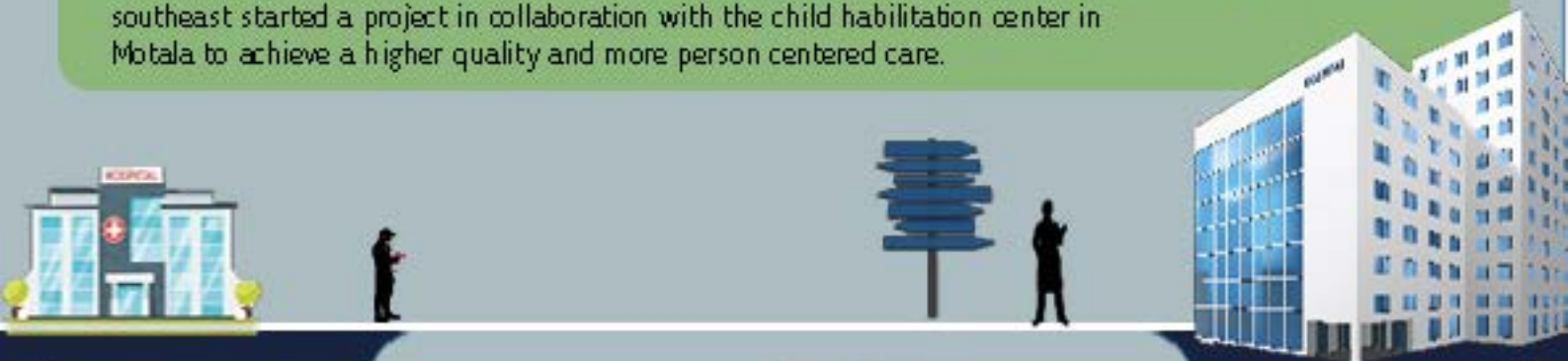


# Mind the gap

## Rare transition from child to adult care

### Introduction

The transition from child to adult care is a very important process with major shortcomings in Sweden today. According to Socialstyrelsen (National Board of Health and Welfare) in Sweden, each transition from child to adult care is a security risk and a problem area. For patients with rare diseases, complex disabilities and major medical needs, responsibilities can sometimes be shared between primary care, specialist clinics and the municipality. Adults with different kinds of disabilities often lack a natural tie to a specific health care clinic even though they have many different symptoms and problems. Collaboration and information transfer is therefore crucial for continuity and patient safety. With this in mind Centre of rare diseases southeast started a project in collaboration with the child habilitation center in Motala to achieve a higher quality and more person centered care.



### Method

The project was carried out at the habilitation center in Motala together with the Centre of Rare Diseases Southeast Region. Five patients participated in the project. The aim was to investigate and create a model for coordinating the transition from child to adult care for patients with rare diseases. A coordinator was appointed to work according to a structured method to increase the conditions for successful transition. The coordinator ensured there was a plan for each patient at clinics that was relevant to them. The goal with the project was for all participants to have a plan, a designated health care contact and to arrange a multidisciplinary conference in connection to the transition.

### Insight

The project showed that the role of a coordinator is very important in the process. It turned out to be difficult to find a natural recipient in healthcare and a designated contact. For each participant a healthcare plan was drawn up. It also turned out, during the project, that a multidisciplinary conference is not always required. It is more important to report to the adult care provider to make the transition successful. In the case of a rare diagnosis, this should be noted in the attention symbol in the medical record.

### Results

Healthcare plan



Designated healthcare contact



Multidisciplinary conference



Report to recipient



### Recommended model

Designated coordinator

Three meetings

Mapping healthcare contacts

Information of the diagnosis

Information healthcare structure

Multidisciplinary conference or report to recipient

Healthcare plan

Designated healthcare contact

Note in attention symbol in medical record

Å Lundin, Centre for Rare Diseases in South East Region of Sweden, Linköping University, Linköping, Sweden,

C. Lilja, Centre for Rare Diseases in South East Region of Sweden, Linköping University, Linköping, Sweden,

C Gunnarsson, Department of Clinical Genetics, Department of Clinical Experimental Medicine, Linköping University, Linköping, Sweden, Centre for Rare Diseases in South East Region of Sweden, Linköping University, Linköping, Sweden

Contact information: [asa.lundin@regionostergotland.se](mailto:asa.lundin@regionostergotland.se)