

**Are specific measures used by those who need them?
Work related measures for adults with Multiple Osteochondromas.**

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Introduction: TRS offers services to some diagnostic groups of rare congenital disorders. In 2015 TRS was assigned as Resource Center for Multiple Osteochondromas (MO). MO may interfere with growth and mobility and cause skeletal and muscular pain. Many undergo operations to remove bone tumors. To generate knowledge, TRS invited those with known MO to a learning seminar for exchange of experiences and information.

Purpose: To obtain knowledge about persons with MO, challenges in daily life and the use of educational and employment measures.

Methods: All participants answered a questionnaire about how the diagnosis had affected education and working life. The section about measures were divided in; adaptations of the physical work environment, facilitation of work tasks and adaptation of working hours and workload. The study was categorized as a quality improvement study and ethical approval was given by the Data Protection Officer.

Results: Twenty-one adults (median age 37, 8 men). 8 were working fulltime.

- More than half of the participants stated that MO had caused pain, fatigue and/or absence which led to consequences for their education. One third had changed their course of education due to the diagnosis.
- Less than a quarter had used measures offered by NAV, school, university or employer.

Conclusion: Most adults with MO experienced challenges in education and work, but only a few had used specific measures designed to help with these kinds of problems.

In order to achieve a better match between those responsible for allocating the measures and those who benefit from them, we believe it is important to highlight the possible reasons why the targeted measures do not get used.

Issues worth further research and discussion:

- Are the measures known among those who need them, in the preventive phase, or when the problems have manifested in sick leaves or absence from studies?
- Is it easier to get help and support for measures leading out of the workforce, than for measures leading to adjustment of workload?
- Do influencers and professionals manage to signal that it is OK to address limitations before the problems grow too big to handle?
- In what regard does the media-discourse about unrightfully use of welfare benefits prevent those in need from applying?