Social Care Pathways

From people with rare diseases' point of view

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Patients’ reports

- A survey by SINTEF, Norway – 2009
  («Sjeldne funksjonshemninger i Norge; Brukeres erfaringer med tjenesteapparatet», SINTEF Helse/Lisbet Grut, Marit Hoem Kvam, Jan Wilhelm Lippestad, for The Directorate of Health)

  http://www.sintef.no/upload/Helse/Levekår%20og%20tjenester/Sjelden_Sammendrag.pdf
- SINTEF is the largest independent research organisation in Scandinavia.

- Generally: If you have a rare diagnosis, the social care services don’t know much about it – they’ve hardly heard about it.
- And: a common experience was that parents or the person herself had to fight for their rights.

Patients’ reports

- Transitions are difficult
    - from kindergarten to school
    - Between the different kinds of schools
    - From school to a job
    - From home to a group home

Patients’ reports

- People in Social care services don’t know about your rare diagnosis. If it doesn’t show, you can risk that they don’t believe you.
- They will not be able to give you the best care.
  - the same for specialists and local health care.
- Persons with visible handicap easier get response on their applies for services.

Patients’ reports

- The resource centre is important, gives good help and support to get a good life quality.
- Gives you a stronger position when you meet the local services. Confirms your information – it is easier to believe them.
- Gives parents knowledge of diagnosis, rights, and gives practical help, support and empathy.

Patients’ reports

- Kindergarten – positive experiences
- School – often difficult to get individual adapted help. Parents might be told that their child’s needs will take resources from the other children.
- Work – you cannot follow your dreams, but often have to take what you can get,
  - or give up because of your disease,
  - and/or demands of efficiency.

Patients’ reports

- Independency is important
- The support should give the possibility to help themselves – to keep self-respect and human worth.
- It can still be a hard fight to get a good life quality.

- Reform in Norway 1990-1991
  - A revolution for people with mental disability
  - No more big institutions
  - Social care services in your home community
  - The idea was: better life conditions, integration and normalization.
    - («Will we meet *them* in the grocery shop?»)

Two PWS-cases:
Boy, 3 Years old

- Diagnosed after 5-6 weeks
- Kindergarten with extra assistance from 1 year of age – regulated diet (no sweets)
- Physiotherapist in kindergarten
- Special educator ¾ hour every day
- Personal assistance for exercising – 10 h/week
- Growth hormones from 1 year

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- The family gets a little compensation from the municipality – for the care of the boy
- Has also been offered respite home for him
- Not difficult to get help – «but you have to know so much to get what you have a right to get»

But…

- Often differences in what kind of service you get, even with the same diagnose.
- Depends on where you live in the country, what doctors you meet, which municipality, or what social service providers know about rare diseases.
- Example: PWS need growth hormones:
  - As early as possible, or wait until 3-4 years of age or up to 6-7?

My daughter, 36

- Lives in a group home:
  - 5 apartments/persons
  - Separate apartment with kitchen, living room, bedroom and bathroom
  - Permanent staff, also at night
  - Pays a rent – market price, but gets economic support from a state fund


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SIRI Ø ARNESEN

Langarinden group home, 1991 -

Service in the group home

-based on individual needs

- Food/diet
- Personal hygiene
- Medicine
- Household
- Exercise in a fitness centre, walk in the nature, swimming etc
- Going to dentist, doctor, physiotherapist etc.
- Help with the economy
- Social contact
- Shopping

After high school

- Adapted work or Day-care Centre
  - Different kinds of work – but must be able to do a proper work – gets a very small salary
- Disablement benefit, regulated by law, from 18 years – important -
- Striving for a normal life

Personal freedom

- My daughter has got *her own home*
- Works every day
- Physical activity – daily program
- Has an Individual Plan for the future – codetermination important
- A group of professionals, caregivers, employer and mother – responsible for fulfilling this.

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The situation today

- Today we have a generation disabled people who have grown up going in kindergarten and in normal school like other children

- They have expectations of a normal life

What they meet

- Many of them are working, but we have too few places offering adapted work
- Some employers don’t want to take disabled people into «normal» jobs.

- Too few municipal group home apartments
- Parents find private solutions, buying or building group homes, get financial support from The State Housing Bank.
- The municipality has to provide service in the private group homes.
- But: our children are «expensive», and the municipality tries to reduce the costs by reducing the service provided.

Common problem

- The caregivers don’t have the knowledge they need to do a proper job.
  - Results in difficulties, for example for the PWS people
    - aggression, weight problems, psychiatric reactions, skin picking etc.

Caregivers

- Need better education –
  - The resource centres have an important task
- Education is necessary also for employers within adapted work

2014

- Life is getting better for persons with PWS:
  - Earlier diagnosis
  - Better health care, better social care
  - Younger people are generally not much overweight
  - Professionals and parents know more
  - Longer life expectancy than 20 years ago

- Things have developed since my daughter was born.

- But what will happen if the politicians reduce the social care resources?