

# Quality education for everyone The UN Sustainable Development Goal 4

## How can Ågrenska and the Rare Disease Community try to contribute?

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Providing an inclusive and equitable quality education and promote lifelong learning opportunities for all by 2030, according to SDG 4, is a broad and comprising task. When it comes to people with rare diseases special challenges present themselves. Specific holistic knowledge is of crucial importance, eg in relation to targets:

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

**4.3**.... ensure equal access to ....tertiary education, including university

**4.4**...substantially **increase the number of youth and adults** who have **relevant skills**, including technical and vocational skills, **for employment, decent jobs**...

The medical diagnosis must be translated into educational and vocational consequences and handling for each individual, aiming at arranging so people can fully use their resources and potential, taken into account their condition, possibilities and needs.

In order to gather information and develop knowledge about consequences Ågrenska has developed two tools:



- A broad instrument for observing children and collecting data comprising education and everyday relevant aspects
- A focus group interview guide collecting data for adults comprising experiences and needs including educational and working life

Up till now we have met more than 5000 families having children with a rare disease and more than 500 adults with rare diseases. We have experienced that consequences and needs persist from childhood into adult life although they may present themselves in different ways due to both personal development and changing requirements.

Professionals thus need knowledge about the rare disease and its consequences in order to adapt their methods and treatment for promoting lifelong learning opportunities and enhance possibilities for employment, ie contributing to SDG 4.

