



NGO COMMITTEE FOR  
**RARE DISEASES**

# Educational consequences of rare diseases



ÅGRENSKA

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A Committee of **CoNGO**



CoNGO  
The Conference of NGOs  
in Consultative Relationship  
with the United Nations



# SDG 4

The Ågrenska work and experiences in relation to target 4.1, 4.2 and 4.5  
and the special challenges that present themselves concerning rare diseases



# SDG 4

## 4.1

By 2030, ensure that all girls and boys complete free, equitable and quality primary and secondary education leading to **relevant and effective learning outcomes**

– individual and disease related definitions necessary

## 4.2

By 2030, ensure that all girls and boys have access to quality early childhood development, care and pre-primary education so that they are **ready for primary education**

- individual and disease related definitions necessary



# SDG 4

## 4.5

By 2030, eliminate gender disparities in education and ensure equal access to all levels of education and vocational training for the vulnerable, including persons with disabilities, indigenous peoples and children in vulnerable situations

- specific knowledge about educational consequences of the diseases is of crucial importance



Of course there is knowledge about special education, and of course there are no exact "syndrome-specific" educational methods, but the medical diagnosis must be translated into educational consequences and classroom handling for each individual.



# Teachers need knowledge about

- \* the individual
- \* the diagnosis
- \* educational consequences of rare diseases
- \* adapting educational methods and contents,  
i.e. how to **bridge the gap between medical and educational aspects**, very often a matter of asking oneself the right questions, based upon info about the diagnosis because origin, consequences and correct treatment are so closely related



# Data gathering

- \* observations of children in the family program
- \* interviews with adults in the adult program



# Family program - observations

Broad instrument comprising important education relevant aspects

Systematic observations





# Family program - observations

- \* 550 children with
- \* 40 different rare diagnoses



# Observations show

- \* Rare syndromes affect many areas of the children's learning and school situation
- \* Medical facts must be translated into educational consequences in order to provide a quality education for children with rare conditions



# A simple practical example

If a child displays concentration problems the appropriate way of teacher acting depends on knowledge about the origin of the concentration problem

If the origin is

- \* tiredness due to heart problems or pain included in the rare diagnose or
- \* a neuropsychiatric symptom included in the diagnose or
- \* a slight intellectual impairment included in the diagnose

the teacher must act in different ways

So in order to choose the right action, and not let the child be subject to his teacher's trial and error, knowledge about origin and the educational consequences are essential



# Adult program - focus group interviews

- \* Needs in relation to official bodies and authorities
- \* Experiences from school years and education



# Adult program - focus group interviews

- \* 390 adults with
- \* 38 different rare diagnoses



# Interviews show

- \* Observations in children are confirmed
- \* Consequences persist and needs remain



# Conclusions

Professionals need knowledge about the rare disease and its educational consequences in order to adapt their methods and treatment for promoting lifelong learning opportunities, enhance possibilities for employment and for a responsible citizenship for people with rare diseases

