

# Activity and participation in young adults with Duchenne muscular dystrophy

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## BACKGROUND

As the result of constantly improving treatment options, persons with Duchenne muscular dystrophy (DMD)\* can now expect to live an active adult life. This calls for increased attention to life purpose and quality of life from the Duchenne man's own perspective.

\* Duchenne muscular dystrophy (DMD) is a rapidly progressing, genetic disease that only affects boys. During their teenage years, boys with DMD will lose ambulation and need personal assistance. In their early adult years, they will typically need respiratory care.

Some persons with DMD have cognitive problems that may cause learning difficulties and difficulties with attention and concentration. These problems may also have a negative effect on the boy's and men's social skills with isolation and poor quality of life as a result.

## AIM

To examine

- whether young adults with DMD are interested in increasing their participation in daily activities
- whether a new interview guide for identifying activity and participation, *Go4more*, can be used to support the young adults in identifying and starting daily activities

## CONCLUSION AND PERSPECTIVE

The interview based on *Go4more* motivated young adults with DMD to identify and start new activities. Participation in the interview sparked new ideas and brought back forgotten thoughts. All participants started new activities, and all participants were still engaged in activities after three months.

It would be relevant to examine whether persons who need support to start specific activities would benefit from a motivational interview based on *Go4more* if another supportive person were included in the work who could help them get started with the activities.

Furthermore, it would be relevant to test *Go4more* on other target groups.

## METHOD

### Study population

Fifteen persons with DMD aged 18 to 30 years living in Central Denmark Region, were invited to participate in the study.

Six of them, aged 22-30, accepted the invitation.

### Interview

Motivational interview based on the guide *Go4more* which helps to

- Identify the respondents' wishes to engage in new everyday activities
- Analyze activity options
- Prioritize which activities to start

Responses were recorded in the *Go4more* guide and subsequently calculated as median and range.

### Go4more

*Go4more* is an interview guide that aims to help young people to identify activities that may be relevant for them to start. The guide is inspired by the Canadian Occupational Performance Measure (COPM), The Model of Human Occupation (MOHO) and by research in motivational structures and coping self-efficacy.

The guide consists of five sections

- A: Examination of present and former education and job situation
- B: Description of present everyday life
- C: Checklist of interests
- D: Analysis of activity options
- E: Choice of and plan for future activities

### Assessment

The project included two follow-up interviews carried out by telephone

- Two weeks after the interview, an occupational therapist who was not involved in the project called each participant to ask about their experience with *Go4more*
- Three months after the interview, the project manager called each participant to follow up on the activities they had started and to register which activities had not been started or had ended.

The telephone interviews were recorded and subsequently thematized.

## RESULTS

### Starting activities

The participants each identified 5 (2-10) activities that they would possibly start (Table 1).

They each wanted to start 2.5 (1-3) activities during the first six months and 0.5 (0-3) activities within two years.

The participants started 2 (0-4) activities of the identified activities and additionally 0 (0-2) activities which they had identified but not wanted to start.

After three months, the participants were still engaged in 2 (1-4) activities.

Table 1. Activities identified, started and still going on

All the participants identified, planned and managed to start activities and were still engaged in activities after three months.

Participant ID	A	B	C	D	E	F
Identified activities	10	8	5	5	6	2
Planned to start before 6 months	3	3	2	3	1	2
Planned to start within two years	3	0	3	0	1	0
Activities started	4	0	3	2	2	1
Activities not planned but started anyway	1	2	0	0	0	0
Activities still going on after three months	4	2	2	2	2	1

### Activities were identified within some of the following categories



More education



Volunteer work



Social activities with family and friends



Managing personal assistance



Practical skills such as cooking or music



Sports and travelling

### Use of the *Go4more* guide

Responses from the telephone interviews about the participants' experience of *Go4more* could be condensed into four themes:

- To be pushed: "Yes, I started thinking about some things, that I hadn't thought about, yes, that they could be important".
- Structure and content of the guide: "It was probably the structure – that you have the interview and then you try to go through the activities. I think it made me think about other things, things I wouldn't have done, if I had to plunge into them right away".
- Importance of knowing the interviewer: "It was nice to talk to someone who had, like, known you for many years. Not just some substitute – or someone like that".
- Hands-on support: "It would have been nice if we could have talked more about how to do, what we talked about. Yes, how to do the things we talked about".

Five participants found that the interview based on *Go4more* was relevant and suited for its purpose. One participant found it insufficient because he needed additional support to start the activities