



# THE POPULATION OF DEAFBLINDNESS IN DENMARK



INSTITUT FOR SYN, HØRELSE OG DØVBLINDHED  
– i gode hænder



## IDENTIFICATION OF DEAFBLINDNESS IN DENMARK

- A responsibility of the two national departments of consultants
- CFD – Acquired deafblindness from 18 +
- CCS – Congenital deafblindness from 0+
- - Acquired deafblindness from 0 - 18



## IDENTIFICATION OF DEAFBLINDNESS IN DENMARK

- In Denmark it has always been a responsibility of the departments of consultants
- Help from an interdisciplinary advising team:
  - Ophthalmologist
  - Audiologist
  - Pediatrician
  - Geneticist
  - Representative from Ressourcecenter of Deafblindness
- No advising team since 2003



## WAYS TO IDENTIFY

- Medical assessments and documents - updated
- Functional assessments – based on observations, videoanalysis, interaction and communication with the person.
- Multidisciplinary assessments – sensory profile, functional tests of hearing and vision and motor skills
- Questions to parents and professionals
- Dynamic tryouts - giving advice, ideas, tools, training in between functional assessments
- Official tests of cognition
- Taking it to the group of colleagues
- Inquiry -one based on the material of K.A and I.R, and one made especial for the elderly



## **CURRENT USE OF THE NORDIC DEFINITION IN PRACTICE**

- Substant of our assessment and identification of deafblindness
- Always a part of our written reports or documents



## CRITERIA OF IDENTIFICATION

- The Nordic definition: Does vision and hearing compensate for each other in communication, information, social participation and orientation? If not – it is identified as deafblindness
- Identified by medical papers – no vision or hearing, genetics
- Identified by medical papers and functional assessments supported by tests according to communication, information, social participation and orientation.



## AN OVERVIEW OF SERVICE USERS?

We only have data of the people with deafblindness, that has been or is in the service system

We don't have a full register – when people leave the service- system, we don't have them registered anywhere

Our overview counts on:

- users of our services (School, residential homes, special counseling)
- users of our collaboration partner CFD (residential homes, special counselling, daycare center)



## AN OVERVIEW OF SERVICE USERS?

- A hypothesis based on the Danish assessment of the population in 1995 says that 0,022% of the population should have deafblindness = 1277
- and 20% of them should have congenital deafblindness = 255
  
- The number of service users is present:
  - Congenital deafblindness = 212
  - Acquired deafblindness = 241
  - Elderly with acquired deafblindness = 450
  
- There are expectably more, that we don't know of – so the old numbers is still reasonable





## AN OVERVIEW BASED ON DIAGNOSTIC CATEGORIES?

- . There is no national register of deafblindness.
- We register the diagnoses of our present service users of counselling for children and youngsters and adults.
- We have this documented 5 years



## ADULTS WITH ACQUIRED DEAFBLINDNESS - DIAGNOSES

CAPOS

CHARGE

CROUZON (AS)

NF2

NORRIS

RUBELLA

STICKLER

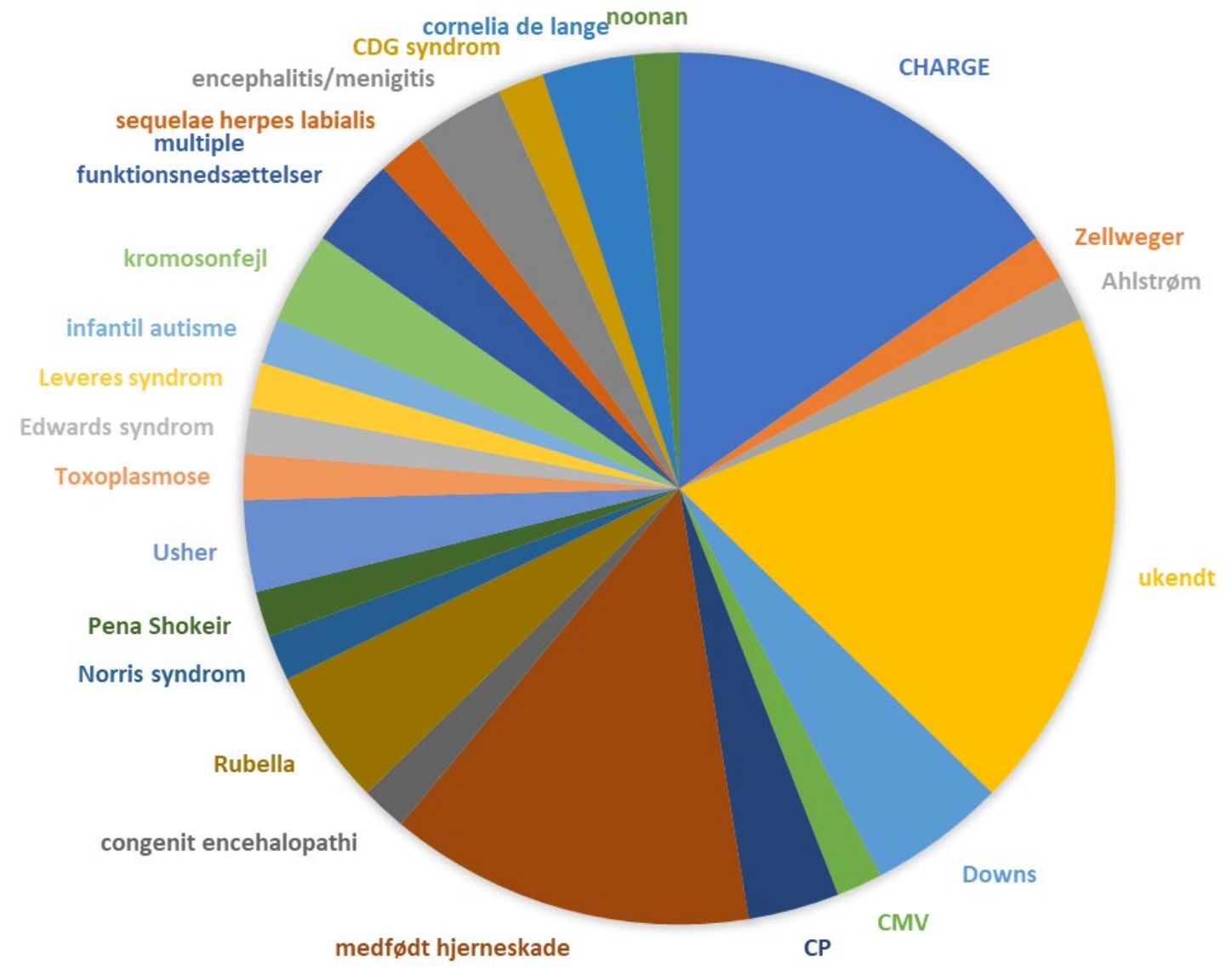
USHER 1, 2, 3

Wolfram



# ADULTS WITH CONGENITAL DEAFBLINDNESS

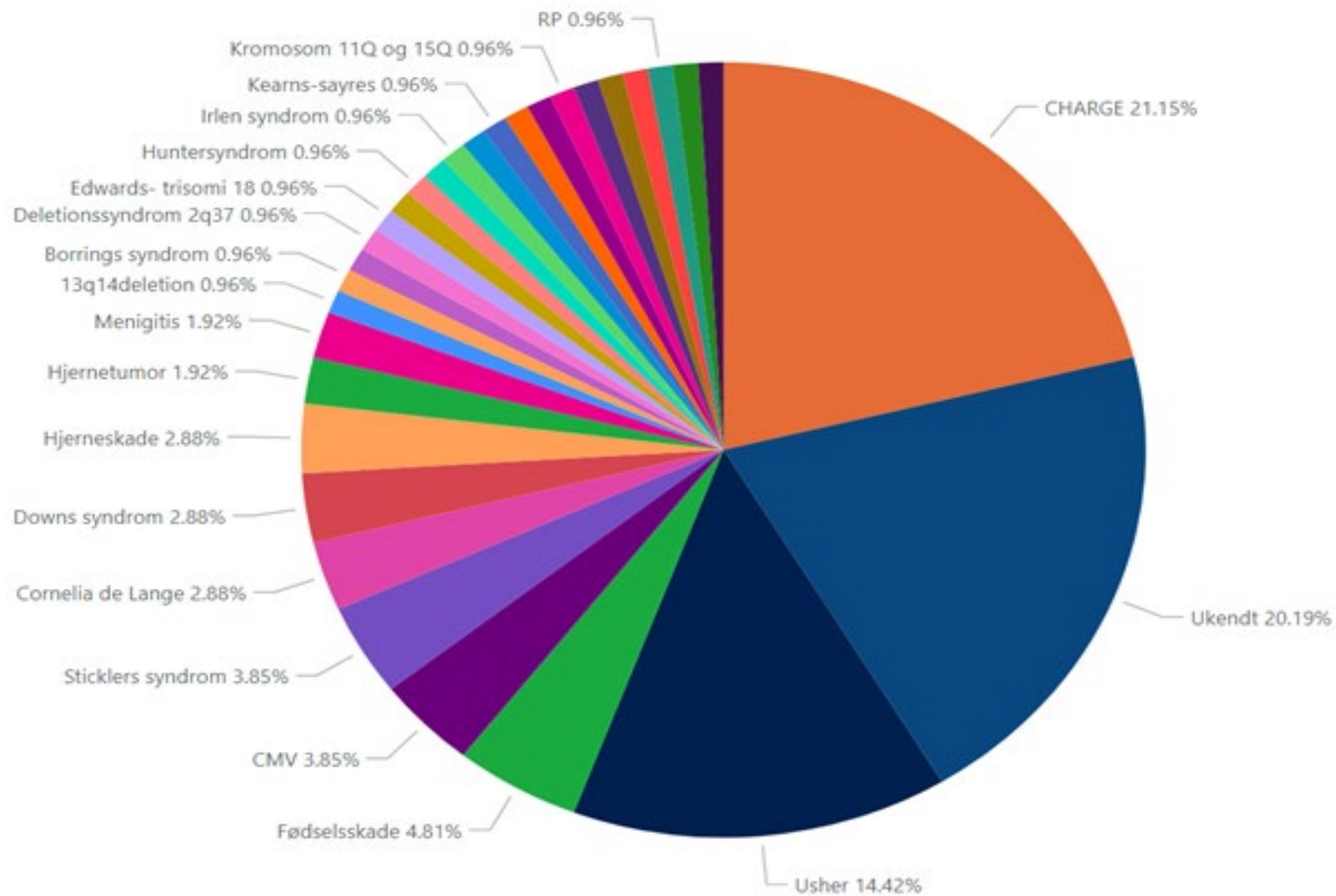
DIAGRAMTITEL





# CHILDREN WITH DEAFBLINDNESS

Målgruppe i forløb 2020





## OVERVIEW BASED ON MEMBERSHIP IN DISABLED PEOPLE ORGANIZATIONS?

- There are 450 members registred in our national organization of deafblind (FDDB)
- Other organizations:
- Parents assosiation of CHARGE
- Parents association of people with congenital deafblindness



## \* IDENTIFYING DEAFBLINDNESS AMONG THE ELDERLY AND "GREY ZONES", A SHARED NORDIC AND INTERNATIONAL CHALLENGE?

- There are discussions about the elderly population – some say there should be 10.000 people with age- related deafblindness. CFD has 440 in their system, and has a different point of view of the amount of elderly with deafblindness. Therefore they have proposed a Nordic network about elderly with deafblindness.
- Always a discussion – if it is to be named deafblindness, when there is a big brain damage.
- Our focus is on – if vision and hearing can compensate in the small nuances of interaction, information and orientation
- Usher kids – early identification through diagnosis, but not shown deafblindness. How to prepare them for the future, so that we don't see too many psychological challenges in the late young life.
- How do we define the impact, that challenges with the vestibular sense has on vision and hearing? Like in CHARGE and Usher.





























TAK FOR I DAG

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