

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

Nordic Conference in work and rehabilitation. Oslo, 1. – 3. October 2018

Brede Dammann.

Social worker at TRS National Resource Center for Rare Disorders –
Sunnaas Rehabilitation Hospital

The focus of my presentation

- Are the prospects of education and work affected for those who have a rare congenital disorder?
- Do people with these disorders utilize available measures with regards to the prospects of staying employed?
- A discussion regarding aspects that can impact the utilization of measures.

The aim of the Norwegian welfare system

- To get as many into the work force as possible
- Full time work as the rule
- Less people on passive income
- There are a set of measures available to achieve participation for all
 - physical adaptation of study- or workplace,
 - adaptation of work tasks
 - workload and working hours.

Measures in the educational system

- Some examples:
 - Facilitation of the physical environment, exams etc.
 - Practical aid
 - Financial assistance from The Norwegian State Educational Loan Fund (Lånekassen)

Work related measures

- Some examples:
 - Physical adaptation of the workplace
 - Economic aid for retraining
 - Wage subsidies for lack of productivity
 - Vocational rehabilitation money

What has been done

- 21 adults with the rare congenital disorder Multiple Osteochondromas (MO) were gathered on a seminar organized by TRS.
- A questionnaire concerning how the disorder has affected education and work was answered.
- We also inquired about their working status and whether they have applied for, and used measures to compensate for the consequences of their diagnosis.

The diagnosis influence on education and choice of vocation

- 11 (52%) were affected due to *pain*
- 11 (52%) were affected due to *fatigue*
- 9 (43%) were affected due to *absence*

- 6 (29%) *changed course of studies due to the disorder*

Participation in the work force

Relation to the labor market (some have part time work in addition to passive income):

- 8 (38%) Full time work
- 13 (62%) Passive income

Utilization of measures in education

- 1 (5%) Received facilitation or measures through the educational institution
 - Facilitation of practice placement periods

Utilization of measures to improve the physical working environment

- 3 (14%) Facilitation or measures through NAV
- 6 (29%) Facilitation or measures through employer

Utilization of measures related to work tasks

- 4 (19%) Received facilitation or measures through NAV
- 6 (29%) Received facilitation or measures through employer

Utilization of measures related to workload and working hours

- 2 had arrangements with adjustment of workload and working hours in cooperation with NAV
- 1 had arrangements with adjustment of workload and working hours in cooperation with employer

Conclusion

- Most adults with MO experienced challenges with regards to education and work.
- Only a few had utilized specific measures designed to help with these type of challenges.
- In order to achieve a better match between those responsible for allocating the measures and those who benefit from them, I believe it is important to highlight some of the possible reasons for why the targeted measures do not get used.

Issues in need of further research and discussion

- How does the media-discourse regarding unrightfully use of welfare benefits prevent those in need from applying?



VG: 16.02.2018



VG 20.01.18

Issues in need of further research and discussion

- Are dedicated measures known among those who need them, in the preventive phase, or after the problems are manifested through sick leave or absence from studies?



Issues in need of further research and discussion

- Do influencers and professionals signal that it is OK to address limitations before the problems become too big to handle?



Issues worth further research and discussion

- It can be easier to get help and support for measures leading out of the workforce, than for measures leading to adjustment of workload



TRS National Resource Centre for Rare Disorders is a part of



Norwegian National Advisory Unit on
RARE DISEASES

<https://helsenorge.no/sjeldnediagnoser>

The Advisory Unit consists of a central unit and nine national resource centres:

- Center for Rare Disorders
- Frambu Resource Centre for Rare Disorders
- National Centre for Rare Epilepsy-Related Disorders
- National Neuromuscular Centre
- NevSom – Norwegian Centre of Expertise for Neurodevelopmental disorders and Hypersomnias
- Norwegian Resource Centre for Cystic Fibrosis
- TAKO-centre – National Resource Centre for Oral Health in Rare Diagnoses
- The Norwegian Porphyria Centre
- **TRS National Resource Centre for Rare Disorders**

