HOLISTIC APPROACH: BRIDGING HEALTH AND SOCIAL CARE

The need to address the ‘Big 5’ from a lifelong perspective: healthcare, social care, school, insurance and labour
Ågrenska and the SDGs

Six SDGs with particular relevance to rare diseases
Ågrenska more than 5 000 families
Rare diseases and the Big 5: a global challenge

- Healthcare
- Insurance
- Social care
- School, Education
- Labour, Occupation
40 to 120 contacts with the Big 5
Silos, gaps, lack of coordination and holistic perspective
Lifelong and optimal life perspective
The Goal

How to get there…

Holistic support
Lifelong perspective
Optimal lives
Families and individuals

To build competence and coping

- Knowledge about the disease and its lifelong consequences
- Knowledge about available support
- Methods
- Network
Professionals in the Big 5

Knowledge about

• The individual and the diagnosis
• Practical consequences
• Coordination
• How to adapt methods and contents, i.e. bridge the gap between medical and practical aspects
Institutions: the system level

Structural Preconditions

• Acknowledge and prioritize holistic approach
• Global challenge – collaboration a possibility and necessity
• Cross boarder, cross silo
• Legislation and regulations
Lifelong and optimal life perspective
A UN RESOLUTION FOR RARE DISEASES WOULD BE A BIG STEP TOWARDS A BRIGHTER TOMORROW
THANK YOU!