

# 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

Robert Hejdenberg  
CEO, Ågrenska



NGO COMMITTEE FOR  
**RARE DISEASES**

Second High Level Event of  
the NGO Committee for Rare Diseases  
21 February 2019



ÅGRENKA

# Ågrenska and the SDGs

Six SDGs with particular relevance to rare diseases

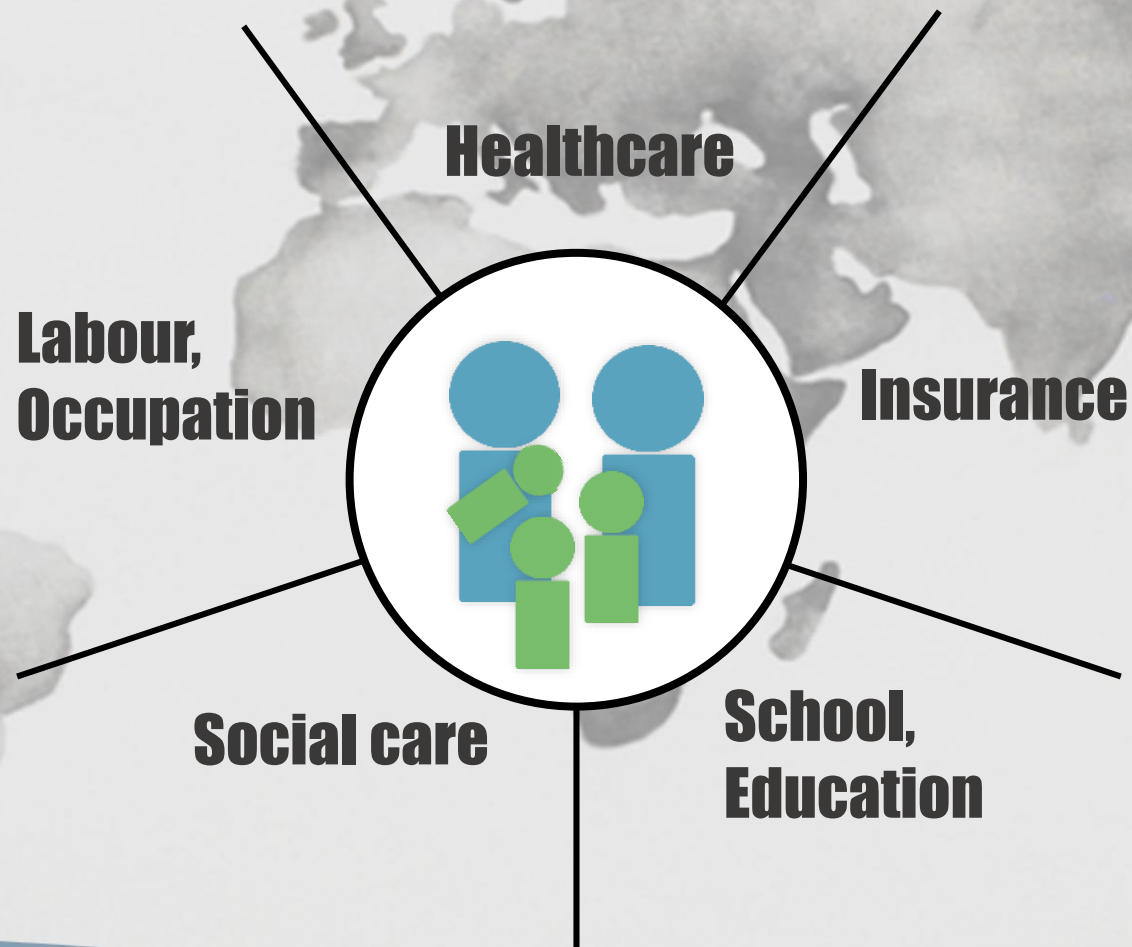


# Ågrenska more than 5 000 families

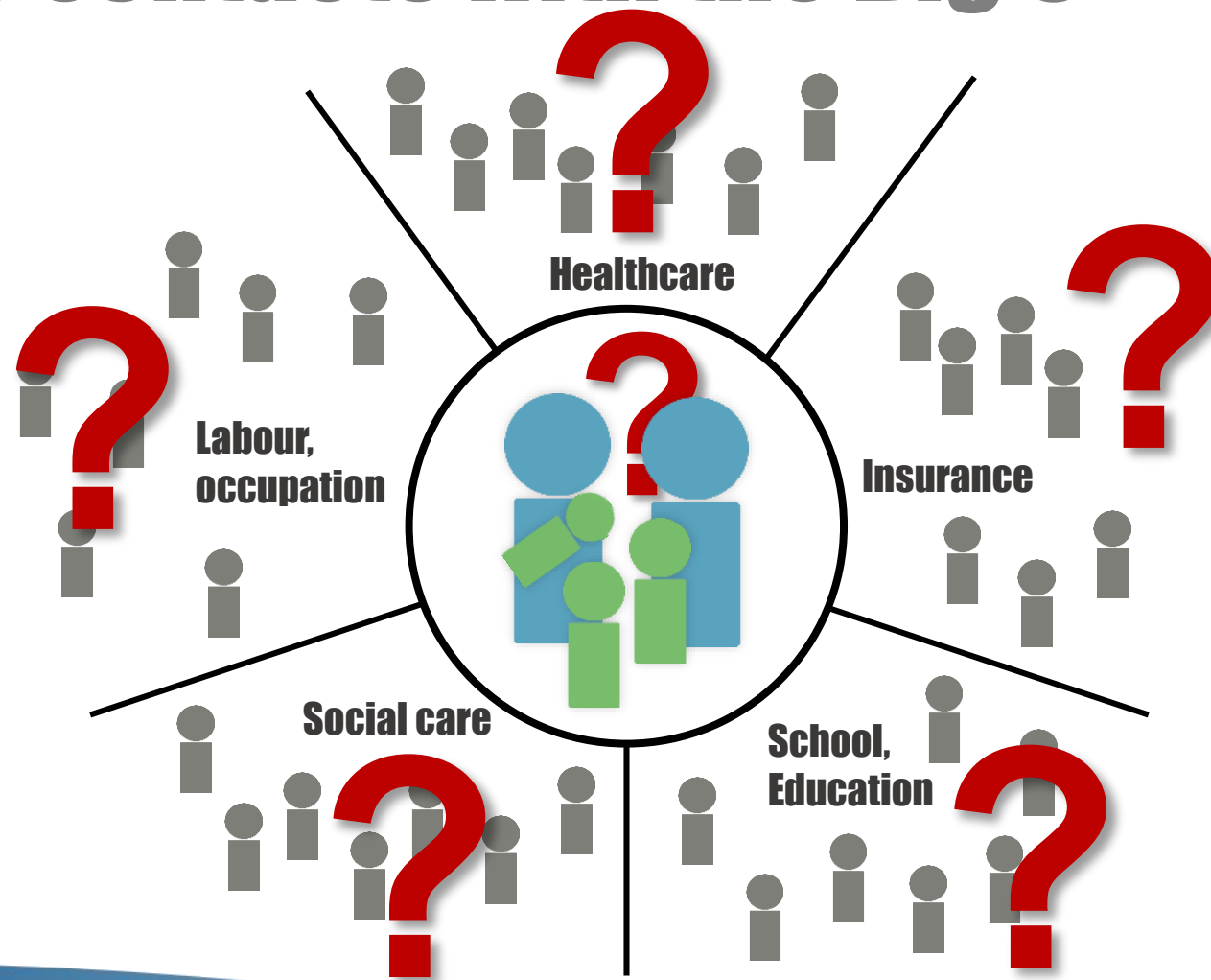


ÅGRENSKA

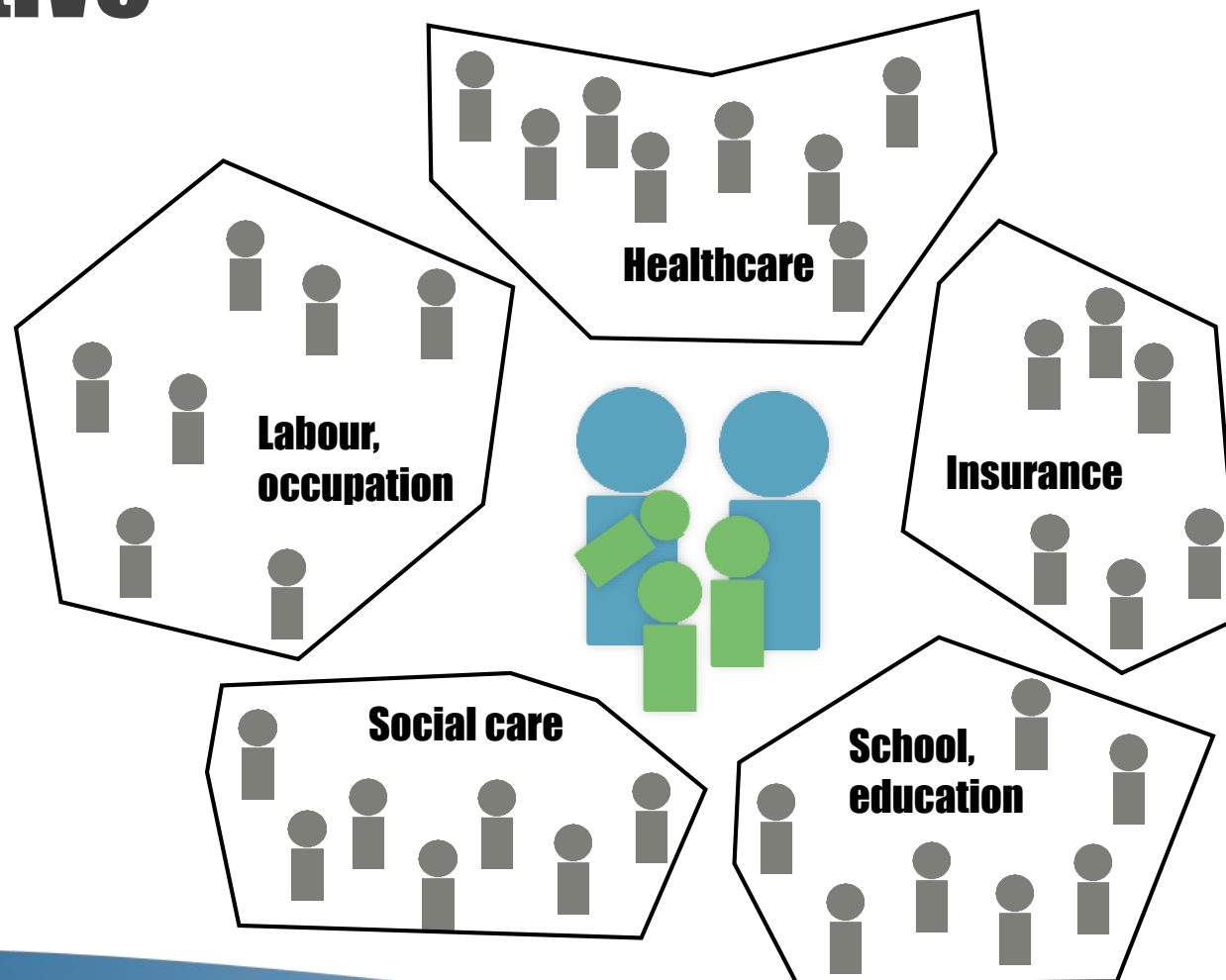
# Rare diseases and the Big 5: a global challenge



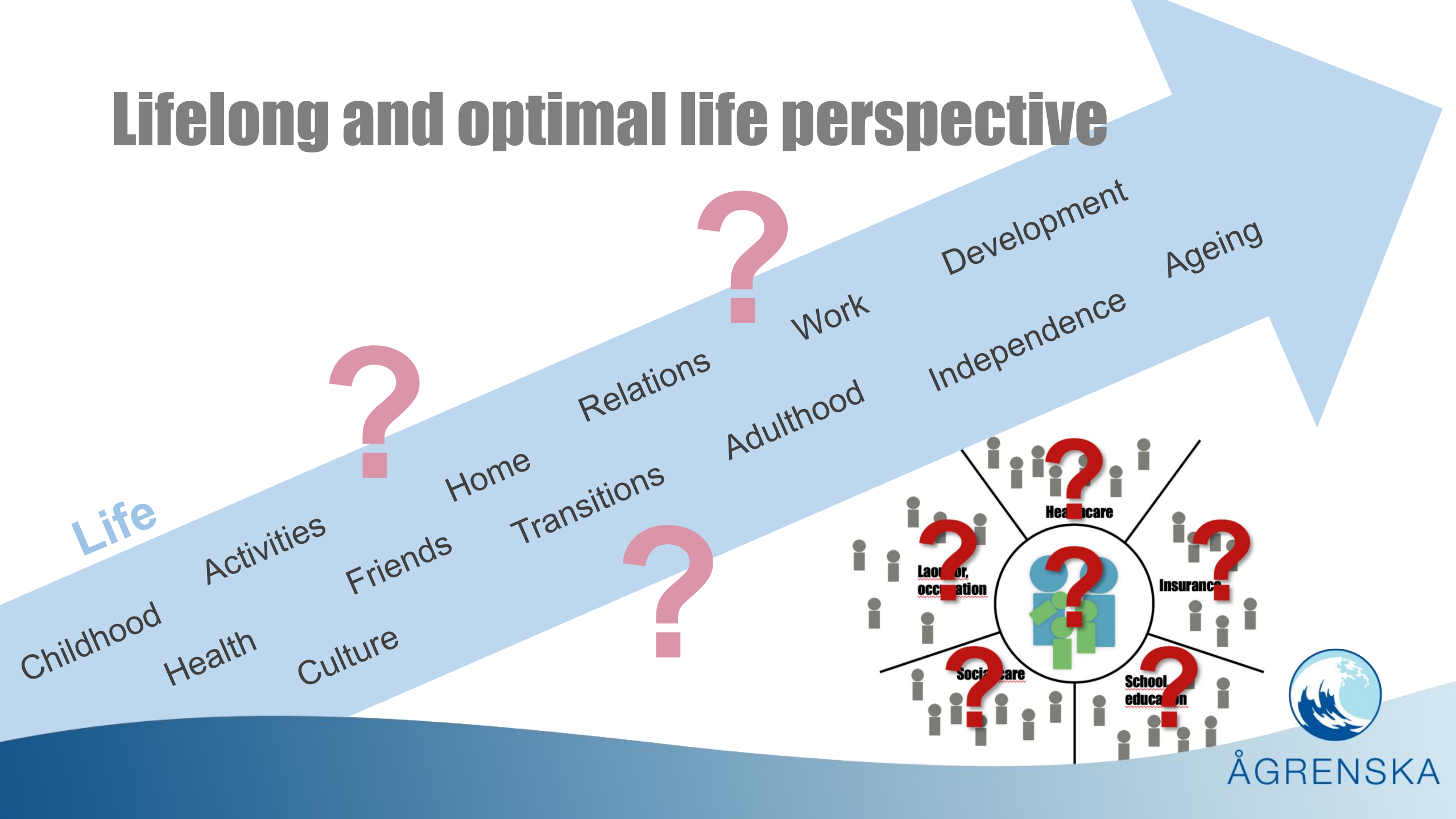
# 40 to 120 contacts with the Big 5



# Silos, gaps, lack of coordination and holistic perspective



# Lifelong and optimal life perspective



# The Goal

Holistic support

Lifelong perspective

Optimal lives

How to get there...

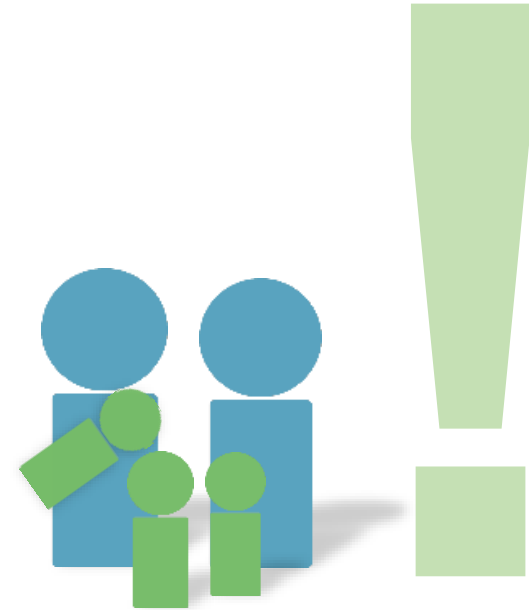


ÅGRENKA

# Families and individuals

## To build competence and coping

- Knowledge about the disease and its lifelong consequences
- Knowledge about available support
- Methods
- Network

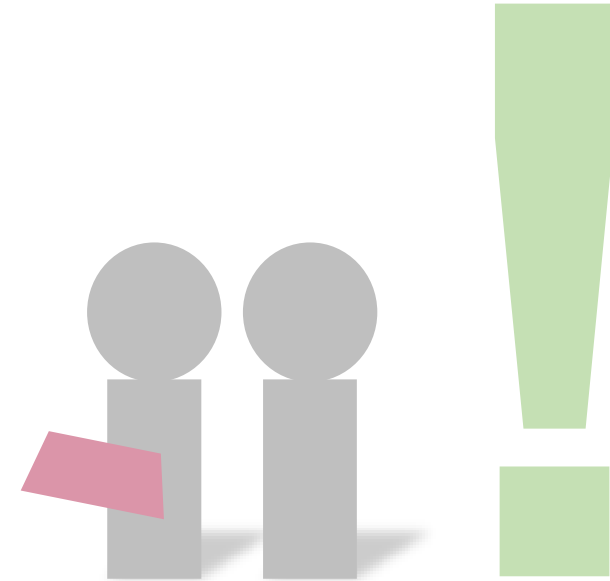


# Professionals in the Big 5

## 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**

Translation

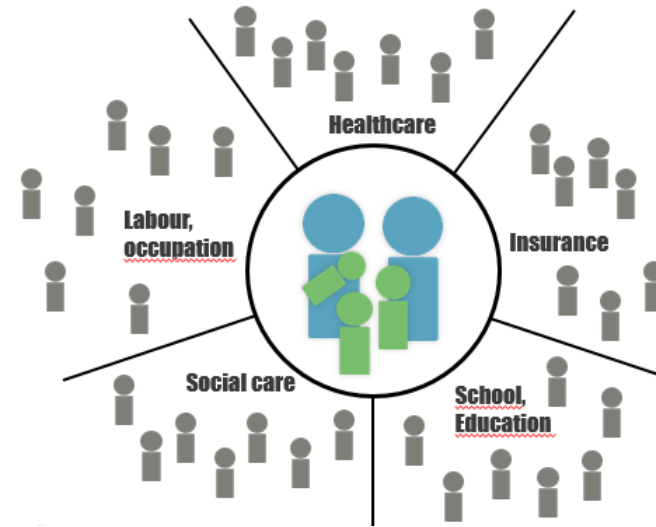


ÅGRENSKA

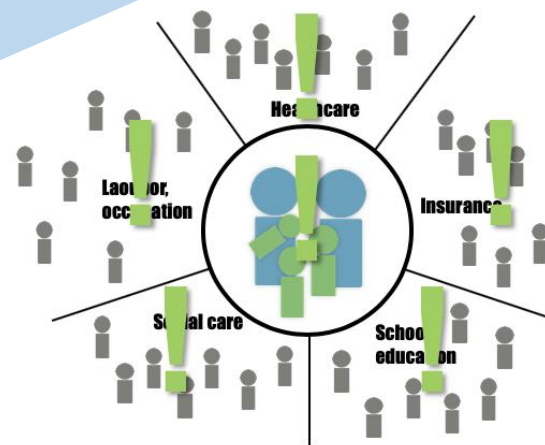
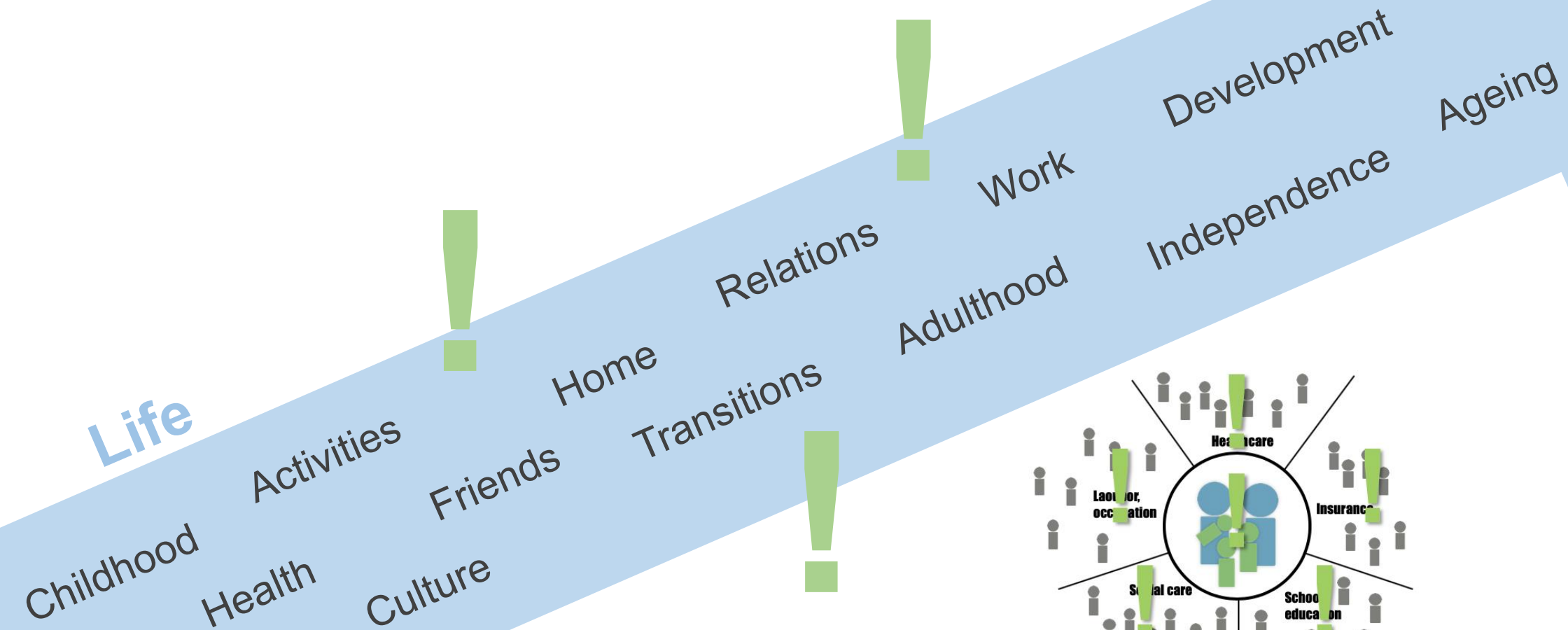
# Institutions: the system level

## 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



NGO COMMITTEE FOR  
**RARE DISEASES**



ÅGRENKA

**THANK YOU!**



ÅGRENSKA

