

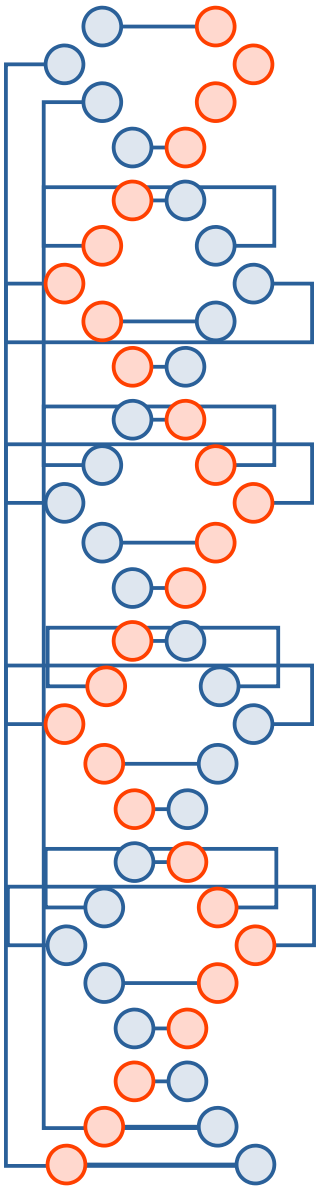
Meaningful Employment for People with PWS Based on the Israeli Model

By

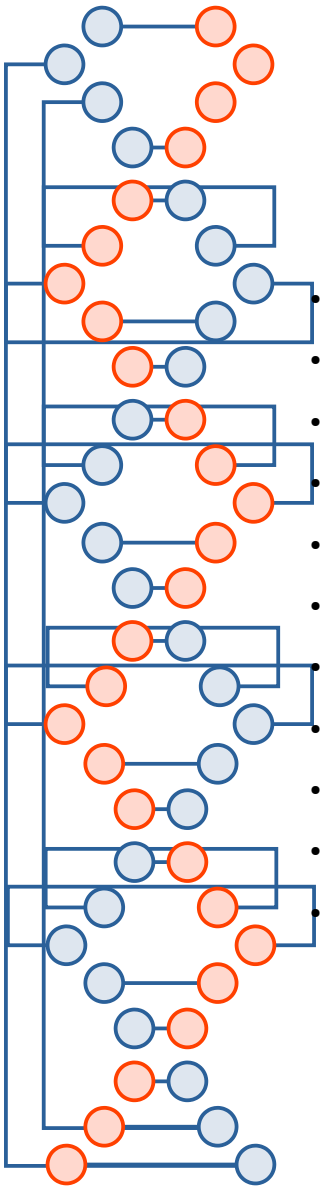
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Factors Determining Ability of Employment



- Age of the person
- Level of cognitive functioning
- Degree of need for staff supervision / ability of the person to withstand temptations
- Degree of availability of food or other temptations
- Availability of transportation to and from work
- Ability to learn a profession or occupation and if so, what are the available opportunities for training
- Motivation of the person to work at a particular job
- Degree of behavioral control/OCD/tantrumming behaviors, etc.
- Degree of ADHD if any
- Additional factors,if any (i.e., autism, epilepsy, diabetes, etc.)

General Types of Employment Opportunities



Sheltered Employment in a Workshop Setting

- Sheltered Employment in a Regular Work Setting

- Group Supportive Employment in a Regular Work Setting

- Individual Supportive Employment

- Group Independent Employment in a Regular Work Setting

- Individual Independent Employment

Examples of Israeli Programs



•Group Training in Care of Elderly Patients in a Facility for the Aged

- Four residents began a program for work with the elderly:

- Four days a week, they sat in class and learned first aide, development in old age, medical problems of aging, problems of communication, nutrition, feeding techniques, hygiene, etc.

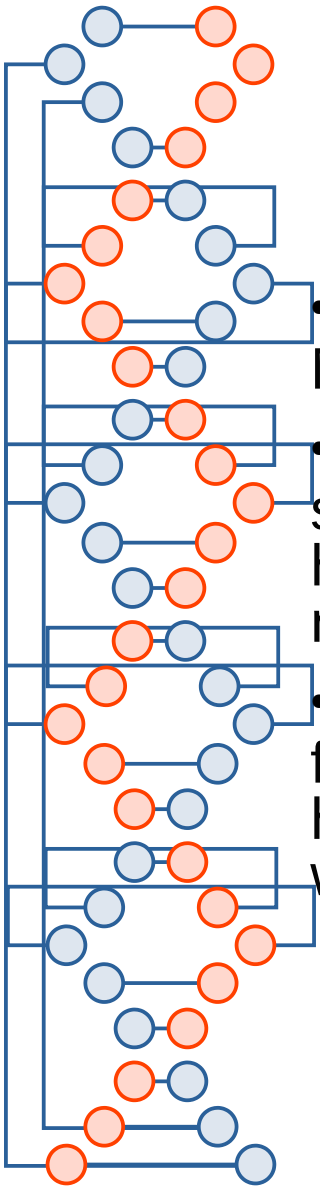
- One day a week, they worked in a facility for aged people with dementia and medical problems

- After several months, they sat in class 3 days a week and worked two days a week

- After several more months, they sat in class two days a week and worked three days a week.

- Then Corona hit and their program was discontinued. The program continued for 3 years

Examples of Israeli Programs

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- Training in sterilization of dental tools in a School of Dental Medicine:
 - One man took a course for 12 months in all the processes of sterilization of all the different tools used in the school, which also has a clinic for low-paying patients and patients with special needs that regular private dentists rarely treat
 - Upon completion of the course, it took them several months to find him a job, but he has worked there for almost 3 years. He has not lost weight the way he did before, but he functions very well and loves his job.

Examples of Israeli Programs

•Teacher's Aide in the Computer Lab of a Local Elementary School

- One man did two years of National Service in the computer lab of the school.
- He was very successful with the children and with the teacher with whom he worked
- Upon completion of the two year program, he was offered a job at the same school doing the same work, helping the teacher and the students in the computer lab
- During his first 1.5 years, he had many issues of food stealing, from the Teachers' Lounge, etc. But during the past 2 years, there have been very few incidents and his BMI is around 19. He loves his job. He now is studying Education at a local teachers' college in Jerusalem.
- The school is in the neighborhood of the group home, so he walks and group home staff have contact with the teacher with whom he works and with the principal

Examples of Israeli Programs

•National Service in the Local Chapter of the SPCA

•One young woman was accepted to a program of National Service at the Jerusalem branch of the Society of Prevention of Cruelty to Animals

•She works with cats

•She cleans cages, feeds the cats, fills the water receptacles, travels independently by public transportation

•She has issues with food stealing from other workers, but not frequently and the staff received training re: this and are dealing with it well

•She has issues of OCD, which affects her functioning, but she does her job well and is appreciated

•She loves her work and hopes to stay there for her second year as well

Examples of Israeli Programs



• **Women Working as Aides in Preschools**

- Two women, who worked previously with the elderly, were offered jobs in two preschools
- The programs serve children from age 6 months until 3 years of age
- They are integrated with the regular staff
- They perform all the tasks that the rest of the staff perform: feeding, changing diapers, playing with the children, dancing with them, reading to them, etc.
- They travel independently taking 2 buses each way.
- They both have had food security issues but have been in pretty good control

Examples of Israeli Programs



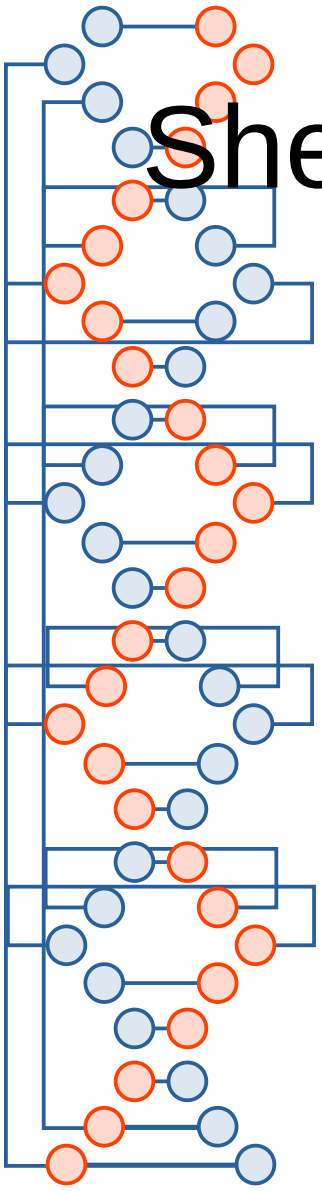
- **A Man who Worked in a Sheltered Workshop, then in a Group Supportive Employment Program and Now in an Individual Supportive Employment Setting**

- He began in a sheltered workshop for 11 years

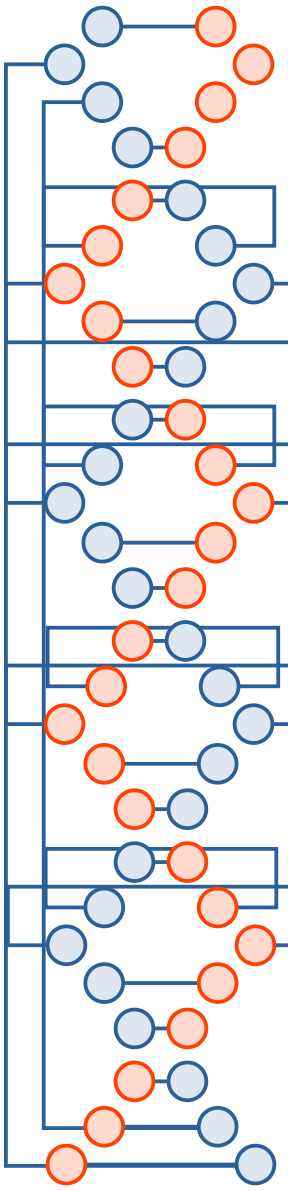
- He then was "promoted" to a Group Supportive Employment Program, where he did essentially the same kind of work but in a regular work setting

Sheltered Employment Long Term

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- We have several lower functioning clients who work long-term in sheltered workshops. They find the work appropriate for them, have few behavioral issues there, are happy in their work and will probably remain there for the foreseeable future.



Age of the Person

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- It is well known that many people with PWS have a lessened degree of behavioral issues beginning in their 30s.
 - Therefore, people with severe behavioral issues may not be able to utilize their native abilities in younger ages.
 - In our experience, people in their 40s have even fewer behavioral issues.
 - At any age, all of the above issues need to be addressed when planning employment for people with PWS
 - However, it becomes easier as the age of the person increases

Levels of Cognitive Functioning



Moderate level of intellectual disability – requires more intensive staff supervision

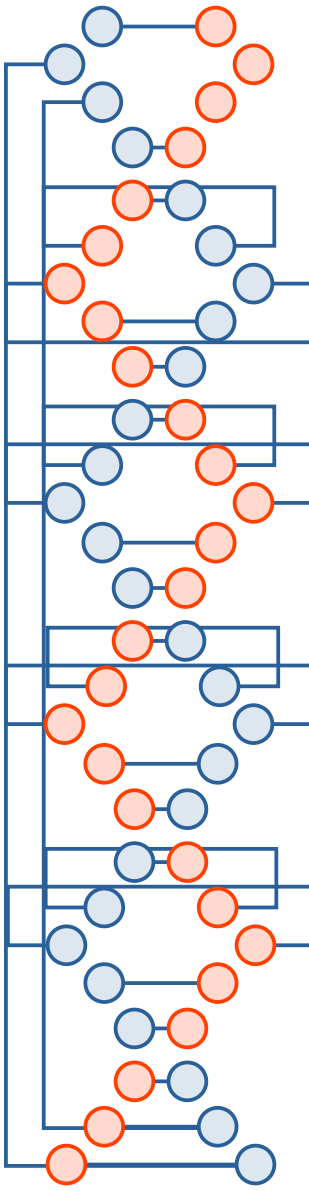
- Mild level of intellectual disability – requires less intensive staff supervision, if there are no additional factors

- Borderline level of intellectual disability – requires supervision based on other factors. This alone would not require supervision

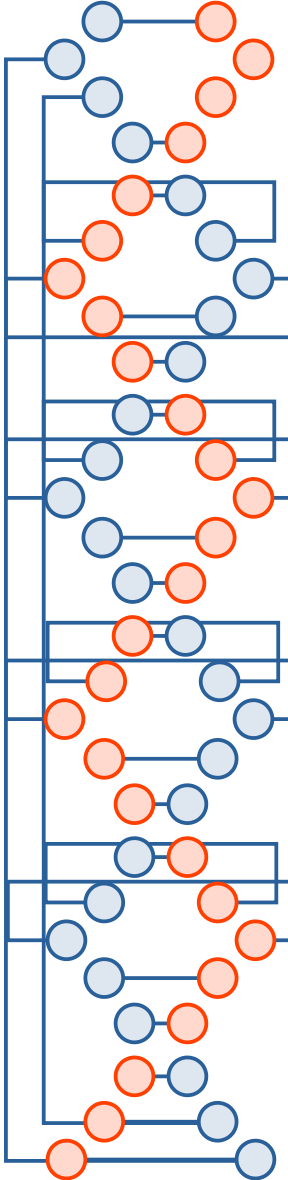
- Low normal level of intellectual functioning – requires supervision based on other factors

- Normal level of intellectual functioning – requires supervision based on other factors

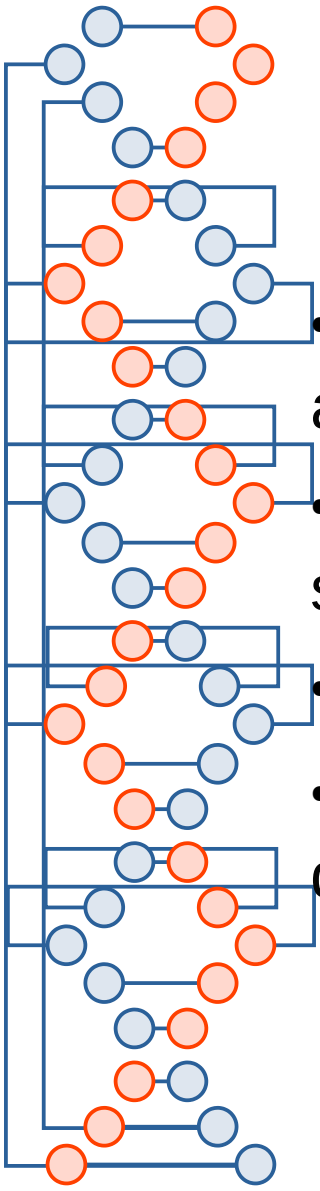
Degree of Need for Staff Supervision

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- Level of anxiety – the higher the anxiety the greater the need for supervision
 - Level of Obsessive-Compulsive Disorder
 - Ability of the person to deal with tempting stimuli (i.e., food, drink, etc.)
 - Level of threshold to frustration (tantrumming, perseveration)
 - Ability to attend and length of time able to attend
 - Need for movement or ability to work seated over time
 - Food Security in place
 - All activities, meals, breaks, and requirements written out and posted

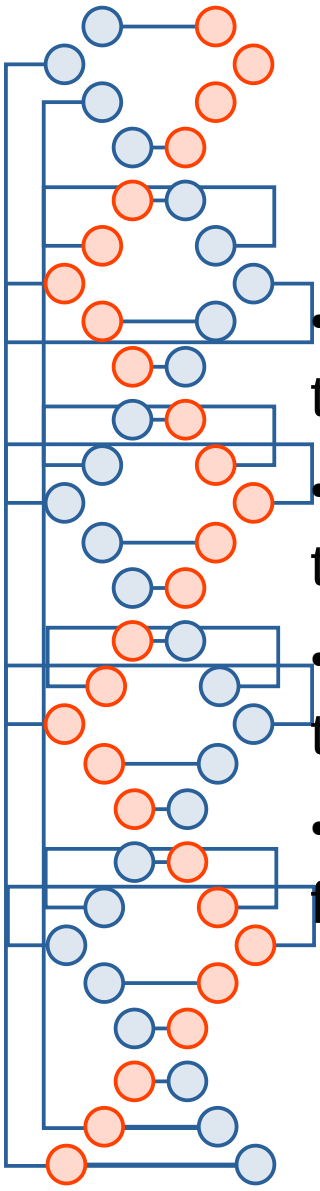
Degree of Availability of Food and Other Temptations

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- Food Security – All foods are locked and out of range of vision of the workers
 - All meal plans are posted (time of meal, contents, place, quantities)
 - No possibility of accessing food outside meal plan
 - Close supervision especially at meal times
 - Close supervision during break times
 - Staff accompaniment of workers to bathrooms and any other places outside the work room

Transportation to and from Work

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- For groups, transportation by van with staff supervision (in addition to the driver)
 - For smaller groups, possibility of public transportation with staff supervision
 - Individuals may travel by public transportation
 - There may be some high-level functioning workers who drive, so they may drive to work

Professional and Occupational Training

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- When group occupational training is available, suitability needs to be evaluated
 - When group professional training is available, suitability needs to be evaluated
 - When group training is not available, individual training needs to take into account suitability and the above-mentioned variables
 - All training needs to take into account the needs of the work force so that appropriate job placement may be made

Motivation of the Worker

•Does the worker want to work?

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•If so, does he have a realistic idea of his skills, abilities, interests, ,etc.?

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•Is his self-evaluation consistent with job opportunities?

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•Does he want to work with the other workers with whom he would be placed on the job?

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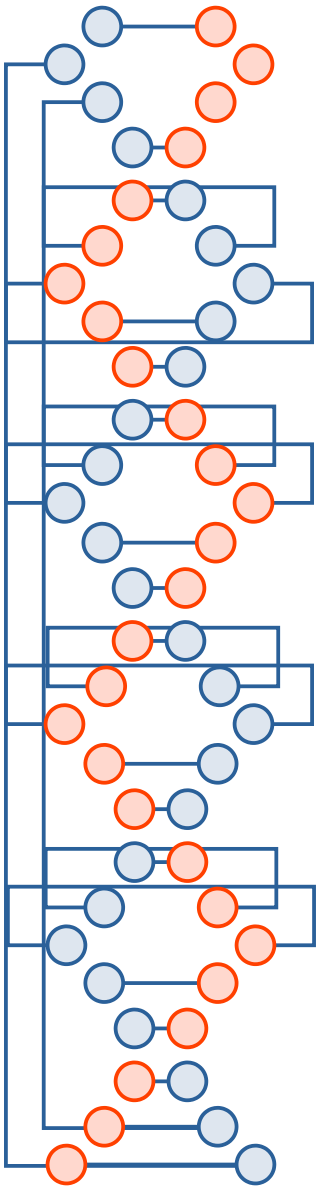
•Are his behavioral skills commensurate with the needs, rules, , etc. of the possible job sites?

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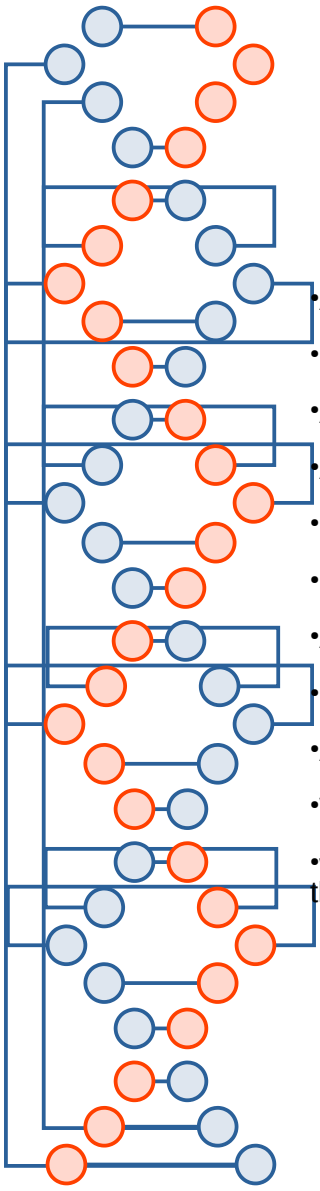
•Is there appropriate remuneration for the job required, thus motivating the worker more?

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•When motivation of the worker changes, are there alternative options?

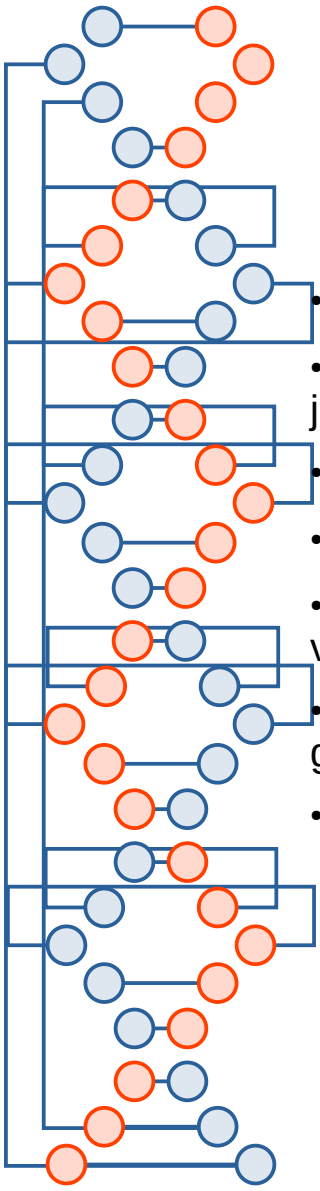


Behavioral Issues Affecting Job Placement

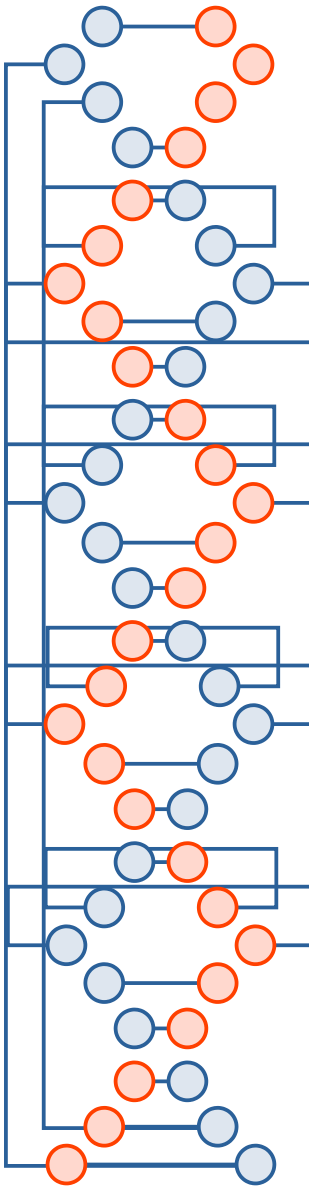


- Are there tantrum behaviors among the workers?
- If so, are the various job placement opportunities able to cope with tantrums?
- Are there known triggers to the tantrums, presenting the possibility of preventing at least some of them?
- Are there obsessive-compulsive behaviors affecting work performance?
- Is the staff on-site well-trained to deal with behavioral issues?
- Is there the option of separating a tantruming worker from the rest of the group, as in a separate room?
- Are there behavioral reinforcements in the work plan in order to allow the worker to feel compensated for behavioral self-control?
- Is the staff providing on-going verbal reinforcement?
- Are the behavioral rules and requirements posted in writing?
- When behaviors preclude the worker from continuing at a particular job site, are there other options without leaving the worker unemployed for long periods of time? It is usually detrimental for the person to be unoccupied for more than short periods of time.

How Can Attention Deficit Disorder be Handled?

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- Is the attention span required for each job commensurate with the abilities of each worker?
 - When attention span is an issue, is there the possibility of allowing movement as part of the job, thus breaking down the attention required to shorter units?
 - Are there stimuli in the work environment which may affect attention to task?
 - Are other workers ' disturbing behaviors causing increased attention deficits?
 - It is possible to reduce problems of short attention spans by providing ongoing verbal and non-verbal reinforcement at intervals based on the average attention span of the group.
 - When the average attention span of the group allows for on-going work, then the staff can gradually increase the demand of gradually longer spans by ongoing reinforcement.
 - Written demands of the job need to be posted and gone over frequently.

Additional Factors Affecting the Worker's Ability to Perform on the Job



•Autism Spectrum Disorder (ASD)-- ASD may affect attention span, quality of attention, behaviors (as tantrumming, obsessive-compulsive behaviors , perseverative behaviors, mood swings, over-reaction to light, sounds, touch, etc.). If medications are being given, they may also affect job performance.

•Diabetes (both Juvenile and Type 2) – Requires intensive staff training, to deal with fluctuations of blood sugar levels, especially when hypoglycemia occurs. Also requires regular meals based on a dietitian's diet plan, including during work hours. When seemingly behavioral issues occur, first the worker's blood sugar level must be checked. Low and high blood sugar levels affect behavior. Also, the staff needs to be trained as to how often blood sugar needs to be checked and if, when, and how much insulin needs to be injected.

•Epilepsy – Medications may affect behavior and job performance.. Also, if there are bodily signs of an impending seizure, the person will react. And the staff needs to be well-trained to deal with a worker during a seizure.

•Other Medical Issues

•Skin picking may affect job performance.

•Acute visual perceptual skills are common in people with PWS, thus, all communication should include visual components.

Types of Employment Opportunities



Sheltered Workshops

- Often for lower functioning workers. There are also workshops with quite sophisticated job skills required for higher functioning workers.

- The work is in a protected environment.

- Staff are constantly present.

- Meals are eaten there, based on the meal plan.

- The workers work in groups.

- Breaks are taken at the workshop

- Job skills are limited.

- Remuneration is limited

- Written schedule of work, meals, breaks, etc. is posted.

- Regular staff not familiar with PWS is trained re: the syndrome and needs of the workers with PWS

Types of Employment Opportunities – Continued



•Sheltered Work in a Regular Work Setting –

- Work sites which can accommodate groups of workers with special needs.
- Often placed in a separate area of the work site
- Given types of work typical of regular sheltered workshops, just that the work site is in a regular job site.
- Staff are constantly present.
- Meals are eaten there based on the diet plan
- The workers work together in groups.
- Written schedules of work tasks, meals, breaks, etc. are all posted
- Transportation is provided with staff present in the van
- Regular staff not familiar with PWS is trained re: the syndrome and needs of the workers with PWS

Types of Employment Opportunities – Continued



•Group Supportive Employment –

- Placement of a group at a regular work site.
- Job tasks are similar to those of regular workers, but less demanding.
- Remuneration is less than that for regular workers.
- A staff person is with the group during all working hours and is also with them during transportation to and from the job site.
- All meals are eaten at the job site with staff supervision, based on the diet plan
- Breaks are taken at the job site.
- All tasks and plans for the day (including meal plans) are written and posted
- Transportation is either by van or on public transportation with staff
- Regular staff not familiar with PWS is trained re: the syndrome and needs of the workers with PWS

Types of Employment Opportunities – Continued



• **Individual Supportive Employment**

- The worker is placed at a regular job site
- Work tasks are similar if less demanding than that of a regular worker
- Remuneration is based on an evaluation by an occupational therapist based on percentage of functioning based on the functioning of a regular worker
- A staff person visits the job site either weekly or more often if needed
- The worker is integrated into the regular work force of the job site
- He must arrive and leave independently, via public transportation
- Regular staff not familiar with PWS is trained re: the syndrome and needs of the worker with PWS, if needed

Types of Employment Opportunities – Continued



•Group Independent Employment in a Regular Work Setting

- Employment in a regular work site
- Tasks are similar to those of regular workers
- A staff person is present with group as needed
- Transportation is usually via van
- The group is integrated into the regular work force
- Remuneration is based on the average functioning as compared to that of a regular worker
- Written daily tasks, meals, etc. should be posted
- Regular staff not familiar with PWS is trained re: the syndrome and needs of the workers with PWS if needed

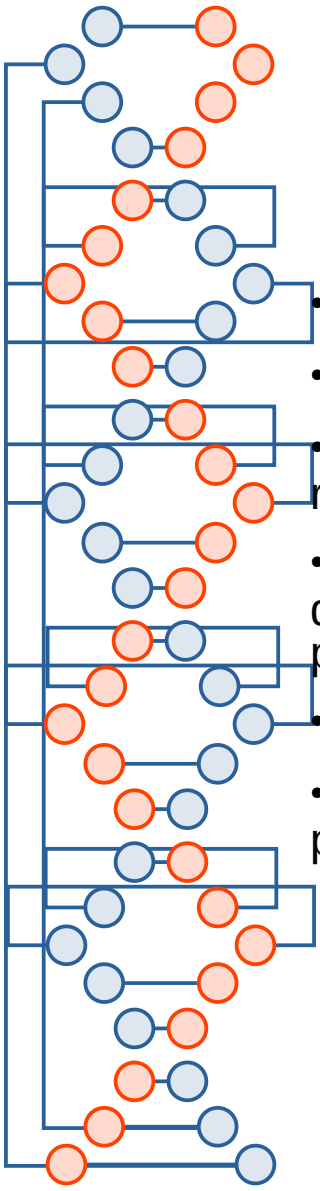
Types of Employment Opportunities – Continued



• **Individual Independent Employment in a Regular Work Setting**

- Employment in a regular work site
- Tasks are similar to those of regular workers
- Staff contact is made intermittently with work site
- Transportation is via public transportation
- The worker is integrated into the regular work force
- Remuneration is based on the average functioning as compared to that of a regular worker
- Written daily tasks, meals, etc. should be posted
- Regular staff not familiar with PWS is trained re: the syndrome and needs of the workers with PWS if needed

Professional and Occupational Training

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- There are many people with PWS who can learn an occupation or a profession
 - There are some vocational training programs that accept groups of trainees
 - There needs to be the option of sending the trainees with a staff person who is responsible for food, behavior, breaks, transportation, and any other needs that arise
 - When group training is not an option, then individual training may be possible, depending on the abilities of the person and the ability of the training facility to provide a degree of supervision
 - The training may be long-term (1 year, 18 months) or short term (3-6 months)
 - Upon completion, job placement is absolutely necessary, even when group placement is necessary

Discussion

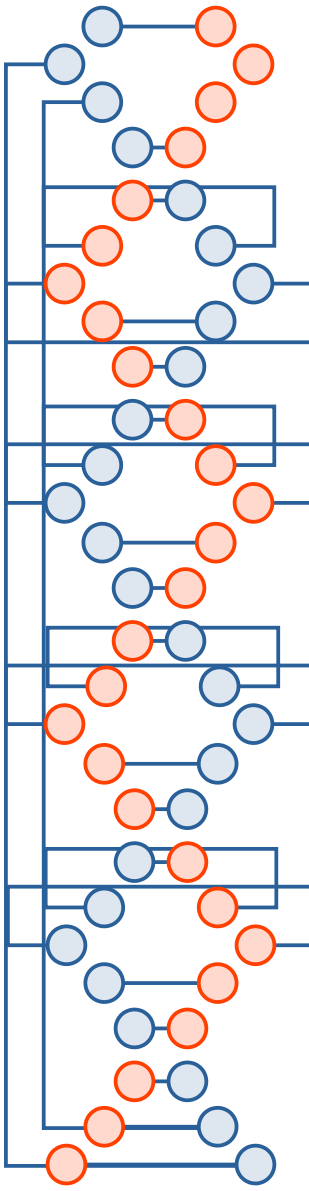


Is there a tendency in various countries for vocational placements to end up being permanent despite progress made by the clients?

Are programs in place in the various countries for vocational training?

Are the placements made with the need to check if and when the client can progress to more sophisticated work and/or a less restrictive environment?

Discussion – Continued



What are the factors taken into account regarding the need for supervision and food security as opposed to job advancement and independence?

How often are clients evaluated for appropriateness of placement?

When a client is placed appropriately in a sheltered workshop, how can he feel properly reinforced even if he cannot move up to a less restrictive environment, over the course of time (maybe years)?

Discussion – Continued



When do the factors regarding progress of the client come into conflict with the agencies providing services?

In Israel, often when an agency places a client in a particular vocational setting, there is a tendency to just leave the client there, even for years, despite increased/improved functioning. How is it in the various countries?