

# Establishing an Online Learning Platform on Rare Disorders Sjelden.no

Elisabeth Bækken, Team leader digital learning  
Norwegian National Advisory Unit on Rare Disorders

## Background

The main task for the Norwegian National Advisory Unit on Rare Disorders is to ensure that people living with rare disorders and their families receive holistic and individually-based care. Our vision is to make rare disorders more known through knowledge and collaboration. The unit consists of nine national Centres of Expertise on Rare Disorders where patients, their families and professionals can seek help and advice.

Research and evidence based knowledge show that lack of knowledge among professionals makes life more challenging for people with a rare disorder. In order to meet the needs for knowledge, the unit has established an open online learning platform; Sjelden.no. The word «rare» translates as «sjelden» in Norwegian, hence the name of the learning platform. The main goal is to make knowledge about rare disorders more easily accessible by providing access to high quality online learning resources. Sjelden.no is striving to maximize the learning outcome in a time efficient manner by incorporating learning methods that have been proved to give the best learning outcome.

## Contents of Sjelden.no

Each centre of expertise takes initiative to make digital resources based on professionals needs. Depending on the size of the resources there will be established small project teams to follow up production.

### Contents

Online training modules  
Video lectures  
Short videos  
Podcasts  
Calendar events

### Target groups

Professionals working in the field of rare disorders including sectors such as government, healthcare, school, kindergarten, special services etc.

### Quality

The resources are developed and approved by the leading experts on rare disorders in Norway, and evaluated by the editorial forum of sjelden.no (peer-review).



## Feedback from users

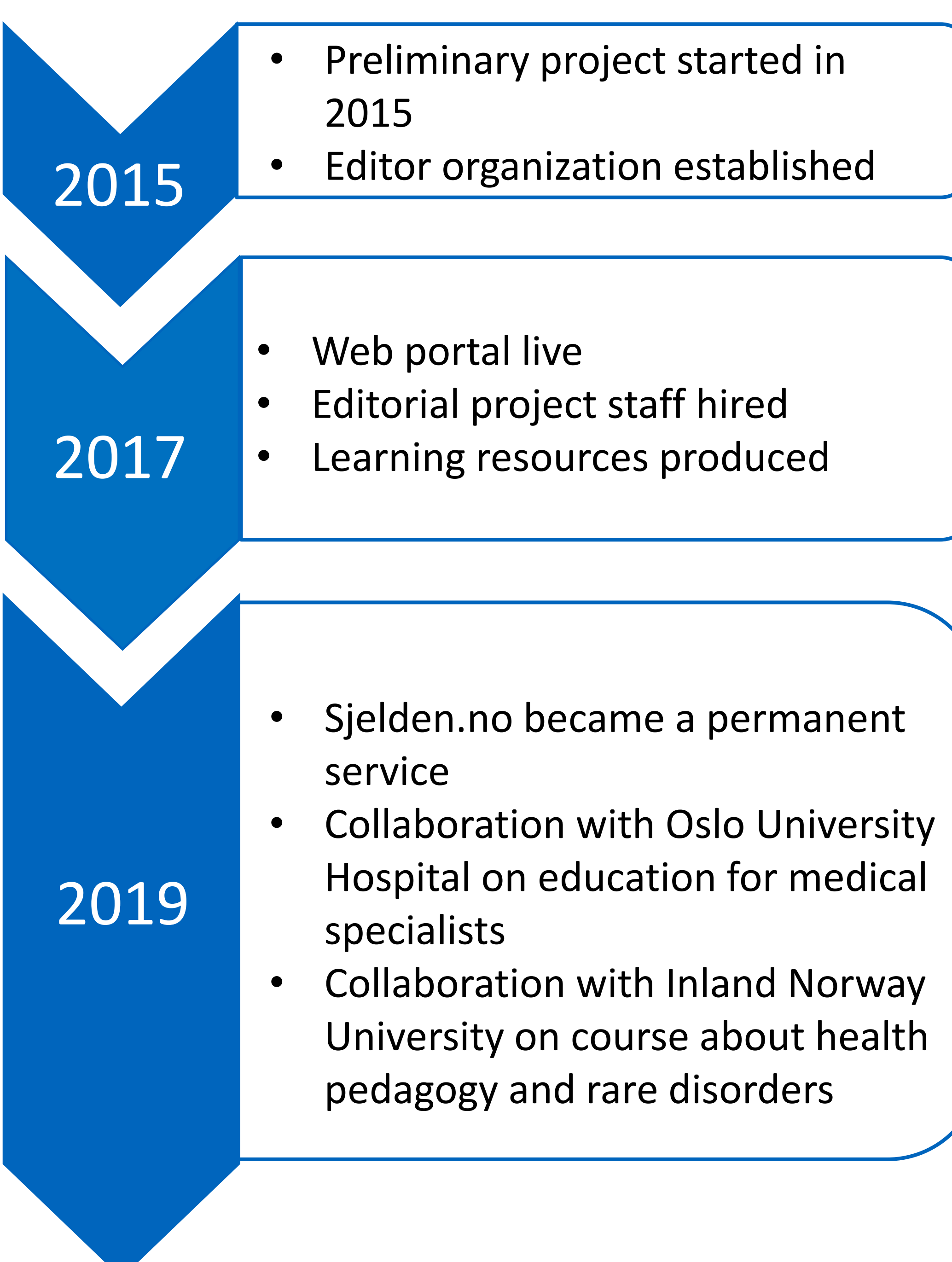
*This course became an eye-opener for me on how important it is to be patient and not give up even though it seems as though the child is not showing much interest in the iPad.*

Learner on course: Angelman and alternative, complementary communication

*We ask the participants to take the online course before we meet. It makes the discussions in the meeting more interesting.*

Physical therapist, Advisor on rare disorders

## Timeline



## Do you want to know more?

Rare Disorders in Norway - Alphabetical order  
<http://Helsenorge.no/Sjeldnediagnoser>

The learning platform  
<https://sjelden.no/>

**Sjelden.no**  
Lær om sjeldne diagnoser

## Contact

Elisabeth Bækken, editor sjelden.no  
tel.: +47 23 02 75 67 / [elbaek@ous-hf.no](mailto:elbaek@ous-hf.no)

Stein Are Aksnes, director  
tel.: + 47 23 02 69 74 / [steaks@ous-hf.no](mailto:steaks@ous-hf.no)