

Children 0-18 years old with Usher Syndrom– Intervention.

**Educational Consultant
Bettina Kastrup Pedersen**

CENTER FOR DØVBLINDHED OG HØRETAB





Who are we?

- Center for deafblindness and hearingloss
- National Counselling service.
- 9 consultants for children
- 5 consultants for adults
- 2 psychological consultant.
- 1 consultant on the Center
- 2 leaders of department
- 1 coordinator
- 2 administrative workers

Collaborators.

- Parents
- educational staff in the local environment
- local authority and regional caseworkers
- the local authority PPR offices
- local and regional eye and ear doctors, and vision and hearing consultants
- local and regional physio and occupational therapists
- local and regional communication centers.
- Geneticist.

How do we start?

- Contact from either, counsellors, schools or families.
- Establishing contact.
- Individual plans.

How many?

- Usher 1 (18)
- Usher 2 (2)

Who are they? And where do they go to school?

- Deaf/hearing loss. (earlier) schools for the deaf. Signers.
Aalborg, Copenhagen, Fredericia.
- Hearing loss, CI, language skills can be limited.
Center classes: Ringsted, Ballerup, Århus.
- Mainstream schools. Inclusion

How do we work in the schools?

- Meetings with teachers and other professionals.
- Courses.
- Work with the children and their classmates.
- Support in creating networks.
- Projects.

Project 2011-2014

- A project with all children with aquired deafblindness and there professionals.
- A school in Copenhagen and a collaboration with children from Center for deafblindness and hearingloss and 2 teachers.

WHY?

- **Counselling individuals.**
- **Difficult to make a common platform for understanding deafblindness.**
- **A need to create a feeling of community, both children and professionals.**
- **A need to make the children be more self-confident and able to reflect on there own situation.**
- **An focus on joy, laughter, success, peers, coping strategies.**

How and where?

- **Collaboration with all the professionals and their leader. 2011**
- **Creating a project. 2012-2014**
- **Meetings; before, in between and after.**

What. Activities

- **Yoga**
- **Rapelling**
- **APA, visiting another school similar to their own**
- **Climbing**
- **Visiting a ZOO and walking in the dark**
- **Meetings with others. (Interviews)**

Adapted Physical Activities (APA)

- An idea that gives possibility to people with function reductions to participate in physical activities adapted to their needs.
- Headlines are Joy and motivation/Empowerment and self-efficacy.
- And the aims are to develop bodily skills and social competences.
- <http://cdh.rn.dk/Afdelinger/Hoeretabsomraadet/APA---Adapted-Physical-Activity>

Did it work?

- **Professionals:**
more united in their focus on deafblindness! Wanted to share their experiences
- **Children:**
Started to feel as a group
Talks about their experiences
Feeling of succes
Saw that the professionels also had difficulties in the activities.
- **Parents:**
Could see the skills in their children
Hope

What else do we do?

- Write articles about our experiences
- Give presentations about Usher Syndrom.
- Collaborate with CFD, National Board of Social Services.
- Collaborate with National Organisations FDDB, parents.
- Nordic Network
- National Usher Conference 2015

Challenges in our work.

- Usher I, school for the deaf. (4)
- Usher I and II, center classes. (6)
- Usher I and II, Mainstream Schools (6)
- 4 Children in either kindergarden or school for special needs.

Transition into adulthood.

- Meetings. (CFD)
- Individual plans. (STU)