

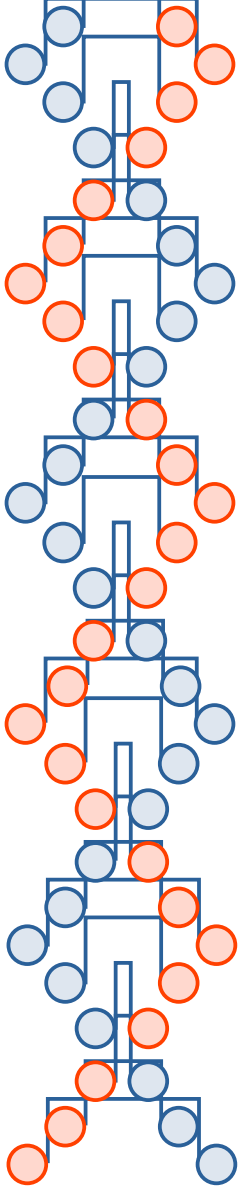
Meaningful Employment for People with PWS Based on the Israeli Model

By

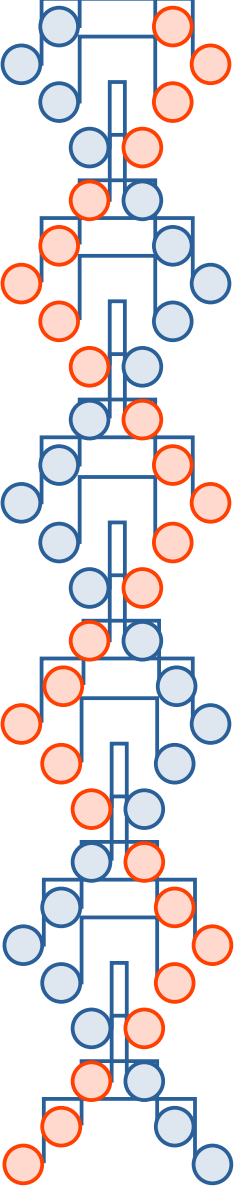
Larry Genstil, Ph.D.

Psychologist

Israel



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/tantruming behaviors, etc.
 - .Degree of ADHD if any
 - .Additional factors, if any (i.e., autism, epilepsy, diabetes, etc.)
 - .Ability to take directions and respect authority
 - .Ability to get along with co-workers



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
(extremely rare for a person with PWS)

- .Individual Independent Employment (extremely rare for a person
with PWS)

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. Up until that time, the program continued for 3 years



Examples of Israeli Programs

- .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 several months to find him a job, but he worked there for almost 3 years. On the job, he had not lost weight the way he did before, but he functioned well and loved his job. He was recently fired for continuously wandering looking for food and difficulties in accepting authority. He needed more supervision which the dental school could not provide.



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 volunteer 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 worked with cats

.She cleaned cages, fed the cats, filled the water receptacles, and traveled via taxi

.She had issues with food stealing from other workers; the staff received training re: this and dealt with it but were not happy about her behaviors

.She had issues of OCD, which affected her functioning, but she did her job well

.She loved her work and was able to stay there for two years

.Due to the lack of close supervision, it was clear that this was not a long-term solution for her



Examples of Israeli Programs

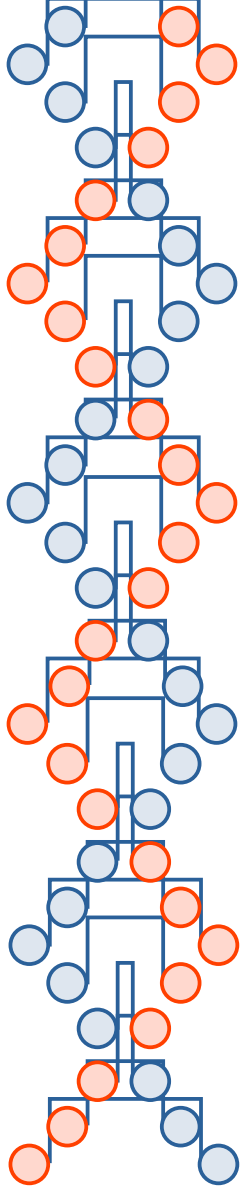
.Women Working as Aides in Preschools

- .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 were integrated with the regular staff
- .They performed 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 traveled independently taking 2 buses each way.
- .They both had food security issues and due to this problem, they both discontinued this employment
- .We learned that the need for supervision is paramount



THE ORIGINAL PLAN FOR DEVELOPING VOCATIONAL PROGRAMS – VOCATIONAL EVALUATIONS

- As the result of the issues causing failures, it was decided to conduct in-depth vocational evaluations
- Each worker with PWS was intensely evaluated over 3 months:
 - *Abilities*
 - *Interests*
 - *Emotional Stability*
 - *Behavioral Functioning*
 - *Ability to Attend to Task*
 - *Attention Span*
 - *Ability to Work with Co-Workers*



Upon Completion of the Evaluations

- .A written evaluation was given for each worker**
- .Plans were then made to implement the recommendations, based on the results of the evaluations**
- .Then COVID hit and all plans were cancelled**

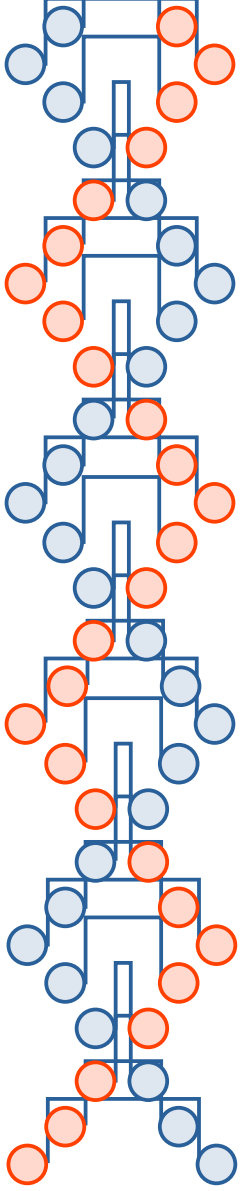
AFTER COVID ...

.As programs began re-opening in Israel:

.There were attempts to partially implement the recommendations of the evaluations

.There are now some occupational training programs, with more being developed

.There are also some on-the-job training programs



Age of the Person

- .It is well known that many people with PWS have a decreased 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



Food Security

As Developed by Drs. Linda Gourash and Janice Forster

All people with PWS require supervision regarding food

The diet plan should be posted for all to see. It needs to include what is to be given, how much, and when, leaving no doubts, no hopes for more or something else and no disappointments, thus improving behavior.

This procedure is crucial to allow better behavioral functioning no matter level of cognitive functioning.



Degree of Need for Staff Supervision

- .Level of anxiety – the higher the anxiety the greater the need for supervision
- .Level of Obsessive-Compulsive Disorder (OCD)
- .Ability of the person to deal with tempting stimuli (i.e., food, drink, etc.)
- .Level of threshold to frustration (tantruming, 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

- .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

- .For groups, transportation by van with staff supervision (in addition to the driver)
- .For smaller groups, possibility of public transportation with staff supervision if worker behaviors allow
- .Individuals may travel by public transportation depending on the need for supervision
- .Despite some with high cognitive levels of functioning, many have behavioral difficulties with independent travel

Professional and Occupational Training

- .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, including degree of supervision required by the person
- .All training needs to take into account the needs of the work force so that appropriate job placement may be made upon completion of the training



Motivation of the Worker

- .Do the workers want to work?
- .If so, is there a realistic idea of their skills, abilities, interests, etc.?
- .Is the worker's self-evaluation consistent with skills, abilities, interests, job opportunities, etc.?
- .Are their social skills such that they can get along with the other workers with whom they would work?
- .Are their behavioral skills commensurate with the needs, rules, etc. of the possible job sites?
- .Is there appropriate remuneration for the job required, thus motivating the worker more?
- .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?

- .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.
- .Often, allowing for movement during job-performance increases attention span



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 tantruming, 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 by an endocrinologist or a diabetes nurse 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. Also, due to these high visual perceptual skills, jobs requiring more visual perception will allow the worker to perform better



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. This staff must provide the degree of supervision required by the worker

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

- .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?