



EJA WP6
Specialised Social Services
Workshop
Guiding Principles for Specialised Social Services
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Prader-Willi Syndrome Group Homes
Denmark



EJA WP6 Workshop on Guiding Principles for Specialised Social Services

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to be happy all life



Adults with rare diseases

- * Important:
- * To be happy and to be loved
- * Avoid serious diseases
- * Have the possibilities for development according to a persons capacities
- * *How can this be realised ?*
- * *How can you live with a rare disease?*

What is important

- * To have a habitation/home where important things in your life can be realised
- * The costs are not necessarily high
- * But knowledge is important
- * Prejudices can be a great obstacle
- * Family, the community/ staff must accept the realities of a given diseases, and work for it !

Why adapted housing

- * Some very special needs demand a special service
- * Planning of daily activities, meals, leisure, work
- * When the disease is so "special" that the needs can not be honoured if the major part of the inhabitants has quite other needs, except if the person has a personal assistant for 24 hours.
- * Even then it can be difficult
- * In adapted housing the residents have the same needs and resources can be used more optimally

Education of staff

- * When a rare disease is very complex with many different symptoms , it takes some time to become "a specialist" carer
- * Education of staff is essential before they start their work in the house /home
- * Later the "expert staff " can educate new staff/carers
- * Continious education of all staff about the disease is also important (new information)

Challenges. Risk for becoming isolated

- * When living in an adapted house facility contact to "outside" is important
- * Being together with others not having the same disease can be inspiring, but should never become a demand
- * Inhabitants in the adapted house can participate
- * (with support) in leisure activities, sports, work where others with other diseases

Why is Prader Willi Syndrome a good example but also very difficult

- * No one can live independently , in spite of...
- * A congenital disease with near normal lifetime if treated correctly
- * Both medical and behavioural problems.
- * Often difficult for the authorities to accept the needs and symptoms of the condition
- * Family/ staff need a very careful education
- * Otherwise it will not be successful

Prader Willi Syndrome

- * Congenital disease
- * Genetically confirmed : chromosome 15
- * Two main symptoms beside many others:
- * 1. extreme floppiness incl. eating difficulties during the first months
- * 2. abnormal interest for food and hunger obvious at age 1-3 years :

No one with PWS can live independently

PWS a long list of symptoms

- * Delayed motor development.
- * Small muscles. Low final height.
- * Hormonal deficiency: Growth hormone, sex steroids
- * Intellectual impairment. IQ ca. 40 “below family “
- * Socially and emotionally immature
- * Behavioral problems: severe in some, not all
- * Psychiatric diseases, especially adults with UPD
- * IF overweight: medical problems: heart, legs etc
- * Scolioses, joints, eye and teeth abnormalities.
- * Abnormal reactions to pain, temperature, emotions

PWS and living ... facts

- * Living without specialized support: the results are:
 - * overweight
 - * behavioral problems
 - * EARLY DEATH (before age 20)
- * No one with PWs has ever lived independently without support without dying at a young age
- * Also adults living with parents are often very or sometimes extremely overweight

PWS . Adult Capacities

- * Varies a lot.
- * Emotional and mental state influences
- * Many are capable of: (most with some guiding)
- * Personal hygiene, dressing
- * Cleaning, laundry, tidying ,gardening
- * Practical jobs(cleaning, sorting, stamping)
- * When secure and calm: good workers.
- * Motor activities: swimming, riding, jogging etc.

How is life in Denmark

- * For many years :
- * most adults with rare diseases most often do not live with their parents
- * Before we had the big institutions , especially for mentally retrained.
- * After 1970-1980, this has changed

To day in Denmark

- * Adults with physical disabilities can live in own apprtment with help according to their needs. Can be 24 hours assistance
- * Most adults with psychiatric diseases live in own appartments, receiving help from psychiatric nurses by regular visits
- * Adults with mental handicap most often live together in houses often 5-8 together with staff support according to their needs.

Where and how do they live

- * Most often adults with different syndromes live together in the same house(group home) and also work together.
- * Education of staff about the various diseases varies a lot. Usually they are informed in general terms but not educated about specific symptoms in a special syndrome.
- * Living facilities with focus on autism and ADHD exists, beside group homes for PWS

Prader-Willi Syndrome before

- * Before 1980-1995 many adults (if alive) lived with their parents or in houses together with 5-7 others with other diseases (mixed group homes)
- * Many stayed at home until the parents could not cope anymore, because the parents found that together with others not having PWS it was often not a successful situation
- * Because food was not sufficiently controlled

PWS specialized living facilities

- * Started in Denmark in 1988.
- * Two adults with PWS were in the same “home”
- * Two of the staff realized that the needs and behavior in PWS were so different to what they had ever seen before, very different from the other inhabitants
- * Because: The main goal in the house was to teach independent living. They saw that this was unrealistic, even not ethically correct to expect

PWS group homes in DK

- * A subgroup in the house was created and a third with PWS moved in, and later one more
- * The two caregivers went to USA to visit PWS group homes.
- * They wrote a book: ***The story of the fridge.***
- * Describes the day for 3 adults with PWS in the house.
- * The conflict with those with PWS :
- * Most of the conflicts started in front of the fridge

Conflicts often started when :

- * A person with PWS did not know if he/ she could have something more to eat during a meal time.
- * A person with PWs was accused for having eaten something without having had the permission.
- * A person expected something that then did not happen, the expectation eventually not known by the staff, a misunderstood message

Perhaps most striking...

Conflicts arose:

When the staff had the expectation or wish that

the person with PWS, eventually just for one evening, should try to behave as if he/ she did not have the PWS.

Example:

send someone alone to a party with 20 Euro

The conclusion

- * PWS is in many aspects different to all other diseases.
- *
- * The staff is facing situations they have never met before.
- * The staff has to understand the disease

What to do ?

- * We buy and prepare and serve the meals
- * We calculate the amounts to eat for each according to their needs
- * Because this is the key problem of the disease
- * We do not discuss food or the amount served
We make a clear plan for the daily activities

This has not been easy

- * Not all staff agreed
- * Not all parents agreed
- * Some of those with PWS did not accept

- * But they succeeded
- * Those with PWS lost weight
- * Conflicts became less
- * Those with PWS relaxed

and then...

- * Staff from habitations where others with PWS lived got in contact

More “sub groups with PWS “ were strated

Staff from various”PWS HOMES” met and exchanged ideas.

.The main principle became:

We take the responsibility for the food and

We have a visible clear plan for the day

PWS in Denmark to day

- * In Denmark we are 5.5 million
- * 150 - 170 ? with PWS
- * We have 10 “group homes PWS”
- * 70-80 adults with PWS are living here
- * Beside there are more facilities with 2-3 with PWS together with others. It can be places where the main “problem” or concern is the behavior.

continuously 5-10 with PWS need a “home”

A “typical” PWS group home does not exist

- * The group homes are different but with some basic similarities:
- * The staff take the responsibility for the food.
- * Persons with PWS are never alone in the kitchen
- * Most places also have someone (educated)preparing the food and in continuous contact with a dietician

The staff in Danish PWS ”group homes”

- * Numbers of staff are according to inhabitants needs
- * Staff/carers are educated: speacial teachers or social workers (3-4 years education). There can be uneducated helpers , but there is always educated staff at job
- * Most places have overnight personel

In the group homes

- * Not all homes have an apartment for each with PWS, some has only a room and inhabitants share bath room, but final goal is a private apartment for each with two rooms (living- and bedroom) and bathroom.
- * No one needs a kitchen as all meals are served
- * No one shares bedrooms

Old age and special needs

- * This year a new section has been established as part of an existing group home:
- * A new house especially for persons with PWS with extra needs has been constructed.
- * Here there are resources for those with more severe disabilities both psychiatric and physically:
- * Why now:
- * Persons with PWS are becoming older/ are surviving

Work

- * Where the persons with PWS work varies a lot
- * Some work together at the same place some so not
- * Most often the place work is not far away

Who pays

- * The adult person with PWS most often receives a full pension from the state.
- * (pension for people with disability is much more than the “pension for old people”)
- * With this you pay the rent for the apartment and food and personal needs
- * Receiving this pension means that you are not capable to work like others, but does not mean that you cannot work. But already “paid” you are not receiving an extra salary for your work.

Who pays also

- * The municipality pays to cover:
- * The staff, running the house.
- * Some homes are municipal
- * Some are regional (5 regions in DK)
- * Some are private in origin , but also paid by the municipality and regions.
- * Not paid by fundings or private organisations
- * Health care system/ health assurance is not involved

Who decides

- * There is no law saying that group homes for PWS have to be established
- * The law says that the municipality has the duty to offer a habitation to a person with a handicap where the persons needs are covered.
- * If you ask for a habitation for a person with PWS you are offered a "mixed home" with access to food
- * Or they try to find an already established home
- * Many social workers do not believe in the problem

Still it is not easy

- * The municipalities are most often not interested in creating a special group home
- * So often for a young person with PWS start at point zero once more
- * ***All Danish PWS group homes have been established because there have been someone with some authority that have understood the problem.***
- * If there is not such a person being responsible for special habitations it is difficult

Grankoglen, the first house designed for PWS



How it started here

- * The story
- * One young women with PWS was living in a mixed group home. Two more young people in the same area needed a place to live.
- * I was contacted, through the Danish PWS association who knew I was looking for a habitation for my son (20 years old)
- * With the four the group home strated

.

1999 Spruce cone on Spruce hill road

- * Started with a rented house in a village
- * 4 young with PWS aged 20-22 years
 - One room for each
 - Sharing 2 bath rooms and one living room

Staff overnight

Education of staff

- * The first month before the young people moved in the staff was educated about PWS
- * Staff visited other PWS group homes
- * Staff from other group homes and medical doctors , dietician etc gave lessons

Adults with PWS living in SpruceCone

- * How the contact to staff is organised
- * Everybody has his/her personal contact person among the staff being “the responsible personel”
- * This person is the responsible for medical visits, buying personal needs, contact to parents etc
- * and first of all to answer important questions so that the one with pWS feels secure, and does not ask everybosity all the time (which many with PWS often do)

Meals

- * Normal days:
- * 7.30 : breakfast
- * 10. : coffe with bread
- * 12.30 Lunch
- * 15.00 coffee with bread and fruit
- * 18.00 Dinner. Served porions
- * 20.30 a drink/ coffee water with bread/ fruit
- * WE days :900(brunch)-2.30 - 15.00- 18.00-21.

To be fit

- * Once a week a physiotherapist comes.
- * Everyone has his/hers individual program
- *
- * individual and group training

beside: swimming and horse back riding
1-3 times per week..

Doctors visits

- * According to needs.
- * Vision : every sec year. Dentist 2 times p.y.
- * All comes 1-2 or more times to the PWS Center in Århus for check up
- * Pædaitric neurologist
- * Orthopædic
- * Dietician
- * And more

The adults and their staff

- * 8 adults with PWS. With various needs
- * 5 girls (25-33 years)
- * 3 boys (19 – 30 years)

- * Staff : 17 (37 hours per week, incl night hours)
- * a leader 37 hours
- * a “cook” comes every morning and prepare

At the beginning

- * The house was part of a bigger institution /house :Spruce hill for adults with cognitive retardation, who worked and trained to become independent and after 1-2 years moved to own appartement
- * So the first Spruce Cone was not a permanent solution
- * So what to do ?

How to continue ?

- * The habitation was not at permanent solution
- * The young persons with PWS went to school or worked
- * At the same time more looked for a place to live

And then

- * The staff and the director wanted to continue!
- * And had the courage
- * An architect was contacted
- * Told about PWS
- * He designed the new house:
- * 8 apartments, for two groups of 4
- * a house with common kitchen, living room etc

The new Spruce



Apartment from outside



Apartment from outside bedroom, livingroom



The house



The gym and meeting rooms



Gym



Livingroom (Mikkell's)



The apartment



Bathroom



Mikkel shows the program for his week



Another apartment



Week plan for 4

	MANDAG	TIRSDAG	ONSDAG	TORSDAG	FREDAG	LÖRDAG	SÖNDAG
Row 1							
Row 2							
Row 3							
Row 4							

Living room



Washing machine. Dryer



A meal



How to prepare the food

- * The cooks works after the guidelines of the dietician
- * All meals are served:
- * The amount served varies according to individual needs

The weight

- * The persons with PWS have their weight measured every morning
- * They often put on weight when visiting families
- * One of the biggest problems about weight management

Dinner at a party day



Crisis ?

- * yes
- * But not because of the food..
- * Other items
- * The pplannings for the days
- * misunderstandings.
- * Can be difficult for all

work



Work and activities

- * Depending on the local possibilities
- * The individual capacities
- * The need for help

School and work at Spruce

- * Everybody has his personal plan for the day
- * There are individual and common activities
- * Those who have psychiatric problems might not be capable of the same activity as others
- * Two women need to rest in the middle of the day
- * 3 men can work outsideio:
- * Garden, office, shop,
- *

“Plan for the week»

	Mond.ay	Tuesday	Wednesd.	Thursday	Friday
morning	All go to the riding school	Girls working with handicraft Boys outside work	school	swimming	School, library
afternoon	Indoor or outdoor work	Indoor or outdoor work	Physical activity physiotherapist	Indoor or outdoor work	

Mikkel and Kasper working



Christopher working



Mikkel ..he loves it



A party.. With others



Mikkel and his primary contact

Lottery

Christmas
Party with
parents



Sunday afternoon



Mikkel and Carina



outdoor



After swimming



Fejøl, they work with horses



Cecilie, Dorthe Karina with Karin(leader)



Pam Eisen in Fejø 2005



Summer camp. 5-6 group homes and more



Also in greenland

A total different culture

But also PW

PWS in Greenland

- * A Nuuk, la capitale della Groenlandia
- * Sono due: Karl 31 anni e Nivi 16 anni
- * Per caso le due famiglie vivono a Nuuk
- * Vivono come fratello e sorella in una casa
- * Personale: 7 (sempre uno nella casa)
- * Nivi va a scuola
- * Karl lavora in una bottega
- * Tutto il personale e` istruito

PWS in Greenland, taken good care of



Nuuk November



Staff



About PWS. Informations to all



Finito

