the person receives monthly does not even pay for 1 week of care.

WHAT SHOULD PARENTS/GUARDIANS DO TO PREPARE THEIR SON/DAUGHTER TO ULTIMATELY LIVE IN A SUPPORTED LIVING HOME?

Every young adult is an individual with different strengths and needs. The goal of every parent/guardian however is to teach this individual to be as independent as possible in their personal care and daily living tasks. The more the young adult with PWS can do for themselves, the less dependent they will be on others for their basic needs. In general, most young adults should be assisted in learning how to shower and do their daily hygiene skills as independently as possible. Teaching these skills and developing routines can assist in helping them to become healthy, happy adults. Many adults with PWS require reminders and oversight to assure that they are performing these skills in a quality manner. Parents/guardians should include instruction in these areas as part of the transition IEP as well as reinforce these skills at home. (SEE Education Section: Daily Living Activities – Skill Development for further information)

IF MY SON/DAUGHTER MOVES IN TO A SUPPORTED LIVING HOME, CAN HE/SHE COME HOME AND VISIT?

In many states, the young adult with PWS can have unlimited overnight visits with their parents or family members without penalty to the residential provider. We are not aware of any limitations on day visits with parents, family members or friends.

In some states however there may be a limit on the number of days the person receiving residential services can be away from their placement overnight. If a person is gone more nights than allowed, the residential provider may not receive payment. It is important to know if this is a restriction and work with the residential provider in order to avoid financial penalties.

WHAT ITEMS DOES THE PERSON WITH PWS NEED TO PROVIDE WHEN HE/SHE MOVES IN TO A SUPPORTED LIVING HOME?

What items a person with PWS needs to provide when he/she moves in to their own home will vary depending upon the provider and the individual situation. In some cases, families are asked to contribute more items to a home including furniture for various areas of the home. In other cases, families may not need to provide much furniture at all. In all cases, the person with PWS will be expected to bring their personal clothes, linens and other items that will help to personalize their room and make this new house their home.

WHO PROVIDES AND SUPERVISES THEIR MEDICAL CARE?

In most cases, a staff person will be responsible in making sure the adult with PWS receives the proper medical and dental care. If the person with PWS has an established health care provider or dentist in the area, this relationship should continue. If this individual has moved to a new community, the staff will help to locate a

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health care professional in the area. It is very important to make sure that staffs have been educated on the unique health issues that persons with PWS can face.

WHAT HAPPENS IN CASES WHERE THE PERSON WITH PWS MOVES OUT OF STATE – WILL THEY BE ABLE TO RECEIVE MEDICAL/DENTAL CARE?

Sometimes when the adult with PWS moves into a home outside of their home state, the residential provider must find a health care provider who is willing to take this person's health insurance. Depending on the situation, this may not be a problem or it could be very challenging. Parents/guardians should learn what medical and dental services are available in this new community – especially for emergency situations.

In some situations, parents/guardians may be asked to secure dental checkups and/or annual health maintenance visits in their home state if their insurance will only cover emergency care out of state.

WHAT CAN THE PARENT/GUARDIAN DO TO SUPPORT THE STAFF WHO ARE PROVIDING CARE TO THEIR SON/DAUGHTER?

It is important for parents/guardians to provide support and create a positive working relationship with the direct caregivers. Communication is important but we must also be respectful of their time. It may be difficult to talk or communicate immediately with a parent/guardian. Their primary focus may be to make sure the needs and routines of residents of the home are being met and they may need to call you back at a later time.

Don't assume the person with PWS is right or correct when he/she shares a concern. Oftentimes, he/she may perceive a situation to be one way when in fact it is very different. Frequently, the young adult with PWS may attempt to put the parent/guardian in a situation against the staff. It is always best to discuss any areas of concern or controversy with the staff in a private meeting or call.

HOW DOES THE ROLE OF THE PARENT/GUARDIAN CHANGE ONCE THEIR SON/DAUGHTER MOVES IN A SUPPORTED LIVING HOME?

The role of parent/guardian changes once their son/daughter lives in supported care. It can be a very big adjustment not only for the person with PWS but also for the parent/guardian. For years, the parent/guardian has had to directly supervise, advocate and educate almost all aspects of their loved one's lives. Now, it will be time to take a step back. The person with PWS will also need to learn to trust new people in his/her life. This too is often a challenging process. Change for both parties is hard and requires patience and understanding. There will be situations that may get handled differently than when the person with PWS lived at home. It is often common that the person with PWS may communicate their frustration with a change and want the parent/guardian to correct things. It is important for the parent/guardian to listen, but realize that the situation may be very different from what their son/daughter is sharing. The parent/guardian should support staff but at the same time support their son/daughter. This is often a very challenging position..

No staff or other professional is going to know your son/daughter like the parent. It is unrealistic to think this will be the case. The parent/guardian needs to support staff, keep them informed, and help all parties to learn. Each parent/guardian needs to choose their level of involvement. Some will be more involved than others. Residential providers need to help and support the parent/guardian as well. Both sides need to be respectful and courteous and make sure time in both their new home and the parent home is a safe, positive experience. Parents/guardians should always feel they can share, advocate and inform – especially in areas that involve health and safety.

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The following is a chart taken from the resource “Finding Common Ground” created by parents and providers from Developmental Disability Services in Dane County, WI 2004.

Finding Common Ground

| PARENT | PROVIDER |
|---|--|
| Respect our role in the person’s life | |
| We love them. We know what we are doing. <ul style="list-style-type: none"> • Advocacy • Family Culture | We’re professionals. We know what we are doing. <ul style="list-style-type: none"> • Advocacy • Agency Culture |
| We know them. <ul style="list-style-type: none"> • Knowledge of what has worked. • Likes and dislikes. | We’re trained to work with them. <ul style="list-style-type: none"> • Knowledge of what works with others. • We learn about people. |
| Defining the family or guardian role | |
| We’ve felt misled by providers in the past. <ul style="list-style-type: none"> • Keep us informed. | We need as much information as possible. <ul style="list-style-type: none"> • Keep us informed. |
| We may be resistant to change. <ul style="list-style-type: none"> • Expectations • Parenthood | We may want to change the way things were done in the past. <ul style="list-style-type: none"> • Expectations • Adulthood |
| It hurts to hear your child’s home called a program. <ul style="list-style-type: none"> • Keeping a house a home. • We want to feel confident in staff. | We work within a system. <ul style="list-style-type: none"> • Ensuring a house meets all the regulations. • We work hard to have skilled staff. |
| We want to choose our level of involvement. <ul style="list-style-type: none"> • We need knowledge and help in defining our role. • We want to feel useful. | We may have preconceived ideas about parental involvement. <ul style="list-style-type: none"> • We need your help in defining your role. • We want you to be useful. |
| Wanting what is best | |
| We want what is best for our sons and daughters. <ul style="list-style-type: none"> • We want to know what works. | We want what is best for the people we support. <ul style="list-style-type: none"> • We want to know what works. |

SERVICES A PERSON WITH PWS MAY BE ELIGIBLE TO RECEIVE

The following is a list of four service programs and resources that persons with PWS may be eligible to receive. In some cases, the person with PWS may need to meet eligibility requirements including personal financial resources.

- 1. State Agency for Persons with Developmental Disability** - Each state has an agency for people with developmental disabilities. It may be titled; Agency for Persons with Disabilities, Department of Social Services, Developmental Disabilities Services, etc. Their mission is to promote opportunities for persons with developmental disabilities to be a part of and participate in the same valued experiences and life events as do other citizens.

Some of the initiatives of the DD Programs includes:

- Support to families, such as respite care
- Provide a case manager
- Coordination with special education and local education agencies
- Community based opportunities to allow people with disabilities to participate in programs, supports, and services that make it easier for people to live, work, and play in their communities

- 2. SSI-Supplemental Security Income** - (Not Social Security) SSI pays monthly benefits to people who have a disability, are blind, and who do not have much income. Monthly benefits can be accessed by both adults and children who qualify. In qualifying for SSI, the Social Security Administration looks at how the disability affects everyday life. The federal definition of disability states:

Definition of Disability: Federal laws define a person with a disability as ***"Any person who has a physical or mental impairment that substantially limits one or more major life activities; has a record of such impairment; or is regarded as having such an impairment."***

People who qualify for SSI can also qualify for food stamps and Medicaid. Eligibility is based on earnings and resources of the adult (18 years or more) or based on the earnings and resources of the parents of children under 18 years of age. The states vocational rehabilitation agency may contact you and offer vocational rehabilitation services so that the individual can work. If you refuse to accept these services, your SSI benefits can be stopped. For more information about SSI call 1-800-772-1213 or visit their website at: <http://www.ssa.gov/notices/supplemental-security-income/>

- 3. SSI-E-(Supplemental Security Income – Exceptional Expense Supplement)** Some states supplement the Federal SSI benefit with additional payments. This makes the total SSI benefit levels higher in those states. SSI benefit amounts and State supplemental payment amounts vary based upon your income, living arrangements, and other factors. Supplemental Security Income Exceptional Expense Supplement is an extra sum of money provided to individuals or couples who already receive the state supplement, or SSI benefits, and who have exceptional medical expenses or care needs.

To be eligible for SSI-E an individual must be currently receiving SSI, living in a residential setting, and need at least 40 hours per month of primary long-term support services. This benefit is often missed because people often believe that the term “long-term support services” only includes services such as assistance in bathing, dressing and grooming; finances and bill paying; on-site supervision for persons with dementia and severe physical limitations; toileting; assistance personal mobility with transferring from bed or wheelchair, positioning in bed to prevent bed sores and feeding. All of these Supportive Home Care needs certainly can make one eligible for SSI-E. But these aren't the only criteria. For information about your state and if SSI_E is available go to: www.socialsecurity.gov/policy/docs/statcomps/ssi_sc

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- 4. Medicaid- A Federal/State program.** This program is designed to provide medical assistance to persons with low income that qualify and cannot obtain medical coverage. Person who receive SSI from the Social Security Administration are automatically eligible to receive Medicaid in most states. More information can be found at: <http://www.cms.gov/>
- 5. Developmental Disabilities Medicaid Waivers** - A waiver is a vehicle that states can use to test new or existing ways to deliver and pay for health care service from Medicaid and the Children's Health Insurance Program (CHIP).

- 1915(b) Waivers are one of several options available to states that allow the use of Managed Care in the Medicaid Program. When using 1915(b), states have four different options:
- **[1915(b)(1)]** - Implement a managed care delivery system that restricts the types of providers that people can use to get Medicaid benefits
- **[1915(b)(2)]** - Allow a county or local government to act as a choice counselor or enrollment broker in order to help people pick a managed care plan
- **[1915(b)(3)]** - Use the savings that the state gets from a managed care delivery system to provide additional services
- **[1915(b)(4)]** - Restrict the number or type of providers who can provide specific Medicaid services (such as disease management or transportation)

Center for Medicaid/Medicare Services (CMS) has begun the process of "modularizing" its current 1915(b) waiver application to separate the various statutory authorities. First in this process is a streamlined application for states to selectively contract with providers under their fee-for-service delivery system. It simplifies the process for documenting the cost-effectiveness of the waiver but requires that states demonstrate maintenance of beneficiary access.

- The 1915(c) waivers are one of many options available to states to allow the provision of long term care services in home and community based settings under the Medicaid Program. States can offer a variety of services under an HCBS Waiver program. Programs can provide a combination of standard medical services and non-medical services. Standard services include but are not limited to: case management (i.e. supports and service coordination), homemaker, home health aide, personal care, adult day health services, habilitation (both day and residential), and respite care. States can also propose "other" types of services that may assist in diverting and/or transitioning individuals from institutional settings into their homes and community.
- Concurrent Section 1915(b) & 1915(c) Waivers - States can apply to simultaneously implement two types of waivers to provide a continuum of services to the elderly and people with disabilities, as long as all federal requirements for both programs are met.
- Section 1115 Research & Demonstration Project - States can apply for program flexibility to test new or existing approaches to financing and delivering Medicaid and CHIP.

WHAT TO LOOK FOR IN RESEARCHING RESIDENTIAL CARE FOR THE ADULT WITH PWS

(Adapted from an article by Mildred Lacy – “A Parent’s Guide to Alternative Living Arrangements”)

It is very challenging to find a residential provider who has the knowledge, experience and personal commitment to provide specialized services for the adult with PWS. There is no “perfect” residential provider. However, there are several who have the knowledge and commitment in learning and providing services to these individuals. The following is a very comprehensive list of questions and things you may want to investigate and consider as you meet and talk with providers. Set priorities and trust your instincts.

WHAT TO LOOK FOR IN THE ADMINISTRATION OF A FACILITY

1. Is the home managed by a non-profit agency or a private (for-profit) organization?
 - a. *“Managed” means hiring, training and scheduling staff and bookkeeping.*
 - b. *In some states, low income persons and/or the disabled may qualify for tax refund/credit if they are paying rent to a private (for-profit) organization or landlord.*
 - c. *Some parents may also purchase a home and hire an agency to manage staff to care for the residents.*
2. How much experience do they have in operating/managing supported care homes?
 - a. *You are seeking an agency that has managed group homes or other supported living residences for the developmentally disabled in general but specifically – if possible – has experience with homes for adults with Prader-Willi syndrome.*
3. Is this home licensed according to state regulations?
 - a. *Some states require certificates of need, health department, human resources, fire department and/or state licensing.*
 - b. *Not all supported living environments require licensing. It varies from state to state and by the number of individuals residing in a home. Many homes with less than 4 individuals may not require any special licensing.*
4. How often is the home inspected and by whom?
 - a. *Inspections are typically conducted annually by a state or local agency. Inspection certificates are to be posted. Inspections will be influenced by licensing requirements.*
 - b. *If a home is unlicensed, does the agency administration conduct inspections and at what frequency?*
5. Is this home well cared for?
 - a. *Look for a clean, organized, danger-free home with nothing in the common area that clients may harm themselves or anyone else by throwing or breaking such as pictures with glass.*
 - b. *For parents who are hiring an agency to staff a home, it is recommended that expectations are clearly communicated and outlined. It should be clear as to who will be responsible for home maintenance such as cleaning, lawn care, snow removal (if needed etc.). It is also recommended that all expectations are put in writing, dated and signed.*
6. What is the admission and release policy?
 - a. *Most agencies require a very thorough admission intake and sharing of information about the resident, including medical and psychiatric records, prior to admission.*
 - b. *Be honest. If it is an agency who is experienced in working with individuals with PWS (as well as other developmentally disabled adults who have challenging behaviors), they should be prepared to assist the resident with most (if not all) challenging behaviors.*
7. Do they provide services 24/7 for 365 days a year?
8. How many residents reside in the home being considered for the person with PWS?
 - a. *Do all residents have PWS?*
 - b. *If not, how is food security and resident rights addressed?*

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- c. *Social activities, camp*
 - d. *Co-pays on health related services*
20. How are residents' money handled?
- a. *Do residents have a bank account?*
 - b. *Are accurate records of the residents' financial transactions maintained?*
 - c. *Is there oversight of a resident's financial transactions by more than one individual?*

MEDICAL, DENTAL, PSYCHIATRIC CARE AND OTHER HEALTH/WELLNESS SERVICES

21. Who is responsible for routine and/or emergency health care?
- a. *Is there a plan for medical emergencies?*
 - b. *If an emergency occurs, what is the channel of communication for informing all parties?*
 - c. *Are parents/guardians informed and updated on the outcomes of all medical and dental appointments?*
 - d. *If desired, is it possible for the parent/guardian to be responsible for all routine medical/dental appointments?*
22. What health insurance is accepted?
- a. *If the resident is covered under their parent's private insurance, do health care professionals in the area accept it?*
 - i. *It is recommended that parents/guardians research and confirm this.*
 - b. *Will local physicians, dentists and other health care providers accept the health insurance coverage the resident has? (Medicaid, Medicare, other)*
 - i. *If crossing state lines, it is extra important to make sure health insurance will be maintained.*
 - ii. *In some cases, residents may be asked to have annual and/or routine health checkups and dental care done in their home communities.*
23. Do they utilize physicians, dentists and other health care professionals in the area who are knowledgeable of PWS and its unique health issues?
24. Are all staff trained and informed of the health care needs of persons with PWS?
- a. *Who is responsible for making all medical/dental appointments?*
 - b. *How are health care findings and recommendations communicated to staff?*
 - c. *Are parents/guardians informed of health care needs?*
25. What supports are in place and who cares for the resident if he/she is ill and unable to attend work/day program?
26. Who is responsible for medication administration?
- a. *Does staff receive training in medication administration?*
 - b. *Are all medications stored in a locked area that is inaccessible to other residents?*
 - c. *What recordkeeping is done?*
 - d. *Do all medications – even over-the-counter medications – require a health care provider's order?*
 - i. *It is important that staff cannot purchase over-the-counter medications and/or herbal products without authority of a resident's health care provider.*
 - e. *Can staff administer injections? (Insulin, Growth Hormone)*
 - f. *How are medication errors handled?*
 - i. *Who is informed?*
 - ii. *What steps are taken to prevent future errors?*
27. Do residents practice fire and/or tornado emergency drills?
28. What types of exercise activities are offered and available to residents?
- a. *Is exercise a daily part of their routine?*

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- b. Are there any behavior motivation programs associated with this activity?*
- 29. Who is responsible for menu planning and dietary oversight?
 - a. Does staff receive training on nutrition and a calorie-controlled diet?*
 - b. Are menus reviewed by a dietician?*
 - c. Who determines if a calorie adjustment must be made?*
 - d. How is food planning for outings managed?*
 - e. Are menus planned for and posted in advance?*
 - i. Not all programs post menus. Some believe this can add to anxiety.*
- 30. What measures are in place for food security and weight management?
 - a. Locks, alarms, pre-event/outing planning?*
 - b. How often is a resident weighed?*
 - c. Who determines goal weight and range?*
 - d. What structure is in place for the timing and scheduling of meals and snacks?*
 - i. How often are residents receiving food and beverages?*
 - ii. Are there any special practices in place for meals and snacks?*
 - iii. Does a resident have input into the selection of any food items?*
 - 1. Some programs allow residents to pick out a certain number of food items (fruits, vegetables...) that staff will incorporate into their menu.*
 - 2. Can a resident have input/choice into special meals at special events (birthdays or holidays)?*

BEHAVIOR MANAGEMENT AND ENVIRONMENTAL CONSIDERATIONS

- 31. What programs and support plans are in place to help prevent and manage behavior challenges for residents?
 - a. Is staff trained to utilize measures to teach, model and encourage appropriate behavior?*
 - b. What is done if a resident demonstrates unsafe behavior resulting in property destruction or physical assault on staff or others?*
 - c. What is done to manage stealing?*
 - i. Do residents have their own room?*
 - ii. Is a search ever performed on the resident or his/her belongings?*
 - d. Are measures in place for a resident who likes to elope?*
 - i. Alarms, increased supervision*
- 32. What strategies are used to help prevent and/or manage a resident with severe skin picking behaviors?
 - a. What if a person needs supervision while doing personal cares and/or showering? Can staff provide this oversight?*
- 33. Are residents allowed to smoke?
 - a. Are there certain rules and/or areas for the resident to follow regarding smoking?*

PROGRAMMING, RECREATION, SOCIALIZATION, AND PERSONAL CARE

- 34. What programs and/or employment opportunities are available for the residents during the daytime hours?
 - a. Is there structure and routine in their day?*
 - b. Who provides these services and what is their experience in working with adults with PWS?*
 - c. How does the resident travel to their workplace or day programming site?*
- 35. Can a resident have access to a phone?
 - a. Are there any restrictions or rules associated with this?*
- 36. Can a resident have access to a computer/Internet?
 - a. Are there any restrictions or oversight provided?*
- 37. What sorts of activities do residents have the opportunity to attend and/or participate in?

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- a. *How are they transported to these opportunities or events?*
 - b. *Do residents spend most of their time in their room or in a common area?*
 - i. *It is important that a resident does not isolate themselves in their room. This often leads to increased problems with skin picking and other social behavior concerns.*
38. Do the residents appear happy?
39. What social skills training and opportunities are available?
- a. *Can a resident invite a friend to visit? Are there any guidelines for this?*
 - b. *What about dating? Is this allowed and under what circumstances?*
 - c. *Can a parent/guardian call and/or visit freely?*
40. Who schedules and arranges for haircuts?
41. Who assists the resident with nail care?
42. What items is the resident responsible for providing in their home?
- a. *Furniture – bed, dresser, other?*
 - b. *Linens, pillows, window coverings?*
 - c. *Clothing*
 - d. *Other items to personalize his/her room*
43. Do residents receive assistance and support for housekeeping and laundry responsibilities?
- a. *Are residents expected to assist in the care and cleaning of their home?*
 - i. *How is this structured and supported?*
 - b. *Are residents assigned a certain day of the week to do their laundry?*
 - c. *How are situations handled when there needs to be a change?*
 - d. *How does staff address hoarding?*
 - e. *Is there any scheduled replacement or evaluation of items that may experience wear and tear (pillows, blankets, window coverings...)?*
 - i. *If yes, who is responsible?*

OTHER QUESTIONS AND/OR NOTES:

CHECKLIST

WHAT TO LOOK FOR IN RESEARCHING RESIDENTIAL CARE FOR THE ADULT WITH PWS

(Adapted from an article by Mildred Lacy – “A Parent’s Guide to Alternative Living Arrangements”)

The following is a checklist that accompanies the handout “*What to Look for In Researching Residential Care for the Adult with PWS*”. It has been designed to assist you as you research residential programs. There is no perfect program. However, there are several who have the knowledge and commitment in learning and providing services to these individuals. Set priorities and trust your instincts.

Name of Agency: _____

Contact Person: _____

| WHAT TO LOOK FOR IN THE ADMINISTRATION OF A FACILITY | Yes | No | Notes |
|---|------------|-----------|--------------|
| 44. Is the home managed by a non-profit agency or a private (for-profit) organization? | | | |
| 45. How much experience have they had operating/managing residences? | | | |
| 46. Is this home licensed according to your state regulations? | | | |
| 47. How often is the home inspected and by whom? | | | |
| 48. Is this home a well-cared-for home? | | | |
| 49. What is the admission and release policy? | | | |
| 50. Do they provide services 24/7 for 365 days a year? | | | |
| 51. How many residents reside in the home being considered for the person with PWS? | | | |
| <ul style="list-style-type: none"> • <i>Do all residents have PWS?</i> • <i>If not, how is food security and resident rights addressed? (If it is proposed that food security not be maintained because of “resident rights,” it will not be a good match for the person with PWS.)</i> | | | |
| 52. How are resident grievances handled? | | | |
| <ul style="list-style-type: none"> • <i>Do residents have a “Bill of Rights”?</i> • <i>Are rules and regulations of the residence posted for residents to see?</i> | | | |
| 53. Do they have a team of professionals that meet to evaluate the needs of the resident and review (and revise) his/her plan of care? | | | |
| <ul style="list-style-type: none"> • <i>Who is on this team?</i> • <i>Is the resident included in any of these meetings?</i> • <i>Is the parent/guardian included in any of these meetings?</i> <ul style="list-style-type: none"> ○ <i>If the parent is unable to physically attend, can they be included via phone or other means (Skype, FaceTime ...)?</i> • <i>How involved are parents/guardians in the team? (How involved do you want to be?)</i> • <i>How often are resident goals established, evaluated and reviewed?</i> | | | |

Transition Planning and Resources for Parents/Guardians of Young Adults with Prader-Willi Syndrome

| STAFF | Yes | No | Notes |
|--|------------|-----------|--------------|
| 54. Do direct care staff receive training about the needs and issues of persons with PWS? | | | |
| 55. Do direct care staff engage with the residents? (Best if you can tour when residents are present). | | | |
| 56. Do staff appear happy? | | | |
| 57. Do direct care staff have a supervisor or other staff person who assists with education, problem solving and listening to their concerns? | | | |
| 58. Do direct care staff eat with the residents? | | | |
| <ul style="list-style-type: none"> • <i>What is the policy for staff eating/drinking in front of the residents?</i> • <i>Is staff allowed to have personal food while working with residents?</i> | | | |
| FINANCIAL AND FUNDING CONSIDERATIONS | Yes | No | Notes |
| 59. How is the home funded? | | | |
| <ul style="list-style-type: none"> • <i>What is the daily rate (also known as a per diem rate)?</i> • <i>How much is expected to be paid by the resident/resident payee?</i> | | | |
| <ul style="list-style-type: none"> • <i>Will the resident be expected to contribute his/her SSI/SSD payments?</i> • <i>If the resident is able to work in a well-paying job – what percent will be used to pay for his/her living expenses? (NOTE: A resident’s SSI/SSD payment will be lower if they earn more money in a paid job.)</i> | | | |
| 60. What other income sources can be used to help to pay? | | | |
| 61. Can the resident go on home visits or be absent from their home without limitation and penalization of funding? | | | |
| 62. What other expenses are parents/guardians responsible for? (<i>Transportation to/from home or other visits, clothing, social activities, camp, co-pays on health related services</i>) | | | |
| 63. How are residents’ money handled? | | | |
| <ul style="list-style-type: none"> • <i>Do residents have a bank account?</i> • <i>Are accurate records of the residents’ financial transactions maintained?</i> • <i>Is there oversight of a resident’s financial transactions by more than one individual?</i> | | | |
| MEDICAL, DENTAL, PSYCHIATRIC CARE AND OTHER HEALTH/WELLNESS SERVICES | Yes | No | Notes |
| 64. Who is responsible for routine and/or emergency health care? | | | |
| <ul style="list-style-type: none"> • <i>Is there a plan for medical emergencies?</i> • <i>If an emergency occurs, what is the channel of communication for informing all parties?</i> • <i>Are parents/guardians informed and updated on the outcomes of all medical and dental appointments?</i> • <i>If desired, is it possible for the parent/guardian to be responsible for all routine medical/dental appointments?</i> | | | |

Transition Planning and Resources for Parents/Guardians of Young Adults with Prader-Willi Syndrome

| MEDICAL, DENTAL, PSYCHIATRIC CARE AND OTHER HEALTH/WELLNESS SERVICES (cont.) | Yes | No | Notes |
|--|------------|-----------|--------------|
| 65. What health insurance is accepted? | | | |
| 66. Do they utilize physicians, dentists and other health care professionals in the area who are knowledgeable of PWS and its unique health issues? | | | |
| 67. Are all staff trained and informed of the health care needs of persons with PWS? | | | |
| 68. What supports are in place and who cares for the resident if he/she is ill and unable to attend work/day program? | | | |
| 69. Who is responsible for medication administration? | | | |
| <ul style="list-style-type: none"> • <i>Does staff receive training in medication administration?</i> • <i>Are all medications stored in a locked area that is inaccessible to other residents?</i> • <i>What recordkeeping is done?</i> • <i>Do all medications – even over-the-counter medications - require a health care provider’s order?</i> <ul style="list-style-type: none"> ○ <i>It is important that staff cannot purchase medications and/or herbal products without authority of a resident’s health care provider.</i> • <i>Can staff administer injections? (Insulin, Growth Hormone)</i> • <i>How are medication errors handled?</i> <ul style="list-style-type: none"> ○ <i>Who is informed?</i> ○ <i>What steps are taken to prevent future errors?</i> | | | |
| 70. Do residents practice fire, tornado and/or emergency drills? | | | |
| 71. What types of exercise activities are offered and available to residents? | | | |
| 72. Who is responsible for menu planning and dietary oversight? | | | |
| <ul style="list-style-type: none"> • <i>Does staff receive training on nutrition and a calorie-controlled diet?</i> • <i>Are menus reviewed by a dietician?</i> • <i>Who determines if a calorie adjustment must be made?</i> • <i>How is food planning for outings managed?</i> • <i>Are menus planned for and posted in advance?</i> | | | |
| 73. What measures are in place for food security and weight management? | | | |
| <ul style="list-style-type: none"> • <i>Locks, alarms, pre-event/outing planning?</i> • <i>How often is a resident weighed?</i> • <i>Who determines goal weight and range?</i> • <i>What structure is in place for the timing and scheduling of meals and snacks?</i> <ul style="list-style-type: none"> ○ <i>How often are residents receiving food and beverages?</i> ○ <i>Are there any special practices in place for meals and snacks?</i> ○ <i>Does a resident have input in to the selection of any food items?</i> | | | |

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| BEHAVIOR MANAGEMENT AND ENVIRONMENTAL CONSIDERATIONS | Yes | No | Notes |
|---|------------|-----------|--------------|
| 74. What programs and support plans are in place to help prevent and manage behavior challenges for residents? <ul style="list-style-type: none"> o <i>Is staff trained to utilize measures to teach, model and encourage appropriate behavior?</i> o <i>What is done if a resident demonstrates unsafe behavior resulting in property destruction or physical assault on staff or others?</i> | | | |
| 75. What is done to manage stealing? <ul style="list-style-type: none"> a. <i>Do residents have their own room?</i> b. <i>Is a search ever performed on the resident or his/her belongings?</i> | | | |
| 76. Are measures in place for a resident who likes to elope? <ul style="list-style-type: none"> o <i>Alarms, increased supervision</i> | | | |
| 77. What strategies are used to help prevent and/or manage a resident with severe skin picking behaviors? | | | |
| 78. Are residents allowed to smoke? | | | |
| PROGRAMMING, RECREATION, SOCIALIZATION, & PERSONAL CARE | Yes | No | Notes |
| 79. What programs and/or employment opportunities are available for the residents during the daytime hours? | | | |
| <ul style="list-style-type: none"> • <i>Is there structure and routine in their day?</i> • <i>Who provides these services and what is their experience in working with adults with PWS?</i> • <i>How does the resident travel to their workplace or day programming site?</i> | | | |
| 80. Can a resident have access to a phone? | | | |
| 81. Can a resident have access to a computer/Internet? | | | |
| 82. What sorts of activities do residents have the opportunity to attend and/or participate in? | | | |
| 83. Do the residents appear happy? | | | |
| 84. What social skills training and opportunities are available? | | | |
| <ul style="list-style-type: none"> • <i>Can a resident invite a friend to visit? Are there any guidelines for this?</i> • <i>What about dating? Is this allowed and under what circumstances?</i> • <i>Can a parent/guardian call and/or visit freely?</i> | | | |
| 85. Who schedules and arranges for haircuts? | | | |
| 86. Who assists the resident with nail care? | | | |
| 87. What items is the resident responsible for providing in their home? <ul style="list-style-type: none"> a. <i>Furniture – bed, dresser, other?</i> b. <i>Linens, pillows, window coverings?</i> c. <i>Clothing</i> d. <i>Other items to personalize his/her room</i> | | | |
| 88. Do residents receive assistance and support for housekeeping and laundry responsibilities? | | | |

OTHER QUESTIONS AND/OR NOTES: (Please use reverse side of this form) _____

Transportation Services

Transportation services may be needed for various purposes. Oftentimes, the purpose for transportation will determine who and how these services are obtained. The two areas that are frequently contracted for specialized transportation services include service-based transportation and medical transportation. Transportation services are often tied to services provided under Medicaid or other contract through a human service agency. Parents/guardians are encouraged to contact their local agency to confirm what steps need to be taken in order to receive them.

HOW ARE TRANSPORTATION SERVICES FOR SERVICE-BASED SITUATIONS ARRANGED AND PROVIDED?

If a person is living at home or in a supported living situation, and transportation services are needed for the individual to go to work or attend other meetings (and in some cases social situations), these services are typically arranged through agencies that are contracted and approved by the local human service agency. In some cases, it may be a bus, taxi or other specialized transportation service. In other cases, an agency that is providing services may have a contract for transportation. In most cases, the transportation agency for service-based situations will be different than the transportation services used for medical appointments.

In some localities, parents/guardians may be reimbursed if they are providing transportation. Parents/guardians will need to learn who and how to secure these services from their local human service agency. There are many special considerations that need to be considered when transportation services are being provided including food security, behavior escalation, as well as vulnerability.

HOW ARE TRANSPORTATION SERVICES FOR MEDICAL APPOINTMENTS ARRANGED?

For the most part, each state contracts with various transportation agencies or entities for specialized transportation services that provide transportation to medical appointments. This service is typically provided under a Medicaid program. Parents/guardians are encouraged to contact their local human service agency and/or their state Medicaid website or agency to see what must be done to have these services arranged. Many require a 48-hour notice. Exceptions may be possible for urgent needs.

WILL PROVIDERS FOR TRANSPORTATION SERVICES NEED TO BE EDUCATED ABOUT PWS?

Yes, all service providers should be educated about PWS. Feel free to share the handout from PWSA (USA) on School Transportation Services.

Important Legal and Financial Issues - Legal Protection for Your Family

The following Information has been provided by Lisa Thornton, Attorney, and Parent of a Child with PWS.



When a baby with Prader-Willi syndrome is born, parents are initially consumed with the medical needs of their child and coming to grips with the fact that their baby likely won't have the kind of life expected. Soon a routine of doctor visits, therapy, and worry settle in as "normal." Nagging fears soon arise about who will care for their child if and when the parents cannot.

Somewhere along this journey, hopefully sooner rather than later, parents of a child with Prader-Willi syndrome will get legal documents in place to protect themselves and their child. Generally, a **special needs trust** should be established for the child with PWS. At age 18 it is generally necessary for a family to secure **guardianship** over the adult child with PWS and the parents should also apply for **Supplemental Security Income** and **Medicaid** for their child. It is also recommended that each parent have a **will** that names a guardian for their minor children, a **power of attorney**, and a **medical directive**. Parents may also want to consider a **revocable trust** as part of their estate planning.

PROTECTION FOR YOUR CHILD

Special Needs Trust: Through special needs trusts parents can leave money for the benefit of their child with PWS without disqualifying the child from government benefits. This money is intended to supplement and not replace those benefits that the child may receive. The fund can be used to purchase items that Medicaid will not such as a home, wheelchairs, vacations, and a personal attendant. Close and trusted family members can act as trustees (the ones who follow the parent's instructions as to how the money should be spent) once both parents pass away. Usually, funds should not be given directly to the child because the child may not be able to manage the money carefully and because the funds would disqualify the child from Supplemental Security Income, the state Katie Beckett waiver, and Medicaid benefits.

Similarly, parents should not give funds to siblings of the disabled child with the understanding that the sibling will then take care of the disabled child. The sibling could spend the money, the future spouse of the sibling could resent the situation, especially if the money disqualifies them from receiving certain benefits of their own, such as student loans for their own children. Divorce or other life events may transfer the funds to another and thwart the parent's wish that the money be used for the disabled child.

Guardianship: Once a child with disabilities reaches 18 years of age, the law considers him an adult and parents no longer are able to make decisions for him. They are no longer his legal guardian and he is presumed competent unless a court determines otherwise. This has many implications for parents. For instance, insurance companies and physicians often will no longer speak with parents regarding the health issues of their child. Supplemental Security Income will belong to your child and parents will not have the legal right to determine how that money is used, unless they become the designated payee. If the child runs away, many law enforcement agencies view the disabled child as an "adult" and will not search for the disabled individual as readily.

Parents should secure guardianship as close to the child's 18th birthday as possible. Most states require that parents hire an attorney to represent their child in the proceedings. The parents can represent themselves or have an attorney, different from their child's attorney, represent them.

Supplemental Security Income: When a disabled child turns 18, parents should apply for Supplemental Security Income (SSI). Often SSI will be denied on the first try, but parents should appeal the denial. See PWS guidelines at <http://www.pwsausa.org/get-information/parent/ssi-letter>. The success rate of these appeals is very high and

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often back payments are awarded. Even if parents can afford to care for their child at age 18 and beyond, it is a good idea to receive this benefit and put it aside to help fund the child's special needs trust.

Medicaid: Medicaid provides long-term medical care for adults and children with PWS. When a child receives SSI, he will automatically qualify to receive medical insurance through Medicaid. This will often be the only insurance for which your child can qualify after the age of about 26, depending on the rules of the parent's private insurance.

PROTECTION FOR PARENTS

Will: A will is a basic legal document that allows you to direct to whom your property will be distributed. The executor is named in your will and is the person that will administer your wishes upon your death. The will is the tool by which you leave assets to your children, grandchildren, charities, or other heirs. If you die without a will, you die intestate. State law will then determine how your assets will be distributed. Under state law, if you die without a will, your child with PWS will automatically receive assets, very likely more than \$2,000 and would become ineligible for government benefits such as SSI, Medicaid, and other state waiver funds.

Power of Attorney: A power of attorney names those to act for you, often a spouse or adult child, while you are still living if you become disabled or incapacitated and cannot make decisions on your own regarding your financial matters.

Medical Directive: A Medical Healthcare Directive names the people you want to act on your behalf when you are unable to communicate your desires for medical treatment. It also states your wishes regarding such items as organ donation and medical research.

Revocable Trust: Some parents will want to choose a revocable trust along with a will that transfers over the parent's assets into the trust upon death as well as a "stand alone" special needs trust. The advantages to this choice are that when the parents die, there will be no need to probate the estate—often a lengthy court process involving attorneys and legal fees. Further, with the new guardian of the disabled child, they will have instant access to funds rather than waiting for an often lengthy and expensive court process. This is also the option families should choose if a grandparent or other person has indicated the desire to contribute money to the child with PWS either through their own estate planning or with life-time gifts.



Letter of Intent: Along with securing appropriate legal documents, parents should also consider drafting a letter of intent. Although not a legal document, this letter provides future caregivers and guardians with a clear understanding of the child's physicians, health and medical concerns, specific care strategies that parents have learned and developed over the years, the child's personality traits and preferences, dietary requirements, financial and legal information, and the parent's vision and hopes for their child's future.

RESOURCES:

1. For a free template for a Letter of Intent, go to:

http://www.sdparent.org/web/site_2825_files/files/1328539903_Letter_of_Intent_Form.pdf

The following is available from PWSA (USA):

2. #255 – Estate and Guardianship Presentation from the 2013 National Conference - CD by Lisa Thornton and Steve Leightman contains the speakers' PowerPoint presentation as well as sample templates for a simple will, special needs trust and letter of intent. \$30.00

Guardianship

WHAT IS A GUARDIAN?

A guardian is a person, institution, or agency appointed by a court to manage the affairs of another individual. The guardian may be given the authority to manage personal and/or financial matters. Each state has specific laws, which govern guardianship proceedings and the guardian's activities. States also have separate laws and procedures for guardianships for minors and for adults with disabilities.

WHEN IS A GUARDIAN NEEDED?

A person with a severe mental or cognitive disability may be unable to exercise some or all of his or her own rights or to protect his or her own interests. A *guardian* is a person appointed by a court to take the place of the person in exercising the rights he or she is unable to exercise; to make (or help make) decisions the person is unable to make independently; and to be an advocate for the person's interests.

Guardianship is created by a court order, and the guardian only has the powers that state law and the court order provide. Any person who is the age of 18 or older is legally an adult, and is presumed to be able to manage his or her own financial affairs, choose where to live, consent to medical treatment, vote, make contracts, marry, and exercise his or her own legal rights as an adult. This presumption does not change because a person has a disability.

The presumption that an adult is competent to make his or her own decisions often comes as a surprise to family members, who may find themselves with no legal right to be involved in, or even know about, care that a relative is receiving. For example, family members may be refused information about the person's needs and treatment because he or she is unable, or refuses, to give informed consent to release of the information.

WHO MAY HAVE A GUARDIAN APPOINTED TO MANAGE HIS/HER AFFAIRS?

State laws presume that an adult 18 years of age or older is capable of managing his/her own affairs. In order to have a guardian appointed, a court must find that the individual has demonstrated a lack of capacity to make or communicate responsible decisions concerning personal or financial matters. The laws of the state in which the individual resides must be reviewed to learn the specifics governing the definition of an incapacitated person.

HOW IS IT DETERMINED THAT A PERSON MAY NEED A GUARDIAN?

The fact that someone has some sort of diagnosis or disability does not equate to the need for a guardian. The primary test for determining the need for guardianship focuses on the ability to make decisions, and to communicate the decisions once made. Most guardianships focus on the ability to make decisions regarding living arrangements, medical care, vocational and educational services, ancillary professional services, care for dependents, and managing finances. The essence of decisional capacity may be encompassed in the following questions:

- Does the individual understand that a decision needs to be made?
- Does the individual understand the options available in making a decision?
- Does the individual understand the potential consequences of the decision and options?
- Can the individual direct the decision to appropriate parties?

WHO CAN ACT AS A GUARDIAN?

The following qualifications for guardians are fairly universal:

- Individuals over the age of 18, who have not been convicted of a felony, and have not been adjudicated disabled
- Non-related professional guardians
- A public or private institution, as long as they do not provide services to the individual.

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- Financial institutions (for estate matters only)

In some states there is a statutory preference for family member as guardian; but in all states the selection of the guardian is in the court's discretion. While most states do not have education or experience requirements to be appointed as guardians, some states provide some assistance such as videos, guardian manuals, or training sessions. For specifics about who may be a guardian, review the individual state guardianship statutes.

HOW DOES A GUARDIAN GET APPOINTED?

A court must determine based on the evidence presented that (1) the individual is incapacitated according to the law of that state and guardianship is appropriate; (2) the individual or entity to act as guardian is qualified; and (3) the authority granted to the guardian is necessary for the safety of the individual.

WHAT ARE THE USUAL STEPS TO APPOINTING A GUARDIAN?

Most states require a preliminary investigation into the need for a guardianship. While the requirements of the investigative report vary greatly, at a minimum the report should:

- Provide a description of the nature and type of disability and an explanation of how that disability impacts the individual's decision making;
- Offer an analysis and results of evaluations of the individual's mental and physical condition, educational level, adaptive behavior and social skills as appropriate;
- State an opinion about the need for guardianship, and provide supporting reasons for this opinion; and
- Recommend suitable living arrangements and treatment or habitation plans and again the supporting reasons for the recommendations. The report should accurately reflect the skills and abilities of the person as well as the deficits and problems. The report must be timely and meet a time frame that is usually stated in the statute.

A petition must be filed to start the proceedings. The petition is the official request for the appointment of a guardian. It is prepared and signed by the person alleging the need for guardianship. Although an attorney may not be required to establish guardianship in some areas, this is a legal process. It may be best to consult an attorney familiar with guardianship proceedings before filing a guardianship petition.

After a hearing date is set, a summons to appear at the proceeding is served on the individual. The summons is the official notice to the person with disabilities about guardianship proceedings, the time, and place.

Notice of the date, time and place of the guardianship proceedings is given to any interested parties, family members, proposed guardian, etc., in order that they can be present at the hearing if they choose.

A hearing is held and evidence presented about the need for guardianship. The alleged disabled person is usually represented by an attorney during the hearing process. Although the hearing may seem to be quite informal, this is an adversarial process and the petitioner must clearly demonstrate to the court that the individual needs a guardian.

During the appointment proceedings, the alleged disabled person has specific due process rights that are defined in the various state laws.

CAN GUARDIANSHIP BE USED IN AN EMERGENCY?

Most states have a special procedure for an emergency appointment of a guardian for a specific purpose. They are usually time-limited and not renewable without a full guardianship proceeding. There is usually a cursory hearing about the specific issue and a guardian's authority is limited to those decisions necessary to address the emergency. Usually this is not a full finding of incapacity, and a full hearing on the guardianship must be scheduled or the emergency/temporary guardianship expires.

WHAT ARE THE DIFFERENT TYPES OF GUARDIANSHIP AVAILABLE?

This also varies from state to state but generally:

- **Guardianship of the person** in which the guardian is granted the authority to make decisions about medical care, residential placement, and release of confidential information.
- **Guardianship of the estate** in which the guardian is granted the authority to manage and make decisions about financial matters, benefits, real estate and other property.

For both personal and financial guardianships, a court may establish either a *full* or a *limited guardianship*. The court can limit a guardianship of the person to recognize the person's ability to vote, marry, drive, sign a contract, choose a place to live, etc.

Most guardianships fall within these general categories although the names or categories of guardians may differ greatly. Review your state laws for specifics.

HOW LONG DOES THE GUARDIANSHIP PROCESS TAKE?

While temporary or emergency guardianships may be appointed quickly within a few days after the petition is filed, it may be two weeks to as long as two months between petitioning and appointment.

HOW DOES A GUARDIANSHIP END?

The court may modify, revoke, or terminate the guardianship if the individual's ability to make and communicate decisions is demonstrated to the court. The procedures governing the modification of guardianships again may vary but every state has procedures to terminate a guardianship.

ADVANTAGES AND DISADVANTAGES OF GUARDIANSHIP

ADVANTAGES: If a person is genuinely unable to protect him or herself, or to understand his or her rights, guardianship can be an important tool for protecting the person from abuse, neglect or exploitation, and for ensuring that there is someone able to understand and assert the person's rights. For example:

- A person may need money for food and shelter, medical care, or rehabilitation services but may be unable to identify or apply for assistance. A guardian can monitor the person's need for assistance, make the application, and appeal if benefits are denied.
- A person who does not understand the value of money may give away his or her monthly check to someone who is exploiting the person's lack of understanding. A guardian can limit access to funds and control how they are spent.
- A person in an institution may be physically restrained much of the day, without being able to challenge what is happening, because this is easier for staff. A guardian can protect the person's right to freedom from unnecessary restraint, to appropriate treatment, and to the least restrictive residential placement.

Thus, a guardianship can protect as well as restrict rights. However, some rights (like the right to vote, to marry, or to consent to sterilization) are considered so personal that a guardian cannot exercise them and they are lost completely unless the court finds that the person is competent to exercise them on his or her own.

DISADVANTAGES: On the other hand, a guardianship that is not justified by the person's real needs, or that is more restrictive than necessary, has substantial costs:

- The process of establishing that a person is incompetent is often a painful one, not only for the person but also for friends and family members who are called upon to squarely face and discuss the question of what the person can and cannot do.
- A person found incompetent loses many basic, day-to-day rights, and may also feel a loss of dignity and respect because he or she must seek the consent and assistance of another person for many activities that other people take for granted. Other people may see the person as less capable than he or she actually is.

Transition Planning and Resources for Parents/Guardians of Young Adults with Prader-Willi Syndrome

- Loss of rights may reduce the person's opportunity to learn to make choices, and thus to develop or keep decision making skills.
- For these reasons, a guardianship should be sought only if it is clearly for the benefit of the person, and not because it is easier or more convenient for others to make decisions for him or her. If a guardianship is sought, it should be tailored to deprive the person of control over a part of his or her own life only when there is a functional reason.

A FINDING OF "INCOMPETENCE" - WHAT DOES THIS MEAN?

The ability of a person to manage his or her own affairs is called "*competence*." Before a judge can appoint a guardian for a person, the judge must find that the person is "*incompetent*."

Legal incompetence is a finding by a court that:

- The person has a mental disability, such as mental retardation, brain injury, chronic mental illness or organic brain damage caused by advanced age. The disability must be long-term and must substantially impair the person from providing for his or her own needs. Physical disability by itself is not enough to establish incompetence.
- Because of the mental disability, the person is substantially incapable of managing his or her property (for financial guardianship) or of caring for himself or herself (for personal guardianship), or both. A person is not incompetent simply because he or she knowingly and voluntarily chooses to do something most of us would consider foolish. All of us have a right to make mistakes. The guardianship law can only be used to protect those who are unable to provide for their own needs, not those who are able but unwilling to do so. A person also cannot be considered incompetent because of failure to understand something that was not explained in the way that he or she was most likely to understand, or because it may take extra time and effort on the part of other people to communicate with the person. These problems should be dealt with in other ways, such as use of interpreters and development and use of alternative communication methods.

It is most useful to think of competence in terms of the person's ability to understand the nature and consequences of a particular action or decision, if information about the action or decision is presented in a form the person is most likely to understand, and then to make decisions that take that information into account. For example, with regard to consent to medical treatment, the test might be whether, after the treatment is explained to the person in the clearest possible way, the person can understand the benefits and risks of the treatment and of any alternative types of treatment, and can make a rational decision based on available facts.

Incompetence is not an all-or-nothing concept. Some people can understand most of the decisions they face in everyday life, but may need help with financial management or complex medical decisions.

HOW SHOULD COMPETENCE BE EVALUATED?

The most useful way to determine whether a person needs a guardian, and for what purposes, is to break down the person's need for support and protection into functional areas, such as medical decisions, personal needs, safety, relationships, etc. For each of these functional areas, the evaluator can then ask the questions:

- What decisions does the person face in this issue area? What decisions is s/he likely to face in the future?
- For decisions relevant to his/her life, is the person substantially able to understand all significant information on the nature, risks and benefits of the various options, if explained to him/her in a form s/he is most likely to understand? If not, is this inability due to a substantial, long-term mental disability?
- Has the person had the opportunity to develop decision-making capacity through training and practice? Has the person had needed evaluation, training, and therapy to develop receptive and expressive language skills or provide alternative communication methods? If not, would this be likely to develop or restore decision-making ability?

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- Where the person lacks the evaluative capacity to make a knowing choice, does this incapacity have a substantial impact on his/her ability to manage finances or care for him/herself?

In this approach, knowledge of the person's day to day skills and of the practical issues he or she is likely to face are at least as important as diagnostic skills. Ideally, information from formal medical or psychological testing should be combined with information gathered from people who know and work with the person in his or her typical environments.

WHAT CAN BE DONE IF THE PERSON WITH PWS IS NOT FOUND TO BE INCOMPETENT - ARE THERE ALTERNATIVES TO GUARDIANSHIP?

Guardianship as a highly intrusive intervention should be used only as a last resort when all other alternatives have been examined. Some of the alternatives to guardianship may be powers of attorney for health care or financial management, living wills, trusts, case/care management services, representative payeeship for public benefits and health care surrogate acts. Individuals may get additional information on alternatives from the bar association, state guardianship association and local social service agencies.

To protect the person's rights, self-image, and opportunity to learn, the powers of a guardian should be carefully limited to areas where the person clearly needs a substitute decision-maker. A *standby guardian* is a person appointed by the court to become guardian upon the death, incapacity or resignation of guardian. The standby guardian must inform the court when he or she begins to exercise the powers of a guardian.

A *temporary guardian* is appointed only for a limited period of time, and his or her powers must be limited in the court order- to authority over specific property or specific acts. For example, a temporary guardian may be appointed to help an individual with a specific decision or situation. Once this decision or situation has been resolved, the temporary guardian is terminated.

OTHER FACTORS THAT AFFECT NEED FOR GUARDIANSHIP

Need for a guardian will depend not only on a person's abilities but also on his or her personal situation. Some people who could clearly qualify for guardianship are functioning well without one. Others who have greater skills may be in need of protection because they are highly vulnerable. Factors include:

- **Availability of informal social supports.** If the person has family, friends or a volunteer citizen advocate willing to play an active role in helping him or her make decisions, he or she may be able to function well without a guardian, so long as he or she is able to know when help is needed and how to seek it. A person who is willing to have his funds deposited into a two-signature checking account usually will not need a financial guardian. A person who brings major decisions to a support circle of family, friends and paid support workers may not need any guardian, or may only need one for complex medical decisions.
- **Availability of formal support services and treatment.** A strong network of support services that both protects the person from unacceptable risks and actively works to help the person develop and practice skills in decision making, health and nutrition, self-protection, personal care, care of the home, etc., can be as protective as a guardianship and more effective in teaching long-term independence.
- **Dependence on services/institutional placement.** Heavy dependence on medical, social or mental health services may itself create a need for guardianship. These agencies can be very powerful, and a guardian may be the only means to provide outside monitoring of how that power is used. This becomes particularly true in services, such as institutions, that are isolated from the larger society and/or have the potential to control every aspect of a person's life. Much depends on the attitude of the person and those around him or her. For voluntary support systems to work, the person must be willing to accept help. Those relied on for help must be supportive of the person's rights. It is essential to be alert for conflicts of interest: family members may be motivated by a desire to hold on to the person's funds; service providers may act out of desire to minimize their own workloads or expenses. Unless there are checks and balances over the power of others, a guardian may be a necessary protection.

HOW DO I LOCATE GUARDIANSHIP INFORMATION IN MY STATE?

To access information on the process of obtaining guardianship for the person with PWS in the state of his/her residency you can:

- Do a search on your computer (Guardianship organizations in the State of ...)
- Go to the website of the National Guardianship Association and click on the link provided to the list of state guardianship organizations. http://www.guardianship.org/state_affiliates.htm

WHAT CAN BE DONE IF THE COST OF GUARDIANSHIP IS TOO GREAT AND ONE IS NEEDED?

It is STRONGLY RECOMMENDED that you seek out the services of an attorney, if you can afford it. The information below should be used by people who cannot hire an attorney. The guardianship process is different for every state where some states are more user friendly than others.

If you are unable to afford the cost of retaining a lawyer as well as other court fees, you may have some options or resources you can explore:

- If you have a law school in your community, contact the main office and inquire if they provide any “pro bono”, free services. Law students may assist with completing paperwork and/or filing of papers.
- Contact an office for free or reduced-fee legal sources. Many communities have lawyers who donate their time and assist with clients who need assistance.
- “Do-It-Yourself” Guardianship. – You can Google this topic online and find information and kits for your state.
 - a. This option is not recommended if the person with PWS is not in agreement with this decision and he/she will contest it.
 - b. This option requires a lot of footwork by the guardian and usually a yearly renewal. It is an option many may not feel comfortable undertaking.

Advance Directives: Decision-Making for Incapacitated Individuals in the Absence of an Advance Directive

WHO CAN MAKE DECISIONS FOR AN INCAPACITATED ADULT IN THE ABSENCE OF GUARDIANSHIP OR AN ADVANCE DIRECTIVE?

Most people who have had personal experience dealing with health care for an incapacitated loved one have not had legal difficulties. That's because, traditionally, healthcare providers have turned to the next of kin for decision-making. If there is agreement between the decision-maker and the doctor, and if there are no objections from other family members, everything generally goes smoothly. But, when there are disagreements, the results can be heart-wrenching.

Over and over, during the coverage of Terri Schiavo's tragic death, television "experts" pronounced that, in cases like hers, when a person hasn't left written directions about health care, all states have laws giving decision-making authority to the spouse. That sounds logical. But it's not accurate.

Forty states and the District of Columbia do, indeed, have laws specifying who can make decisions for a patient who does not have an advance directive. In many – but not all – of those states, a spouse is designated as first in priority, followed by adult children, parents, and siblings. Other states have different procedures for deciding who will speak for a patient.

For example, (1) in Tennessee, the supervising healthcare provider selects the decision-maker after giving consideration to the patient's spouse, adult child, etc. (2) Similarly, in Indiana, any of those listed (spouse, parent, adult child, sibling, etc.) can decide for the incapacitated patient. (3) West Virginia gives the patient's attending physician or an advanced nurse practitioner the right to select the decision-maker from the priority listing based on who the physician or nurse believes would be the best decision-maker. (4) Thus, if the doctor doesn't agree with the patient's spouse about what should or should not be done, that physician can designate someone else (a parent, sibling, or close friend of the patient) as the decision-maker. And then there's Connecticut where decision-making is left to the physician in consultation with the next of kin. (5) Note that this means only that the next of kin must be consulted. It does not mean that there must be agreement. Essentially, the doctor calls the shots.

In California, a patient can orally designate someone to make decisions when treatment begins. That designation is in effect only during the course of treatment or illness, or during the stay in the healthcare institution where the designation is made, or for 60 days, whichever period is shorter. (6) That's of little help, however, if the patient is not conscious when admitted for care.

Contrary to what was said so often during the Schiavo case, Florida law does not give first priority to a spouse, but to a court-appointed guardian. (7) A spouse is second to a guardian on Florida's priority list. Although Michael Schiavo was Terri's husband, his authority to remove her food and fluids came from his status as her court-appointed guardian.

RESOURCE: <http://www.patientsrightscouncil.org/site/advance-directive-protecting-yourself-and-your-family-part-two/>

(Editor's Note: In cases where the person with PWS is their own guardian, it is imperative that a responsible adult ask the person with PWS to sign an advance directive so someone he/she knows and trusts can assist in making important lifesaving or life-ending decisions when he/she is not in a position to do so.)

Supplemental Security Income (SSI)

This section is designed to help parents understand Supplemental Security Income and to make tools available to help with the application process. In this section you will find forms and definitions that will assist in providing SSI the necessary information to be approved for this program.

WHAT IS SSI (SUPPLEMENTAL SECURITY INCOME)?

SSI is a program of the Social Security Administration designed to provide cash assistance to people who have not worked, are unable to work, or can't work enough to meet basic living expenses. Those who receive SSI are automatically eligible for Medicaid as well.

IS THIS DIFFERENT THAN SOCIAL SECURITY DISABILITY?

There is often confusion about Social Security and Supplemental Security Income (SSI) because you apply for both programs with the Social Security Administration. **But, the programs are different.**

- **Social Security benefit** programs are "entitlement" programs. This means those workers, employers and the self-employed pay for the benefits with their Social Security taxes. The taxes that are collected are put into special trust funds. You qualify for these benefits based on your work history (or your spouse or parent). The amount of the benefit is based on these earnings. **You must have been employed to receive funds from this program.**
- **SSI** is a needs-based program for people with limited income and resources. Resources are assets or things that you own. The program is paid for by general tax revenues -- not from the Social Security trust funds. The benefit amount is based on federal and state laws which take into account where you live, who lives with you and what income you receive. **You do not need to have been employed to receive funds from this program.**

CAN A CHILD WITH PWS BE ELIGIBLE FOR SSI BEFORE AGE 18 YEARS?

Before they turn 18, most children with PWS are not eligible for SSI because the strict income eligibility criteria are based on the family's income. If your family income and assets are low, he/she may be eligible and you can apply at any time.

WHAT IS DIFFERENT ONCE HE/SHE TURNS 18 YEARS OLD?

After turning 18, most people with PWS are eligible for SSI because eligibility is then based solely on his or her individual income and assets and disability. So, even if an application was denied in the past, it is important to apply again. SSI approval provides a guaranteed monthly income for your child and automatic eligibility for Medicaid in every state.

HOW AND WHERE DO I APPLY FOR SSI?

When applying for SSI, you can complete a large part of the application by visiting www.socialsecurity.gov. You also can call 1-800-772-1213. You can ask for an appointment with a Social Security representative in your local office. The process to apply can be lengthy so it is important to start as soon as possible.

WHAT DO I DO IF DENIED?

Even if you are denied initially, **do not give up**. According to the New York Times (12/8/07), two-thirds of initial applications are approved after a first denial. If you receive a denial, contact staff at PWSA (USA) immediately and they can help you with the appeal process.

WHAT IS SSI-E?

SSI-E, also known as Supplemental Security Income – Exceptional Expense Supplement is a supplement of the federal SSI benefit with additional payments that is offered by some (not all) states. This makes the total SSI benefit levels higher in those states. SSI benefit amounts and state supplemental payment amounts vary based upon income, living arrangements, and other factors. Supplemental Security Income Exceptional Expense Supplement is an extra sum of money provided to individuals or couples who already receive the state supplement, or SSI benefits, and who have exceptional medical expenses or care needs.

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To be eligible for SSI-E an individual must be currently receiving SSI, living in a residential setting, and need at least 40 hours per month of primary long-term support services. This benefit is often missed because people often believe that the term “long-term support services” only includes services such as assistance in bathing, dressing and grooming; finances and bill paying; on-site supervision for persons with dementia and severe physical limitations; toileting; assistance in personal mobility with transferring from bed or wheelchair, positioning in bed to prevent bed sores and feeding. All of these Supportive Home Care needs certainly can make one eligible for SSI-E. But **these aren't the only criteria**. Some individuals with PWS qualify due to the fact that they require 24/7 support with constant supervision in all environments for food security and behavior management.

For information about your state and if SSI-E is available go to:
www.socialsecurity.gov/policy/docs/statcomps/ssi_sc

Frequently Asked Questions about SSI

SHOULD I HIRE A SOCIAL SECURITY DISABILITY ATTORNEY?

Most parents do not hire an attorney unless they get to the third, and final, appeal stage. An attorney can be especially helpful at that stage. However, as we are not able to give legal advice, we encourage you to explore all options. In almost every part of the country, you can find a social security attorney to consult with and he/she can explain to you their possible role so you can make an informed decision.

IF APPROVED FOR SSI BENEFITS, DOES THAT MEAN MY CHILD CANNOT WORK?

Your child can work and still receive SSI benefits. The SSI program has built-in work incentives to allow people to work without losing benefits. We encourage people with SSI to explore work opportunities. You can begin to work and continue to receive SSI benefits as long as your wages and other resources do not exceed the SSA's income limit for SSI; however, your monthly benefit amount will be reduced in proportion to your income.

WHO QUALIFIES FOR SSI?

Qualifying is based on evidence of Functional Limitations.

Qualifying for disability benefits (SSD or SSI) is a matter of proving one's case through:

- A) Strong objective medical evidence and vocational evidence, combined with
- B) A logical, rational argument for approval that is based on the Social Security Administration's rules and regulations, i.e., administrative requirements.

Though there is a list of medical impairments with detailed approval criteria, the majority of claims are not approved in this manner (listing-level requirements tends to be very specific and, in most cases, a person's medical evidence will not contain this level of detail). For the vast majority of claimants, winning a claim will involve proving that they have functional limitations that rule out the ability to engage in work activity.

In the Social Security Disability and SSI system, a simple diagnosis of a condition will not result in an approval for benefits. **The emphasis is on how the individual's condition affects, and limits, their ability to engage in normal daily activities, and the ability to perform work activity.**

For this reason, potentially anyone qualifies for disability benefits through one or both of the disability programs administered by the Social Security Administration...provided they can do the following:

1. Prove they have at least one severe medical impairment that is documented by objective medical evidence.
2. Prove that the condition has resulted in the types of limitations that, given the particular demands of their past work, make it impossible to return to their past work. For example, a person whose past work required them to climb ladders but now has significant degenerative disc disease would probably be found to be unable to return to this type of work.
3. Prove that they also cannot switch to some type of other work that they would usually qualify for--were it not for their combination of medical factors and vocational factors (this would include their age, education, and job skills).
4. Finally, the person's disabling condition must last at least one full year while being severe enough to make it impossible for them to engage in work activity. Note: a person does not have to wait until they have been out of work for a full year before applying. You can apply for disability at any time and SSA (through a disability examiner or judge) will be able to review the evidence and determine whether or not your condition will be disabling for this length of time.

Qualifying For SSI

INFORMATION FOR PARENTS

Below are headings that will help in the description of a person with PWS and why they need SSI. Use each heading to describe your child. For example, under Activities of Daily Living, customize the paragraph with details about your child. “Laura is unable to prepare or select food. She risks overeating or binge eating which could result in death...”

Activities of Daily Living: People with PWS are unable to prepare or select food. They risk overeating or binge eating which could result in death. Parents and caregivers must use locks and alarms to prevent this from happening. There must be constant vigilance to prevent overeating in all environments. It is common to see the person with PWS steal, yell, scream and hit – in order to get food. Persons with PWS often do not select appropriate clothes for the weather. The hypothalamus controls the body’s thermostat; a malfunction in this area causes them to feel hot and cold in an abnormal manner. When it is suggested to change their clothes, varying degrees of behavior outbursts are seen. Most need verbal prompts to complete hygiene including brushing of teeth. Some require 1:1 assistance because of fine motor weaknesses.

Social: Most people with PWS have few or no friends. Because of the unpredictability of social situations, they easily become frustrated and need to leave a group activity. Many have extreme behavior outbursts when they lose a game or perceive any situation as being “unfair”. Unless ongoing social skills are implemented, many become isolated.

Economic Self Sufficiency: It is a lifelong challenge for persons with PWS to remain in school or employed. The constant need for supervision; incidents of stealing food and/or money and frequent behavior outbursts cause many to quit school lose their jobs or become involved with the legal system. They do not do well with change. It is common to see behavior escalation when a task is changed or other students have different responsibilities. If food is present, they are distracted and focus primarily on how to obtain it – not their work assignment. They often refuse to follow directions or do tasks that they do not want to do. **It is also common for these individuals to quit a job because of a conflict at work.** Transportation issues are often problematic. Because of the food-seeking risk, they are unable to drive or take public transportation independently. Many suffer fatigue and cannot work for long periods of time without rest. Some fall asleep on the job. They have poor money management skills and need someone to assist them to assure they do not spend paychecks on food or other misleading gimmicks.

Learning: Persons with PWS vary widely in the area of measured IQ. Most are in the borderline range. Those with higher IQ’s face greater difficulty because they are often more clever and manipulative at getting food. Approximately 90% of persons with PWS have a cognitive delay. If there is food in the environment, they become easily distracted and agitated. Some get in trouble by assaulting staff when they feel threatened (someone either takes or threatens to take their food or some other possession). They have impulse control problems and can escalate quickly. Some have language delays and become frustrated when others do not understand what they are saying.

Self-Direction: People with PWS often make bad choices in many areas of their life. In addition to the food seeking, they may put themselves in very risky situations. If food is an enticement, they will go with strangers: shoplift; exit moving vehicles; lie as well as use other unsafe behaviors. Many people with PWS pick at their skin and other openings of their body. Many suffer severe skin damage and infections because of this. They do not feel pain properly so they can be injured or hurt themselves and not know this. Because of hypothalamic malfunctioning, they often do not run a fever if they are very ill. “All persons with Prader-Willi syndrome qualify for an Axis I Diagnosis of Personality Change due to a medical condition. (310.1) DSM IV” (see attached material).

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The cognitive rigidity/inflexibility usually causes poor judgment, sequential processing problems, egocentrism/difficulty taking another's point of view and the inability to tolerate uncertainty. Many people who are not in appropriate residential settings can and do end up inappropriately in the justice system because of the behaviors that are a manifestation of their disabilities. In the long run, this is a major financial drain on taxpayers.

Capacity to Live Independently: To date, there have been no successful situations where a person with PWS has lived successfully in an independent situation. When attempted, persons experienced extraordinary weight gain and health complications. People with PWS are living successfully in homes where their nutritional and behavioral needs are being addressed 24 hours a day and they are carefully monitored. Assisted living that does not provide for 24/7 supervision does not supply the needed supervision for this population to stay safe.

Handouts

The following pages include forms that have been found to be helpful. Some may be used in documenting and sharing information about the person with PWS for parents/guardians in applying for SSI. Another, the Vocational Checklist for the Person with PWS may be helpful for those persons with PWS who are applying at the age of 18 years or older. We are also including a sample rental agreement form that parents/guardians may want to use if they are “charging” the person with PWS room and board. This is often necessary in order for the individual to continue to receive these payments without exceeding the \$2000 limit on assets. SSI can be used to pay for food, shelter and clothing.

Forms/Handouts:

- Prader-Willi Syndrome - SSI Disability Evaluation Checklist - FOR PHYSICIANS
- Prader-Willi Syndrome - SSI Disability Evaluation Checklist - FOR PARENTS
- Prader-Willi Syndrome - SSI Disability Evaluation Checklist - FOR OTHER SOURCES
- Vocational Evaluation Checklist for an Individual with Prader-Willi Syndrome
- Sample Rental Agreement

Prader-Willi Syndrome

SSI Disability Evaluation Checklist - FOR PHYSICIANS

| | |
|----------------------------------|--|
| Legal Name of Applicant | |
| Social Security Number | |
| Date of Birth | |
| Physician Completing Form | |

Dear Physician,

The above noted patient who is under your care is applying for Social Security Supplemental Income (SSI). The medical evidence of disability will be very important in the evaluation conducted by Social Security. In addition to a letter of support describing this patient's medical condition, please complete the following evaluation checklist recommended by Social Security for applicants with Prader-Willi syndrome. Thank you.

MEDICAL

Does (or has) this patient experienced any of the following:

| | Yes | No | Unknown |
|---------------------------------------|------------|-----------|----------------|
| Obesity | | | |
| High Pain Threshold | | | |
| Temperature Instability | | | |
| Thick Saliva | | | |
| Hypotonia | | | |
| Skin Picking | | | |
| Hypothyroidism | | | |
| Growth Hormone Deficiency | | | |
| Unusual Response to Anesthesia | | | |
| Adverse reactions to some medications | | | |
| Water Intoxication | | | |
| Respiratory Concerns | | | |
| Lack of Vomiting | | | |
| Gastroparesis | | | |
| Severe Gastric Illness | | | |
| Skin lesions and bruises | | | |
| Hyperphagia and food seeking | | | |

Transition Planning and Resources for Parents/Guardians of Young Adults with Prader-Willi Syndrome

| | | | |
|---------------------|--|--|--|
| Orthopedic problems | | | |
| Sleep Apnea | | | |

BEHAVIORAL ISSUES

This patient:

| | Yes | No | Unknown |
|--|------------|-----------|----------------|
| Is subject to uncontrollable fits of rage. | | | |
| Is limited in sequential reasoning. | | | |
| Is subject to perseveration. | | | |
| Is subject to inappropriate and socially unacceptable behaviors. | | | |
| Is subject to impaired judgement. | | | |
| Is subject to exhibiting oppositional defiant behavior. | | | |
| Demonstrates cognitive rigidity and inflexibility. | | | |
| Engages in disruptive behavior. | | | |
| Demonstrates impulse control disorder. | | | |
| Demonstrates factitious disorder. | | | |

This form was completed by:

| | |
|--------------------------|--|
| Name: | |
| Signature: | |
| Date Completed: | |
| Address: | |
| Telephone Number: | |

This form was developed by the Supplemental Security Income Project of the Prader-Willi Syndrome Association (USA) based on recommendations discussed at the "Social Security Administration Compassionate Allowance Outreach Hearing on Rare Diseases" held in Washington, D.C., Nov. 4-5, 2007. It is NOT an official Social Security Administration form. For additional information, please call 800-926-4797.

Prader-Willi Syndrome

SSI Disability Evaluation Checklist - FOR PARENTS

| | |
|---|--|
| Legal Name of Applicant | |
| Applicant's Social Security Number | |
| Name of Parent(s) Completing Form | |
| Address | |
| Telephone Number | |

Instructions: Your child is applying for Social Security Supplemental Income (SSI). In order to establish a qualifying disabling condition, Social Security needs as much information as possible about your child's day to day experiences. Please answer the following questions and make sure to give details and/or examples. After you have completed this form, make sure to ask your physician to sign the form as well.

Does the Applicant Experience?

| | | | |
|--|---------|--------|-------------|
| Uncontrollable fits of rage. Please explain: | ___ Yes | ___ No | ___ Unknown |
| Limited sequential reasoning. <i>(Trouble connecting one thought to another, actions with consequences, etc.)</i> Please explain: | ___ Yes | ___ No | ___ Unknown |
| Perseveration. <i>(Repetition of words, questions and phrases)</i> Please explain: | ___ Yes | ___ No | ___ Unknown |
| Inappropriate and socially unacceptable behaviors. Please explain: | ___ Yes | ___ No | ___ Unknown |

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| | | | |
|---|----------------|---------------|--------------------|
| <p>Impaired judgement. Please explain:</p> | <p>___ Yes</p> | <p>___ No</p> | <p>___ Unknown</p> |
| <p>Oppositional defiant behavior. <i>(Characterized as stubborn, "difficult", etc.)</i> Please explain:</p> | <p>___ Yes</p> | <p>___ No</p> | <p>___ Unknown</p> |
| <p>Cognitive rigidity and inflexibility. <i>(Difficulty adapting to new ways of learning, resistant to change)</i> Please explain:</p> | <p>___ Yes</p> | <p>___ No</p> | <p>___ Unknown</p> |
| <p>Disruptive behavior. Please explain:</p> | <p>___ Yes</p> | <p>___ No</p> | <p>___ Unknown</p> |
| <p>Impulse control disorder. <i>(Acts without thinking through consequences; wants immediate gratification)</i> Please explain:</p> | <p>___ Yes</p> | <p>___ No</p> | <p>___ Unknown</p> |

Transition Planning and Resources for Parents/Guardians of Young Adults with Prader-Willi Syndrome

| | | | |
|---|---------|--------|-------------|
| Factitious disorder. <i>(Lies or makes up stories)</i> Please explain: | ___ Yes | ___ No | ___ Unknown |
| Food Seeking Behavior Please explain: | ___ Yes | ___ No | ___ Unknown |

| | |
|--|--|
| Physician's Confirmation I have reviewed this form and it is an accurate assessment of this person's disability. | |
| Name of Physician: | |
| Signature of Physician: | |
| Date: | |
| Telephone Number: | |

This form was developed by the Supplemental Security Income Project of the Prader-Willi Syndrome Association (USA) based on recommendations discussed at the "Social Security Administration Compassionate Allowance Outreach Hearing on Rare Diseases" held in Washington, D.C., Nov. 4-5, 2007. It is NOT an official Social Security Administration form. For additional information, please call 800-926-4797.

Prader-Willi Syndrome

SSI Disability Evaluation Checklist – OTHER SOURCES

| | |
|--|--|
| Legal Name of Applicant | |
| Applicant's Social Security Number | |
| Name of Person Completing Form | |
| Address | |
| Telephone Number | |
| Relationship to Applicant: (Clergy, Case Manager, Social Worker etc.) | |

Instructions: The applicant listed above is applying for Supplemental Security Income (SSI). In order to establish a qualifying disabling condition, the Social Security Administration needs as much information as possible about this person's day-to-day experience. Please answer, based on your experience, the following questions and, where possible, give details and/or examples. Thank you!

Does the Applicant Experience?

| | | | |
|--|---------|--------|-------------|
| Uncontrollable fits of rage. Please explain: | ___ Yes | ___ No | ___ Unknown |
| Limited sequential reasoning. <i>(Trouble connecting one thought to another, actions with consequences, etc.)</i> Please explain: | ___ Yes | ___ No | ___ Unknown |
| Perseveration. <i>(Repetition of words, questions and phrases)</i> Please explain: | ___ Yes | ___ No | ___ Unknown |

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| | | | |
|---|----------------|---------------|--------------------|
| <p>Inappropriate and socially unacceptable behaviors. Please explain:</p> | <p>___ Yes</p> | <p>___ No</p> | <p>___ Unknown</p> |
| <p>Impaired judgement. Please explain:</p> | <p>___ Yes</p> | <p>___ No</p> | <p>___ Unknown</p> |
| <p>Oppositional defiant behavior. <i>(Characterized as stubborn, "difficult", etc.)</i> Please explain:</p> | <p>___ Yes</p> | <p>___ No</p> | <p>___ Unknown</p> |
| <p>Cognitive rigidity and inflexibility. <i>(Difficulty adapting to new ways of learning, resistant to change)</i> Please explain:</p> | <p>___ Yes</p> | <p>___ No</p> | <p>___ Unknown</p> |
| <p>Disruptive behavior. Please explain:</p> | <p>___ Yes</p> | <p>___ No</p> | <p>___ Unknown</p> |

Transition Planning and Resources for Parents/Guardians of Young Adults with Prader-Willi Syndrome

| | | | |
|--|-------------------------------|------------------------------|-----------------------------------|
| <p>Impulse control disorder. <i>(Acts without thinking through consequences; wants immediate gratification)</i> Please explain:</p> | <p align="center">___ Yes</p> | <p align="center">___ No</p> | <p align="center">___ Unknown</p> |
| <p>Factitious disorder. <i>(Lies or makes up stories)</i> Please explain:</p> | <p align="center">___ Yes</p> | <p align="center">___ No</p> | <p align="center">___ Unknown</p> |
| <p>Food Seeking Behavior Please explain:</p> | <p align="center">___ Yes</p> | <p align="center">___ No</p> | <p align="center">___ Unknown</p> |

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Vocational Evaluation Checklist for an Individual with Prader-Willi Syndrome

Student: _____ Work Setting: _____

Evaluator: _____ Date: _____

| COMMUNICATION | Agree | Disagree | COMMENTS: (please indicate if student requires assistance – verbal prompts, visual reminders or other aids/ assistance) |
|---|--------------|-----------------|--|
| Understands verbal language. | | | |
| Needs time processing ideas and questions. | | | |
| Responds verbally to questions and interactions. | | | |
| Uses pictures / gestures to communicate. | | | |
| Expresses questions and concerns to co-workers and supervisors appropriately in proper tone and volume. | | | |
| Able to read at a basic level. | | | |
| Utilizes strategies when introduced to new work tasks or responsibilities. (schedule, checklist, simple written directions) | | | |
| Communicates appropriately when needing help, assistance or additional work. | | | |
| Uses appropriate non-verbal communication. | | | |
| WORK BEHAVIORS | Agree | Disagree | COMMENTS: (please indicate if student requires assistance – verbal prompts, visual reminders or other aids/ assistance) |
| Understands and completes work-related tasks appropriately. | | | |
| Performs 2-3 step sequencing activities. | | | |
| Conducts multi-step tasks with accuracy. | | | |
| Works at appropriate rate. | | | |
| Needs additional time to complete tasks. | | | |
| Stays attentive and alert. | | | |
| Requires breaks and/or utilizes strategies to stay alert and awake. | | | |
| Follows rules and directives. | | | |
| Completes job with accuracy and quality. | | | |
| Requires demonstration and practicing of new skills. | | | |
| Stays in approved work areas as designated by staff. | | | |
| Handles changes in work assignments using appropriate strategies. | | | |

Vocational Evaluation Checklist for an Individual with Prader-Willi Syndrome

| WORK BEHAVIORS cont. | Agree | Disagree | COMMENTS: (please indicate if student requires assistance – verbal prompts, visual reminders or other aids/ assistance) |
|---|--------------|-----------------|--|
| Uses appropriate strategies to manage negative feelings or emotions. | | | |
| Has difficulty managing emotions when faced with new tasks or expectations. | | | |
| Requires additional incentives to complete work tasks. | | | |
| SOCIAL SKILLS | Agree | Disagree | COMMENTS: (please indicate if student requires assistance – verbal prompts, visual reminders or other aids/ assistance) |
| Initiates conversations at the correct time and context of situation. | | | |
| Responds appropriately to social interactions. | | | |
| Shares with peers. | | | |
| Waits and/or take turns with peers. | | | |
| Requires extra supervision around money and personal belongings of others. | | | |
| Needs coaching and/or modeling from others for some social situations. | | | |
| Verbalizes and demonstrates an understanding of appropriate workplace social behavior and conversations. | | | |
| Dresses with appropriate clothing for the weather and temperature. | | | |
| Wears clean clothes, combs hair and uses good hygiene. | | | |
| FOOD SECURITY AND OTHER HEALTH AND SAFETY ISSUES | Agree | Disagree | COMMENTS: (please indicate if student requires assistance – verbal prompts, visual reminders or other aids/ assistance) |
| Requires and receives supervision around all food sources to ensure food security (break rooms, vending areas, special food collection drives). | | | |
| Requires supervision and strategies to prevent skin picking. | | | |
| Uses bathroom facilities independently. Uses proper hygiene. | | | |
| Reports any falls and/or injuries to an identified staff person. | | | |
| Requires the administration of medication in the work setting. | | | |
| Requires special transportation to/from work. | | | |

RENTAL AGREEMENT OR RESIDENTIAL LEASE

(Sample)

Residential Lease agreement. This lease dated on _____, 20 __, between _____ (Owner/Landlord) and _____, (Resident/Tenant).

In Consideration of the Owner/Landlord leasing certain premises to the Resident/Tenant and other valuable considerations, the receipt and sufficiency of which consideration is hereby acknowledged, the Parties agree as follows:

1. **TERMS: RESIDENT** agrees to pay in advance \$_____ per month on the ____ day of each month.
2. **UTILITIES: RESIDENT** agrees to pay ____% of all utilities.
3. **CONDITIONS OF PREMISES: RESIDENT** acknowledges that he/she has examined the premises and that said property condition checklist, if any, and/or all other items provided by OWNER are all clean, and in good satisfactory condition except as may be indicated elsewhere in this agreement. RESIDENT agrees to keep premises and all items in good order and good condition. At the termination of the Agreement, all of the above items in this provision shall be returned to OWNER in good condition except for reasonable wear and tear.
4. **INSURANCE: RESIDENT** acknowledges that OWNERS insurance covers premises but does not cover personal property.
5. **INSPECTION: OWNER** may enter, inspect, and/or repair the premises at any time in case of emergency. OWNER shall give 24 hours to prospective renters, for normal inspections and repairs. OWNER is permitted to make all alterations, repairs and maintenance that in OWNER'S judgment is necessary to perform.

RECEIPT OF AGREEMENT: The undersigned RESIDENT has read and understands this agreement and hereby acknowledges receipt of a copy of this Rental Agreement.

Resident signature: _____

Date signed: _____

Owners or Agency signature: _____

Date signed: _____

Financial Resource Planning

As parents and guardians plan for the future, it is important to make sure there is planning and consideration of what resources the person with PWS may have. If not addressed, a person with PWS may not receive disability benefits because they have too much money and/or resources. Once the person with PWS is approved to receive SSI, if he/she does not already have a checking account, one should be opened so these funds can be directly deposited into it. This account serves as a tracking mechanism for the government in monitoring the person's assets. Parents, guardians and/or the person with PWS must make sure assets remain below \$2000. Most families charge room and board to the individual receiving SSI so that their funds do not accumulate to this figure. We have included a basic sample rental agreement that parents/guardians may want to use when the person with PWS is receiving SSI and living at home. We have also attempted to provide some information on some new legislation (ABLE Act) as well as resources that outline information on resource planning

ABLE ACT

(Achieving a Better Life Experience Act of 2014)

WHAT IS THE ABLE ACT AND HOW DOES IT BENEFIT A PERSON WITH A DISABILITY?

The Achieving a Better Life Experience (ABLE) Act would ease the financial burden for individuals with disabilities by creating tax-free accounts that can be used to save for disability-related expenses. These accounts can be created by individuals to support themselves or by families to support their dependents.

The bill would create tax-exempt, state based private savings accounts to fund disability-related expenses to supplement benefits currently provided by Social Security, Medicaid, employers, and private insurance. The account shall be treated in the same way as a qualified tuition program, such as a 529. A 529 account allows families to save money for an individual's education without being disqualified for certain aid programs and prevents tax penalties on the money saved and any income earned from it.

WHAT EXPENSES WOULD QUALIFY UNDER THE ABLE ACT?

Expenses would qualify as disability-related if they are for the benefit of an individual with a disability and are related to the disability. They include education; housing; transportation; employment support; health, prevention, and wellness costs; assistive technology and personal support services; and other expenses.

WILL THESE ACCOUNTS IMPACT MEDICAID ELIGIBILITY?

ABLE accounts will have no impact on Medicaid eligibility. Those receiving Supplemental Security Income (SSI) from Social Security shall have those payments suspended while maintaining excess resources in an ABLE account.

Below is a summary of the bill:

Title I: Qualified ABLE Programs

- (Sec. 101) States as the purposes of this title to: (1) encourage and assist individuals and families in saving private funds for the purpose of supporting individuals with disabilities to maintain health, independence, and quality of life; and (2) provide secure funding for disability-related expenses of beneficiaries with disabilities that will supplement, but not supplant, benefits provided through private insurance, title XVI (Supplemental Security Income) and title XIX (Medicaid) of the Social Security Act, the beneficiary's employment, and other sources.
- (Sec. 102) Amends the Internal Revenue Code to exempt from taxation a qualified ABLE program established and maintained by a state, or by an agency or instrumentality of the state, to pay the qualified disability expenses related to the blindness or disability of a program beneficiary, including expenses for education, housing, transportation, employment training and support, assistive technology and personal support services, health, prevention and wellness, financial management and administrative services, legal fees, and expenses for oversight and monitoring, funeral and burial expenses.

Requires officers and employees who have control of the qualified ABLÉ program to make reports as required by the Secretary of the Treasury. Imposes an additional 10% tax on individuals who do not use distributions from an ABLÉ account for disability expenses. Subjects ABLÉ accounts to the penalty tax for excess contributions and for failure to file required reports.

- (Sec. 103) Requires amounts in ABLÉ accounts to be disregarded in determining eligibility for means-tested federal programs, except distributions for housing expenses under the supplemental security income program and for amounts in an ABLÉ account exceeding \$100,000. Suspends the payment of supplemental security income benefits to an individual during any period in which such individual has excess resources in an ABLÉ account, but does not suspend or affect the Medicaid eligibility of such individual.
- (Sec. 104) Amends the bankruptcy code to exclude funds placed in an account of a qualified ABLÉ program from a bankruptcy estate, but only if: (1) the designated beneficiary of such account was a child, stepchild, grandchild, or step grandchild of the debtor; (2) such funds are not pledged or promised to any entity in connection with any extension of credit and are not excess contributions to an ABLÉ account; and (3) such funds do not exceed \$6,225 during a specified time period.
- (Sec. 105) Amends the Internal Revenue Code to permit contributors to or beneficiaries of a qualified tuition program (529 program) to direct the investment of contributions to a 529 program (or any earnings thereon) up to two times in any calendar year (currently, no investment direction is allowed).

Title II: Offsets

- (Sec. 201) Amends title II (Old Age, Survivors, and Disability Insurance Benefits) of the Social Security Act to change the age at which disability benefits are no longer subject to reductions from 65 to the normal retirement age range as set forth in such Act.
- (Sec. 202) Amends title XVIII (Medicare) of the Social Security Act to: (1) accelerate the beginning date for adjustments of relative value targets for mis-valued services in Medicare physician fee schedules from 2017 to 2016; and (2) treat items and services for vacuum erection systems furnished on and after July 1, 2015, in the same manner as erectile dysfunction drugs for purposes of defining covered drugs under Medicare part D.
- (Sec. 204) Amends the American Taxpayer Relief Act of 2012 to delay to January 1, 2025, the implementation of oral-only end stage renal disease (ESRD)-related drugs in the ESRD prospective payment system.
- (Sec. 205) Amends the Internal Revenue Code to increase the Inland Waterways Trust Fund financing rate to 29 cents per gallon for fuel used after March 31, 2015.
- (Sec. 206) Amends the Internal Revenue Code to treat Internal Revenue Service (IRS)-certified professional employer organizations (PEOs) as employers for employment tax purposes (thus allowing such PEOs to pay wages and collect and remit payroll taxes on behalf of an employer).

Sets forth IRS certification requirements for PEOs, including independent financial review and reporting requirements. Requires a PEO, each year, to post a bond equal to the greater of 5% of the PEO's liability during the preceding calendar year (not exceeding \$1 million) or \$50,000.

- (Sec. 207) Amends the Internal Revenue Code to exclude dividends received by a U.S. shareholder from a controlled foreign corporation from the definition of "personal holding company income" for purposes of personal holding company taxation.
- (Sec. 208) Amends the Internal Revenue Code to require an annual inflation adjustment to tax penalty amounts for: (1) failure to file a tax return or pay tax, (2) failure to file certain information returns or registration statements, (3) noncompliance of tax return preparers, (4) failure to file partnership or S corporation returns, and (5) failure to file correct information returns or correct payee statements.
- (Sec. 209) Amends the Internal Revenue Code to increase from 15 to 30% the rate of the continuous levy on payments due to a Medicare provider or supplier for overdue taxes.

Resources:

The ABLE Act: <https://www.congress.gov/bill/113th-congress/house-bill/647>

There are often many questions about resources and planning for the person with a disability. Other than the ABLE Act that was mentioned above, there have not been many changes in this area for several years.

“One Step Ahead – Resource Planning for People with Disabilities Who Rely on SSI and Medicaid” can be downloaded from the website of the Wisconsin Board for Persons with Developmental Disabilities at:

http://www.wi-bpdd.org/publications/2010/OneStepAhead_ThirdEd.pdf

Personal Health Education, Transitioning to the Adult Health Care System, Educating Health Care Professionals and Health Insurance Coverage

The multifaceted topic of “health” encompasses many areas and issues as a young adult with PWS transitions into the adult world.

WHAT HEALTH TOPICS SHOULD THE YOUNG ADULT WITH PWS BE EDUCATED ON AND BE INCLUDED IN THE IEP?

Note: What information and how much information that can and should be shared with the young adult with PWS will be an individual decision based on the student’s cognitive abilities and family choices.

Some of the topics you may want to include in the student with PWS’ transition IEP include:

- Education and awareness of the health issues related to PWS – altered pain response, gastric illness, and altered temperature control (just to name a few).
- Education and awareness of other personal health conditions. (Diabetes, low bone density, seizure disorder...)
- Medication education:
 - What medications are the student taking?
 - Why and when should they be taking them?
 - What are the side effects of the medications?
 - When and how are medications refilled/re-ordered?
 - ▣ Contacting the pharmacy
 - ▣ Contacting the health care provider
 - What other special things should the student know and/or avoid?
 - ▣ Alcohol intake
 - ▣ Sun exposure
 - ▣ Taking other Over-the-Counter medications
- Medical and dental appointments:
 - Who are the health and dental professionals that care for the student?
 - Is the student his or her own guardian?
 - Who makes the appointments?
 - How is this done – what information is needed?
 - Does someone need to “authorize” contacting the health/dental care provider?
 - What needs to be considered when scheduling an appointment?
 - ▣ Transportation
 - ▣ Insurance
 - ▣ Timing and availability of someone to accompany the young adult with PWS
- Medical Emergencies:
 - What is an emergency and when is 911 called?
 - Who should be contacted for a “minor emergency”?
 - What should be done if a parent or caregiver needs medical help?

WHEN IS IT NECESSARY TO CHANGE FROM THE PEDIATRIC TO THE ADULT HEALTH CARE SYSTEM?

Changing from the pediatric to the adult health care system can be a challenging and difficult transition. It is always hard to establish trust in a new health care provider – especially one who may not be as informed about PWS, as well as one who is knowledgeable of the individual needs of the young person with PWS. Typically, this transition process begins around the age of 18-21 years. This will depend on the health care professional and what he/she suggests. Some may keep patients under their care for a longer period of time. Others may be

Transition Planning and Resources for Parents/Guardians of Young Adults with Prader-Willi Syndrome

trained to care for both children and adults. It is a question that should be discussed with the person's personal health care professional.

HOW WILL I KNOW WHAT HEALTH CARE PROFESSIONAL TO CHANGE TO?

The primary care provider should be the person to help select or recommend a new physician and facilitate communication and the process of transitioning care. Specialists should also provide referrals and assistance with this process. Networking with other parents of adults with PWS in your area is another way of seeking out health care professionals who have knowledge and experience in working with adults with PWS. "Sharing providers" is often a very effective way of encouraging education about PWS since the health care professional will have more than one patient with this disability.

WHAT RESOURCES ARE AVAILABLE TO HELP EDUCATE A NEW PHYSICIAN OR OTHER HEALTH CARE PROFESSIONAL?

PWSA (USA) can provide the new physician with a packet of information to help educate him/her about PWS. Contact their office (1-800-926-4797) between the hours of 8 am to 5 pm EST. Have the address of the physician available to share with office staff.

PWSA (USA) also has medical professionals who are willing to provide consultative services to other health care professionals if requested. This is a professional to professional service. It is advised to have the health care professional contact PWSA (USA) at 1-800-926-4797. Contact information will be shared so that these professionals can be connected.

It is always advisable to carry a Medical Alerts brochure with you at all times to share with a health care professional when unplanned or emergency care is needed. This can be viewed and/or downloaded online at www.pwsausa.org.

Most health care professionals utilize websites to access information about health care conditions or issues that they may not see very often. "**Up To Date**" is a clinical resource most clinicians trust to present reliable information in a concise format. Information on PWS can be found on this website. Share this website resource with your health care provider and store this website on your phone or in another location so you can access and share easily: www.uptodate.com

WHAT OTHER THINGS NEED TO BE CONSIDERED WHEN TRANSITIONING TO THE ADULT HEALTH CARE SYSTEM?

1. Guardianship:

- a. What is the guardianship status of the person with PWS?
 - i. If the person is his/her own guardian:
 1. The medical provider is not legally able to discuss or share health information with anyone unless the person with PWS has signed a consent to do so.
 2. Oftentimes, the person with PWS may be willing to have the parent or another adult serve as a "health care advocate" to make sure all pertinent information is shared and understood. No matter what – a signed consent by this individual must be obtained.
 - ii. If the person with PWS has a court-appointed guardian – make sure that a copy of the guardianship papers is shared with the health care professional and scanned in to his/her health record.

NOTE: If the guardian is not the person taking the individual with PWS to the medical appointment, proper consent and authorization papers should be obtained and brought to each appointment.

WILL HEALTH INSURANCE OR HEALTH CARE COVERAGE CHANGE WHEN THE PERSON TURNS 18 YEARS OLD?

There are several things that may impact the answer to this question. The world of insurance coverage is in a constant state of change. Even though we have shared some situations – **we strongly advise that parents/guardians contact their insurance carrier, the Social Security Administration and/or a Human Service representative to confirm their individual situation.**

The following briefly summarizes some of the issues:

1. If the young adult with PWS has been receiving their health insurance coverage under their State Medicaid program prior to the age of 18 years, he/she may need to take steps to assure that this continues. Prior to the age of 18 years, Medicaid coverage (as the primary health insurance) is typically dependent upon the assets of the parents. Once a person turns 18 years old, they no longer are tied to their parent's income and assets so they most likely will still qualify, however steps may be needed to confirm and/or change things. They may qualify for additional funding and coverage under the Supplemental Security Income (SSI) program under the Social Security Administration. In some cases, persons with PWS may have been receiving Medicaid under a program called Katie Beckett, which is not income dependent. It is a program however that is age dependent and a child can only receive funding up until the age of 19 years. A child must meet strict eligibility requirements including meeting the federal standards of disability as defined by the Social Security Administration.
2. If the young adult with PWS applies for Supplemental Security Income (SSI) and begins to receive this funding, Medicaid is typically attached to it. Discuss this with a human service representative or contact the Social Security Administration office in your area.
3. If the young adult with PWS has been receiving health care coverage under their parent's insurance plan, this should continue. Since the passage of the Affordable Care Act (Obamacare) in 2010, dependent children are able to remain on their parent's health insurance until the age of 26 years.
 - a. Some insurance providers allow coverage beyond this age for dependent disabled children.
 - b. Some may terminate this coverage once the person moves out of the parent's home if they no longer meet "dependent" criteria as defined by the Internal Revenue Service (IRS).
 - c. Check with your insurance carrier.
4. If the young adult with PWS' parents or legal guardian (sometimes grandparents assume care for their disabled adult grandchild) begins to receive Medicare – insurance coverage may change to Medicare as well. Contact the Social Security Administration for specific information about this situation.

Saving and Transforming Lives!

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**8588 Potter Park Drive, Suite 500
Sarasota, FL 34238**

**Tel: 800.926.4797 or 941.312.0400
Fax: 941.312.0142**

**E-mail: info@pwsausa.org
Web: www.pwsausa.org**

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