

Nordic experience of  
cooperation between families  
and local authorities, from  
parents view

# Principles of Danish support

A social occurrence

- Equality
- Solidarity (public responsibility, tax-finance)
- Compensation
- Sector responsibility
- Decentralization in authorities
- Active social intervention
- User influence/ involvement
- Holistic view

# Important DK laws – families with children

- Law of social service
  - Information and coordination
  - Covering of necessary extra costs
  - Covering of lost earnings
- Law of the folkeskole (primary and secondary school)
  - Entitled to instructions and training adapted to the child's situation, the possibilities and the needs of the individual.
  - Pupils whose education is depending on support in the predominant part of teaching time.

# A study from 2001 explored

- How parents of children with disabilities experience the collaboration with the danish social system
  - Municipalities, Counties and the services (i.e. kindergarten)

# Parents experience as studied

- In many cases the effort from the social service systems have succeeded, so parents are satisfied with the interventions.
  - 1/3 very positive towards the municipality
  - 1/5 very negative
  - 1/3 both positive and negative
  - Rest neutral

# The problems parents experience:

- -Lack of information,
  - services,
  - the actual disability
  - rights
  - Difficulties tied to the group of “social occurrences”.
  - the double role of the social counselor
    - Difficulties in collaboration and communication

# Parents experience as discussed

- Support is experienced to be very different from one municipality to another.
  - Ex. Compensation for loss of earning. In some municipalities its given to ensure the wellbeing of the entire family. In other municipalities loss of earnings are not provided for the parents even if the child with a disability is very ill.
  - Ex. Some municipalities find it natural as part of the caretaking for parents to pay for courses for parents, some find that this kind of education, is not a necessary extra cost in taking care of the child.

# More experiences

- Lack of cooperation between sectors/  
sectorresponsibility neglect.
  - Ex. Many professionals, suggest very different interventions.
  - The coordination is in praxis often the parents task and burden. – Some parents say this is the biggest burden of all, in raising a child with disability.
  - Solutions in praxis are often not individualized



# Parents expectations

- Parents of children with disability in general say:
- Feel lucky to live in a country that recognizes the importance of giving professional support to parents who have a child with a disability.
- Good support is
  - Focused on the individual Child (not only the diagnosis)
- The child's right to development
- The entire family's right to well-being and development.
- Modern families want mutual experiences, care and support, and everybody's individual rights.

Research (2005): HOW support is delivered for an entire family's well-being is crucial.

- The study illuminate the meanings of being a supporter as narrated by nine parent-selected professionals.
- Findings: a personal and professional philosophy on *being* and *doing* is crucial when helping parents care for their child.

# Meaning

- Being confident that it is always possible to help, means to seek unique solutions for each child and family.
- Being a trustworthy partner of parents, means to trust in parents as invaluable partners as well as to exert efforts to gain the parents' trust, seeing parents as both persons and the child's carer, and being sensitive to parents' vulnerability.
- Enabling parents to gain competence and confidence in parenthood embraces the knowledge and skills necessary for the competence as their child's carer and respecting parental authority.

# In summary

- Parents are in general positive towards the collaboration with the local authorities
  - the idea, that you address only one authority, who will guide you further
  - the idea, that you should be compensated for the disability
  - That you have same access and rights as everyone else
  - The genuine supporters/systems

# Parents in general

- Are negative towards
  - Lack of information
  - Lack of coordination
  - Differences in interpretation of the laws between municipalities.
  - When economic consideration in praxis goes before the rights of individuals and families