

Examining the effect of networks for students with special educational needs

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Fewer students with disabilities complete upper secondary education than students without disabilities. Danish students with Duchenne muscular dystrophy (DMD), attending either a mainstream or a special needs school, their teachers and parents participated in a cross-sectional and intervention study about factors hindering or promoting the best possible schooling and school experience. The study was based on virtual online networks and seminars and results were accumulated from interviews and questionnaires. We found that teachers benefited most from physical networking and parents most from virtual networking. The students only made little or no use of the networks. The teachers' need for access to expert knowledge about DMD was met. More than 80% of the teachers and parents said they would continue using the networks if they were made permanent.

Keywords: networks; primary and upper secondary school; special educational needs; hindering and promoting factors; Duchenne muscular dystrophy

Introduction

Studies show that young people with no upper secondary schooling are at greater risk of being marginalized in the labour market and in society at large (Jensen and Jensen 2005; Ejrnæs 1992), and several studies point to the fact that fewer people with a physical disability enrol in an upper secondary educational programme than young people without a physical disability. Even fewer in the first group complete a higher education (Capacent 2009; Krog 2009; Højberg and Steffensen 2008; Center for Ligebehandling af Handicappede 2005; Rahbek et al. 2005).

Denmark has signed the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities and ratified the Salamanca Statement, thus committing Denmark to take an inclusive approach to all students (Alenkær 2008; Tetler 2008).

Students in Denmark either attend a mainstream class at a mainstream primary and upper secondary school, a school for children with special educational needs (SEN school) or a special educational needs class (SEN class) at a mainstream school. Children attending SEN schools or SEN classes usually have cognitive difficulties, but in some instances they are enrolled in a SEN school because of accessibility issues or the availability of physiotherapy. SEN schools and SEN classes

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are characterized by fewer students, more teachers and pedagogues, and children with various types of functional disabilities, physical as well as cognitive. Normally students with functional disabilities attend mainstream schools, but typically there are only few of them at each individual school and rarely more than one in a class.

Many children with muscular dystrophy do well in school (von Gontard et al. 2002; Riviere and Lecuyer 2002) while others are not at the same academic level as their peers without muscular dystrophy.

One of the best described muscular dystrophy groups in national and international literature and the target group of this study is boys with Duchenne muscular dystrophy (DMD) (Hinton 2000; Wicksell et al. 2004; Billard et al. 1992; Greve 1993), a rapidly progressive, neuromuscular disease that only affects boys. Boys with DMD are wheelchair dependent around the age of 12, require practical help during adolescence and depend on permanent assisted ventilation due to respiratory insufficiency from the age of 20 approximately (Muskelsvindfonden 1996). According to the Scandinavian Consensus Programme for DMD (Sejersen et al. 2003), 25% to 30% of children with DMD are mentally retarded and most of them have specific cognitive or language problems. For a large portion of these children, a special needs programme is often the best possible solution (Catlin and Hoskin 2006). Experts also emphasize the importance of a special educational effort for some children and youths with reduced functional capacity no matter how it is organized (Kirkebæk 2009).

Practical experience and studies by the National Rehabilitation Centre for Neuromuscular Diseases in Denmark (RCfM) have shown that teachers generally lack specific knowledge about their students' disabilities and competences and need help and guidance to identify relevant expectations of and challenges for the students. If a school has no previous experience with disabled students, its teachers will not be able to seek advice from experienced colleagues. Many teachers of disabled students have, thus, requested an opportunity to exchange knowledge with teachers who are experienced in this field. One study points to the teacher's feeling of powerlessness and incompetence in their job as an essential barrier to inclusion (Sloth 2005).

Starting mainstream school is normally unproblematic for boys with DMD, but in fourth through sixth grades (age 9–13) they often find themselves isolated intellectually and socially. The reason for this is multifaceted: Absence from school due to regular physical therapy, adaptation of aids, hospitalizations, etc; Many day-to-day functions are much more time-consuming for them than for their classmates; DMD is a progressive disease resulting in a gradual loss of functional abilities which they have to learn to cope with. The boys have not always been met with the same challenges, expectations and demands as other boys; They have received special care from family members, teachers and pedagogues to such an extent that they have lost their ability to take initiative, identify their needs, accept or object to things, and make decisions (Højberg and Steffensen 2008); And finally, the lack of accessibility and technical aids may be a hindrance to participate in the class as an equal.

Research question

The adequacy of the Danish school system is a topic for continued discussion, but this study takes its point of departure in the existing school system, acknowledging

the fact that a significant number of boys with DMD have special educational needs that would possibly not be met without the existence of SEN schools. Within the given framework, the study aims to identify factors that either hinder or promote good schooling and a good school experience. Furthermore, the study wants to examine whether the establishment of physical and virtual networks for parents, teachers and students could be a promoting factor.

Material and method

Population

All boys with DMD registered with RCfM as per 1 August 2006, who in the school year 2006/2007 attended kindergarten through fourth grades, and all boys with DMD registered with RCfM as per 1 August 2007, who in the school year 2007/2008 attended sixth through eighth grades were invited to participate in the study. The study population was made up of a total of 60 boys of which 33 attended a mainstream school and 27 a SEN school. The parents of two boys said they were too busy with other projects, and the parents of four boys did not respond to the invitation to participate in the study. The analysis population, thus, consisted of 54 boys, their parents and teachers (Table 1).

Design

The study was a combined cross-sectional and intervention study. The cross-sectional study consisted in accumulating knowledge about the factors that hinder or promote the best possible schooling and school experience and was carried out at the beginning and end of the project. The intervention consisted in examining the effect of networks and was carried out in the shape of instruction and exchange of knowledge at seminars and dissemination of information and communication on websites for teachers and parents (SKUD06.dk) and the oldest students (MSN Messenger).

Data were assessed for mainstream schools and SEN classes/schools to account for the differences and similarities between the two types of school. In the study we refer to both SEN class and SEN school as SEN school although we are aware that

Table 1. Number of students represented in SKUD's cross-sectional study at project start and end.

	Students represented			
	Project start (nationwide n = 54 students)		Project end (3 regions n = 40 students)	
	Mainstream school n = 30 students	SEN school n = 24 students	Mainstream school n = 22 students	SEN school n = 18 students
Teachers	20 (67%)	22 (92%)	8 (36%)	14 (83%)
Parents	30 (100%)	24 (100%)	20 (91%)	13 (75%)
Students	29 (97%)	24 (100%)	19 (86%)	18 (100%)

Note: Responses from teachers and parents correspond to the number of students they represent.

there are several differences between the two types of schools and schooling (Center for Ligebehandling af Handicappede 2010).

The study was carried out in the period 1 October 2006 to 31 December 2008. It was launched under the name *Project SKUD* – School and education project for children and youths with DMD, and the project was funded partly by RCfM and partly by grants from the Danish Ministry of Education.

In accordance with legal requirements, RCfM has been authorized by the Danish Data Protection Agency (Datatilsynet) to collect, register, process, and publish data about neuromuscular patients for scientific and research purposes. Furthermore, the collection of data is authorized by written consent from the individual patient.

Cross-sectional study

At project start, the cross-sectional study comprised the total analysis population. At the end of the project, the cross-sectional study had been limited to include the 43 persons from the analysis population living in the regions North Denmark Region, Central Denmark Region and the Region of South Denmark due to resource issues. Three of the boys who had declined to participate in the study lived in one of the said regions, and this gave an analysis population of 40 boys for the final cross-sectional study (Table 1).

The cross-sectional study at project start was carried out as interviews with teachers, parents and students on the basis of a structured questionnaire. The interview guide allowed for both yes/no answers as for more elaborate answers.

Interviews were carried out by the project leader during visits to the home or school. A few participants were interviewed over the telephone, either for practical reasons or because the person had wanted it that way.

The follow-up cross-sectional study at project end was carried out using a self-reported questionnaire filled in by teachers and parents, while the students were primarily interviewed over the telephone or, in a few cases, at home, at school or in-house at RCfM. Many questions were repetitions of the questionnaire used at project start with all factual questions omitted to avoid too many repetitions. Some questions were only posed to one or two of the respondent groups as not all groups were able to answer all questions (Figure 1).

The teacher category was mainly made up of ‘class teachers’, that is, teachers responsible for the contact between school and home, social activities such as school camps, etc. In a few cases, they were replaced by other teachers or a classroom assistant who knew the student well.

Data analysis was grouped into four themes: (1) Academic and cognitive skills; (2) Social competences; (3) Opinions, expectations and knowledge; and (4) Organizational, environmental and resource factors. Themes were defined on the basis of a described model for planning, understanding and explaining an intervention in practice (Yeo, Berzins, and Addington 2007; Gielen and McDonald 1997). Data at project start were sorted by respondent groups – teachers, parents and students respectively – and analysed under the four themes with the aim of assessing factors concerning schooling and school experience of students with DMD.

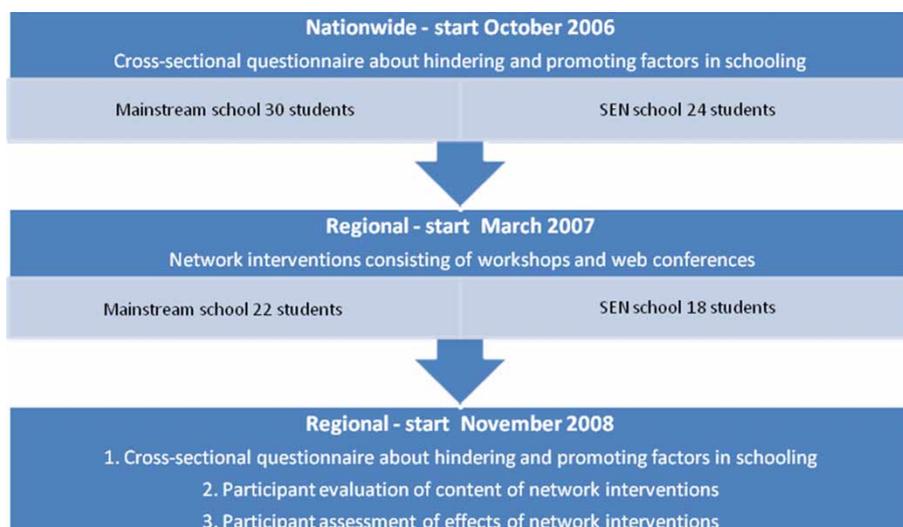


Figure 1. Flowchart of nationwide and regional questionnaires, network interventions, participant evaluations and assessments.

Data at the follow-up were analysed for the same four themes as at project start. At least two of the three respondent groups were included in the assessment to ensure a higher representation and to triangulate responses (Malterud 1996).

Intervention study

Physical and virtual networks were structured with a view to facilitate dialogue between participants, disseminate information from RCfM and gather knowledge for RCfM to be distributed among the participants.

The effect of network interventions was assessed using a questionnaire for teachers and parents at project end and by spot evaluations at seminars. Traffic on websites was registered on a monthly basis. The number of students represented appears from Table 2.

Table 2. Number of students represented at SKUD seminars and websites.

Network	Students represented	
	Mainstream school	SEN school
Seminars for teachers of all students	9 (41%, n = 22)	13 (72%, n = 18)
Seminars for parents of young students	5 (38%, n = 13)	1 (10%, n = 10)
Seminar for old students	1 (11%, n = 9)	5 (63%, n = 8)
SKUD06.dk for teachers of all students	13 (59%, n = 22)	15 (83%, n = 18)
SKUD06.dk for parents of all students	17 (77%, n = 22)	6 (33%, n = 18)
MSN Messenger for old students	0 (0%, n = 9)	3 (38%, n = 8)

Note: The number of students which could have been represented are listed in parenthesis.

Networks

The networks could be accessed in various ways: Participants could ‘meet’ online via emails and conference sites or they could meet face-to-face at meetings and seminars.

Seminars

Seminars were arranged for teachers, parents or students respectively and potential participants from the three selected regions were invited by mail or email. All seminars included both presentations and experience-sharing, and participation was free of charge.

We arranged four seminars for the teachers at which we discussed the most recent medical research in DMD, disabilities in general, cognitive and psychosocial problems and pedagogy/teacher-related topics. Two of the seminars were aimed at primary school teachers and two were for all teachers.

We gave a seminar for the parents of the youngest students about practical help and the schools’ need for information. Finally, we had reserved one seminar for the oldest students about the MSN Messenger platform and team building.

SKUD06.dk

The website SKUD06.dk was designed as a closed discussion forum for teachers and parents respectively and with a shared platform for teachers and parents on which they could read and upload information about topics of interest and RCfM could post information.

Class teachers, other teachers, pedagogues and classroom assistants affiliated with the student had access to the teachers’ forum. The project management (the project manager and one journalist) had access to all forums and could upload new information to all platforms.

MSN Messenger

The oldest group of students with DMD was offered access to a virtual network. They were approached by an ad hoc project worker with an invitation to contact him first and then to establish contact with the other participants.

Ethical issues

The idea of interviewing the students gave rise to some ethical considerations. Would the youngest students be able to answer the questions? Would they experience stigmatization because they were given special attention? Would they be forced to answer questions that they would not otherwise have been asked to consider at such a young age? Nevertheless, we decided to include all the students, one of the reasons being that all the participating families were familiar with RCfM prior to the study. We also decided to approach the parents before the interviews to give them an opportunity to prepare the student for our visit. Furthermore, students at all grade levels were interviewed but not asked to self-report. Some of the students had difficulties in understanding certain questions which we then attempted to rephrase. Finally, we decided to ask fewer questions to the students than to their parents and teachers.

Results

1. National cross-sectional study at project start regarding hindering and promoting factors in schooling

Mainstream school

Teachers of mainstream classes characterized the boys with DMD as students who are not quite at the same academic level as their peers but who have adequate social skills. The students were described as having some difficulties in the class, and the majority of teachers said it is a challenge to have students with DMD in their class. In spite of all this, most teachers expected the same of students with DMD as of other students. When asked whether it is a problem to have a personal assistant in the classroom, an equal number of teachers answered yes, no and don't know. Three fourths of the teachers said they did not have adequate knowledge about muscular dystrophy.

In assessing their children's academic skills, the parents were more positive than the teachers although they did report a significantly higher number of problems with personal assistants than the teachers. A very small number of parents found that their sons lacked expectations for future career opportunities and half of them did not think the teachers knew enough about muscular dystrophy.

More than half of the students could not point to anything negative about their class, and fewer of them knew what they wanted to be when they grew up.

SEN school

A much larger portion of the students at SEN schools were characterized by their teachers as lacking age-appropriate academic skills and social competences. Conversely, these same teachers reported that the students had fewer problems in class but more than half of them said it was a challenge to have the student in their class. Teachers at SEN schools rated their own knowledge of DMD the same as teachers at mainstream schools.

Parents agreed with the teachers about the boys' academic skills but did not find having personal assistants in the classroom as problematic as the teachers. Less than half of the parents did not believe their sons had any expectations as to future career opportunities but almost half of them found that the teachers knew enough about muscular dystrophy.

More than half of the students could not point to anything negative about their class and even fewer of them had any idea of what they wanted to be when they grew up.

Factors relating to both types of school

Physical impairment as a consequence of muscular dystrophy was considered the dominant reason why it was difficult for the boys to be in a class. When posed to the students, the question was accompanied by the question 'what is good about being in the class?' to which the majority of students in both types of schools (approximately half of all the students) answered friendships with classmates.

When teachers referred to the special challenges related to having a student with muscular dystrophy in their class, they typically meant practical problems and extensive planning of all school and extracurricular activities to accommodate for his

special needs. (A table of data from project start regarding schooling and school experience of boys with DMD can be obtained from the corresponding author).

II. Regional cross-sectional study at project end regarding hindering and promoting factors in schooling

(a) Academic and cognitive skills (Table 3)

Mainstream school. A little more than half the teachers rated the student's academic skills poorer than that of his peers' while even more said that the student was good or fairly good at remembering messages and staying concentrated on the things he liked to do. His ability to remember academic information and concentrate on the things he was supposed to do did, however, not receive the same positive rating.

Parents rated the student's academic and cognitive skills higher than the teachers did, especially the student's ability to remember messages and keep his concentration and self-esteem.

The students strongly disagreed with their parents' and teachers' assessment of their ability to remember messages.

SEN school. Students at SEN schools are at a considerably lower academic level than students at mainstream schools.

In spite of that, almost just as many respondents said that the student was good or fairly good at remembering academic information, and even more said that the student was good or fairly good at remembering messages. All teachers and the majority of parents said that the student's ability to concentrate on the things he was supposed to do was good or fairly good, and the student's self-confidence was rated high or fairly high while his self-esteem was rated even higher.

Many of the respondents said there were subjects the students did not participate in, but the students tended to disagree.

Factors relating to both types of school. Parents as well as teachers and students said that typically, students did not participate in subjects that require physical exercise or activities, and the teachers added that the students did not participate in some academic or creative subjects or activities. The parents and especially the students did not share this perception. Physical impairment was generally stated as the main reason for non-participation, and all the students exclusively pointed to this as the reason.

(b) Social competences (Table 3)

Mainstream school. The students' social competences was reported as good or fairly good, but none of the students or teachers said that the student frequently took part in planning recess activities.

Parents were very positive about the students' ability to socialize in their leisure time, while more than half of the students did not share their parents' opinion.

SEN school. Most of the respondents said the students had good or fairly good social competences, but none of the students, and only few of the teachers answered in the affirmative when asked whether the student frequently takes part in planning recess activities.

Table 3. Academic and cognitive skills and social profile of students with DMD.

	Mainstream school			SEN school		
	Yes	No	Don't know	Yes	No	Don't know
Academic level lower than peers (T + P)	44 (63–25)	39 (12–65)	17 (25–10)	82 (86–77)	7 (0–15)	11 (14–8)
Good or fairly good at remembering academic information (T + P + S)	73 (62–85–73)	17 (25–15–11)	10 (13–0–16)	77 (64–85–83)	17 (29–15–6)	6 (7–0–11)
Good or fairly good at remembering messages (T + P + S)	62 (75–90–21)	9 (12–10–5)	29 (12–0–74)	80 (78–84–78)	7 (7–8–6)	13 (15–8–16)
Good or fairly good at concentrating on things he likes to do (T + P + S)	89 (76–100–90)	1 (0–0–5)	10 (24–0–5)	96 (93–100–94)	0 (0–0–0)	4 (7–0–6)
Good or fairly good at concentrating on things he has to do (T + P)	79 (62–95)	15 (25–5)	6 (13–0)	93 (100–85)	7 (0–15)	0 (0–0)
High or fairly high self-confidence (T + P)	64 (63–65)	27 (24–30)	9 (13–5)	78 (72–85)	15 (14–15)	7 (14–0)
High or fairly high self-esteem (T + P)	81 (75–85)	11 (13–10)	8 (12–5)	85 (93–77)	12 (0–23)	3 (7–0)
Shows good or fairly good social competences (T + P + S)	89 (88–85–95)	11 (12–15–5)	0 (0–0–0)	88 (86–84–95)	4 (7–0–5)	8 (7–16–0)
Mostly has a say in recess activities (T + S)	0 (0–0)	91 (88–95)	9 (12–5)	10 (21–0)	77 (71–83)	13 (8–17)
Classmates frequently visit student at home (P + S)	66 (75–58)	34 (25–42)	0 (0–0)	34 (46–22)	63 (54–72)	3 (0–6)
Is frequently visited by other than classmates (P + S)	54 (70–37)	46 (30–63)	0 (0–0)	24 (31–16)	70 (62–78)	6 (7–6)
Does frequently go places with classmate other than home (P + S)	51 (70–31)	39 (25–53)	10 (5–16)	33 (38–28)	61 (54–67)	6 (8–5)

Note: Data listed as average (%) of total responses from the respondent groups first and answers from the respondent groups respectively are shown in parenthesis: Teachers (T), Parents (P), Students (S).

The students did not spend nearly as much time with classmates in their leisure time as students in mainstream classes, and parents of SEN school students believed that their sons spent more time with classmates outside school than their sons said they did.

(c) Opinions and expectations (Table 4)

Mainstream school. Approximately half of the teachers expected the same of the students' academic performance as they did of their peers' whereas their expectations of the students' ability to complete mainstream upper secondary education were not quite as high. Parents generally had higher expectations than the teachers, notably that the student would graduate from lower secondary school and be capable of attending an upper secondary educational programme. Asked whether they received the same amount of homework as their classmates, the students' responses stood out in that they all said that they did. The majority of all respondents had not considered changing school.

Teachers, parents and students all found it was important to continue with an educational programme after ninth grade. On a scale from 0 to 10 where 0 is 'Not important' and 10 is 'Very important', the teachers, on average, found the importance to be 9, the parents 8.9 and the students 7.4.

SEN school. More parents than teachers believed the teachers expected the same of the student as of their classmates, but the teachers said the question was somewhat difficult to answer because their teaching was tailored to the individual student. None of the parents and only a small portion of the other respondents had considered changing schools. None of the teachers expected the student to graduate from ninth grade, neither that the student was qualified to continue in a mainstream upper secondary school. Parents and students alike were unsure of what to expect after primary and lower secondary school.

Teachers, parents and students at SEN schools found education beyond ninth grade to be less important than respondents at mainstream schools. On a scale from 0 to 10 where 0 is 'Not important' and 10 is 'Very important' the teachers rated the importance to be 3.8 on average, whereas the parents rated it 6.7 and the students 6.1.

(d) Organizational, environmental and resource factors (Table 5)

Mainstream school. Teachers and parents considered the teachers' lack of knowledge about DMD a problem. Parents and students pointed to accessibility as a problem whereas teachers did not report any lack of accessibility at the school. Far the majority of the parents said that the student received practical help at school while only half of the teachers said the same. Most respondents found the scope of practical help appropriate and said that a computer was available for the student, and especially the parents found the teacher-parent cooperation satisfactory.

SEN school. Teachers at SEN schools know more about muscular dystrophy than teachers at mainstream schools, and this seemed to be the general belief. Help with practical matters and availability of computers were not considered problematic, and especially the parents were very satisfied with the school-home cooperation.

Table 4. Opinions and expectations of students with DMD at project end.

	Mainstream school			SEN school		
	Yes	No	Don't no	Yes	No	Don't no
Is expected to write same amount of papers as classmates (T + P + S)	58 (50–50–74)	28 (37–25–21)	14 (13–25–5)	34 (21–38–44)	43 (64–46–17)	23 (15–16–39)
Has same amount of homework as classmates (L + E)	82 (63–100)	12 (25–0)	6 (12–0)	70 (57–83)	23 (28–17)	7 (15–0)
Is given special consideration during class periods (T + P + S)	32 (25–35–37)	61 (75–45–63)	7 (0–20–0)	35 (50–23–33)	58 (43–69–61)	7 (7–8–6)
Is given special consideration during recess (T + P + S)	21 (37–10–16)	71 (63–70–79)	8 (0–20–5)	36 (36–38–33)	59 (64–46–67)	5(0–16–0)
Has considered changing school (T + P + S)	17 (25–15–10)	80 (75–85–79)	3 (0–0–11)	39 (7–0–11)	55 (86–100–78)	6 (7–0–11)
Expects to take 9th grade exam (T + P + S)	72 (63–90–63)	7 (12–5–5)	21 (25–5–32)	11 (0–15–17)	50 (79–54–17)	39 (21–31–66)
Expectations re. qualifications for mainstream upper secondary school (T + P + S)	53 (38–70–53)	15 (25–5–16)	32 (37–25–31)	11 (0–16–17)	49 (86–38–22)	40(14–46–61)
Will an extra year (10th grade) improve qualifications for upper secondary school (T + P + S)	49 (50–45–53)	14 (0–20–21)	37 (50–35–26)	33 (21–62–17)	29 (50–15–22)	38 (29–23–61)
Do you/your son expect he will have a job as an adult (P + S)	52 (50–53)	10 (20–0)	38 (30–47)	28 (23–33)	4 (8–0)	68 (69–67)

Note: Data listed as average (%) of total responses from the respondent groups first and answers from the respondent groups respectively are shown in parenthesis: Teachers (T), Parents (P), Students (S).

Table 5. Organizational, environmental and resource factors for students with DMD at project end.

	Mainstream school			SEN school		
	Yes	No	Don't no	Yes	No	Don't no
Do you as a teacher/does the teacher know enough about muscular dystrophy (T + P)	28 (37–20)	27 (13–40)	45 (50–40)	52 (43–61)	15 (7–23)	33 (50–16)
Are there rooms at school the students cannot access because of muscular dystrophy (T + P + S)	20 (0–35–26)	71 (88–60–63)	9 (12–5–11)	11 (14–8–11)	86 (86–84–89)	3 (0–8–0)
Does the student receive practical help in school (T + P + S)	75 (50–90–84)	21 (38–10–16)	4 (12–0–0)	90 (88–94–88)	6 (6–6–6)	4 (6–0–6)
Is the scope of practical help appropriate (T + P + S)	86 (88–80–89)	8 (0–15–11)	6 (12–5–0)	85 (71–84–100)	10 (21–8–0)	5 (8–8–0)
Are there any problems related to the practical help at school (T + P)	21 (12–30)	58 (50–65)	21 (38–5)	11 (7–16)	63 (57–69)	26 (36–15)
Does the student have a computer at school (T + P + S)	85 (100–75–79)	12 (0–15–21)	3 (0–10–0)	84 (87–77–89)	11 (7–15–11)	5 (6–8–0)
Does the teacher-parent cooperation work (T + P)	68 (50–85)	7 (0–15)	25 (50–0)	79 (64–93)	3 (0–7)	18 (36–0)

Note: Data listed as average (%) of total responses from the respondent groups first and answers from the respondent groups respectively are shown in parenthesis: Teachers (T), Parents (P), Students (S).

III. Participant evaluation of content of network interventions

Results of seminars

Evaluations from seminars were characterized by a high approval rating of the presentations and topics which were considered relevant, educational and inspiring, and teachers frequently mentioned exchange of experience and the lectures as the most rewarding feature of the seminars, whereas their lack of time was mentioned as a major obstacle. Parents most frequently mentioned the chance to meet other parents as the best seminar feature and geographic distance and difficulty in understanding material as the major obstacles.

Teachers were highly motivated for learning more about cognitive difficulties, expectations and challenges in boys with DMD and they pointed to social and psychological factors as other relevant topics. They suggested supplementary topics such as scanning of school books, computer technology in general, technical aids, disability sports and more examples from 'real life' and said they wished there had been more time for sharing experience and discussion.

They were very satisfied that parts of the seminars were divided into themes for teachers in mainstream schools and SEN schools respectively and into student age and functional level, and there was a widespread agreement that seminars should continue.

Activity at SKUD06.dk

The following themes were discussed at the website SKUD06.dk: education; pedagogical and practical help; school camps and field trips; accessibility and technical aids; computer technology; muscular dystrophy and disabilities (about the muscular dystrophy diagnosis and living with a disability); friends and leisure time; and about SKUD (features related to the project). One single theme – Cooperation – was not discussed (A table of recorded data can be obtained from the corresponding author).

In their closed forum, the teachers made a total of 1068 searches. The topic most frequently searched in was School camps and field trips with most searches related to the topic Accessible school camps, and this was also where teachers uploaded most contributions. The theme Pedagogical and practical help was visited frequently, and under this topic the Role of the personal assistant received special attention. Fewest searches were made for the topic Teaching.

Parents made a total of 435 searches in their forum and were most interested in Accessibility and technical aids, notably the topics Electric wheelchair and Mobile phone, and this is where the parents uploaded most contributions. Under the theme Pedagogical and practical help, the topic Role of the personal assistant was the most popular whereas the Computer technology theme was not visited by the parents in their own forum.

The joint parent-teacher forum had 1095 searches most of which were aimed at the Muscular dystrophy and disabilities theme, notably the topic Psychological support to boys with muscular dystrophy, descriptions of various books, reports and films, and an ultra short description of the target group. The theme About SKUD was frequently visited, and this was also where they could find monthly newsletters. The themes Pedagogical and practical help and School camps and field trips were not

visited in the joint forum. The topics scanning of books, Sports at school and Motivation each had more than 100 searches.

Results of SKUD06.dk

At the seminars teachers or parents were asked to evaluate the website SKUD06.dk with the following results:

Scientific articles placed on SKUD06.dk were positively received, and notably those dealing with academic and cognitive factors were singled out by many, but articles about problems in everyday life and new technical aids were also mentioned as useful.

It was suggested that we present articles with advice on computer technology and more topics related to school camps.

There were different opinions on the usability of the website. Many respondents emphasized that it was a good place to find help along with its user-friendliness and the procedure of sending a reminder by email every month informing about news at the site was received positively.

Other respondents reported difficulties in entering the site due to either technical barriers, forgotten passwords or an illogical lay-out of the site and many respondents said the site was slow, that they felt bad about not getting started and that they were pressed for time.

Teachers described information, knowledge bank, articles and instructions as the best features of SKUD06.dk and problems with accessibility and lack of clarity as the website's weakest points. Parents frequently mentioned awareness and focus on disabled children as the best about SKUD06.dk and their own lack of involvement and initiative and not being online very often as its biggest flaws.

Results of the virtual platform MSN Messenger

The 16 oldest students were invited to participate in an MSN communication session. Six persons did not wish to participate, the ad hoc employee was never able to get in touch with two persons, and four said they were interested but never online. Four persons communicated online with the project worker but it was not possible for us to register whether the four participants communicated with each other.

IV. Participant assessment of effects of network interventions

Mainstream school

Almost half of the respondents (parents and teachers) said that SKUD had given the teachers more knowledge about muscular dystrophy and an almost similar number of respondents said they were unsure about that but none of the teachers answered 'No' to the question (Table 6).

According to the teachers, SKUD had no effect on the students' academic level or their ability to remember or concentrate, but they had noticed an effect on the students' social competences. They did not find SKUD had changed the schools' views on what to require and expect of the students, nor its views on accessibility and the need for improvements.

Table 6. Effect of network interventions for students with DMD.

	Mainstream school			SEN school		
	Yes	No	Don't no	Yes	No	Don't no
Has SKUD given you/the teachers more knowledge about muscular dystrophy (T + P)	45 (50–40)	12 (0–25)	43 (50–35)	56 (50–62)	11 (14–8)	33 (36–30)
Has SKUD changed the student's social competences (T + P)	34 (63–5)	55 (25–85)	11 (12–10)	7 (0–15)	63 (79–46)	30 (21–39)
Has SKUD changed the schools requirements of expectations of the student (T + P)	25 (25–25)	49 (63–35)	26 (12–40)	19 (15–23)	47 (71–23)	34 (14–54)
Has SKUD changed your perception of the student's need for practical help (T + P)	21 (37–5)	79 (63–95)	0 (0–0)	18 (22–16)	64 (57–69)	18 (21–15)
Has SKUD changed the student's academic competences (T + P)	2 (0–5)	69 (63–75)	29 (37–20)	11 (0–23)	63 (79–46)	26 (21–31)
Has SKUD influenced the student's ability to remember and concentrate (T + P)	0 (0–0)	85 (75–95)	15 (25–5)	7 (0–15)	55 (71–39)	38 (29–46)
Has SKUD made you aware of the need for changes to the school's accessibility (T + P)	40 (0–80)	55 (100–10)	5 (0–10)	11 (7–16)	74 (86–61)	15 (7–23)
If SKUD was permanent, would you participate (T + P)	82 (88–75)	11 (12–10)	7 (0–15)	85 (93–77)	11 (7–15)	4 (0–8)

Note: Data listed as average (%) of total responses from the respondent groups first and answers from the respondent groups respectively are shown in parenthesis: Teachers (T), Parents (P).

In contrast to this, almost all parents said that SKUD had changed their perception of the students' need for practical help.

Parents found SKUD to be a fine initiative but said they had not used it as much as they would have liked. They hoped the project had given a boost to the schools' awareness of their sons' special needs and problems related to schooling and education.

SEN school

More than half of the respondents said that SKUD had brought more knowledge about muscular dystrophy to the teachers while one-third were unsure about that (Table 6).

None of the teachers thought that SKUD had had an effect on the student's academic or social qualifications, and most teachers did not think SKUD had changed the schools views on what to require and expect from the student, nor its views on accessibility and the need for improvements. A small portion of the parents thought SKUD had had an effect on the student's academic qualifications and the school's requirements and expectations.

Factors related to both types of school

More than half of the teachers said that they had participated in SKUD as much as they wanted to. The reasons stated for non-participation were matters of time or the fact that they had only recently begun to teach the student and therefore not been able to join SKUD from the beginning. The majority of all respondents said they would participate in SKUD if it was permanent while only very few of them said they would not.

Teachers and parents were asked to evaluate their expectations of the project and the outcome of their participation in networks (Table 7).

Discussion

Material and method

The initiative to establish networks to improve the educational conditions for this group of students has not previously been studied and no comparative studies have

Table 7. Evaluation of SKUD.

	Mainstream school		SEN school	
	Teachers (n = 8)	Parents (n = 20)	Teachers (n = 14)	Parents (n = 13)
Has SKUD met your expectations?	9.2 (8–10)	5.1 (0–10)	5.9 (0–10)	5.9 (0–10)
Outcome of physical networks and seminars	7.8 (0–10)	2.9 (0–10)	3.9 (0–10)	2 (0–8)
Outcome of virtual network and SKUD06.dk	3.8 (0–9)	3.3 (0–8)	3.2 (0–6)	2.5 (0–8)

Note: Mean assessment on a scale from 0 to 10, where 0 means 'No/Nothing' and 10 means 'A lot'. Range in parentheses. Data at project end.

been made of students in mainstream and SEN schools. Although commenting on the generalizability to other target groups should be exercised with great care, young persons with DMD could be comparable with other minority groups characterized by a combination of cognitive and physical difficulties, disease progression, stigmatizing and massive dependency of other people. For instance, young persons with epilepsy, cerebral palsy or spina bifida or other groups of young people who are introduced to new life-extending treatments.

The intervention study included students with DMD in three regions which gave us an opportunity to generalize at the national level as the analysis population, at the time of analysis, consisted of 40 students in the three selected regions out of a total national population of 60 students of which 54 participated in the study.

The cognitive functional level varies considerably in children and young persons with DMD (Hinton 2000; Billard et al. 1992) and there are, thus, both students with DMD at mainstream and SEN schools. This calls for a similar division of study design which, in turn, complicates the assessment of data, analysis and results, but on the other hand strengthens the validity of the study in that it minimizes the risk of study data bias (Malterud 1996). For the same reason, data from mainstream schools and SEN schools are kept separate (Table 1).

Initially, attendance for the project was high with 90% of the study population represented in the cross-sectional study at project start. In the final cross-sectional study of three regions, representation was even higher with 93% of the study population represented. Representation in networks ranged from 0% to 83% with a total mean representation of 43% (Table 2).

Participation from teachers in mainstream schools at the end of the cross-sectional study was 37% which we consider to be very low. Although many children with functional impairment are now physically integrated in mainstream schools, no extra measures are taken to ensure that the teaching is also inclusive (Alenkaer 2008). Much of the national and international literature discusses this issue (Tetler and Langager 2009; Booth 2004; Moos et al. 2006; Tetler 2000; Cornwall 1996), but it has not been the primary focus of this study. However, during the study we experienced that teachers often find it difficult to give priority to extracurricular activities such as filling in questionnaires. Moreover, their interest in making the extra effort may be very little as it is unlikely there will be another student with muscular dystrophy at their school in their time. Teachers at SEN schools seemingly had more time to participate than teachers at mainstream schools and this also became apparent when more employees from one SEN school were able to attend the same seminar. SEN schools may see such days as an investment for future use because they have good reason to expect more students with similar problems. Their need for special knowledge about students with DMD might be greater as they usually deal with both physical and cognitive problems.

Responses were triangulated at data assessment to ensure answers from at least two respondent categories. This allows for more answers to the same questions and gives a higher mean response rate. To give readers an insight into the responses of each group, we have chosen to add these, knowing that deviations might be based on few answers.

Almost all the students were enrolled in the project but few of them participated actively in the formation of networks. The most active participation was seen in students from SEN schools which was also the group who reported the smallest number of friends outside school (Table 3), and we can thereby conclude that their

incentive to network was greater. At the same time, they were the ones who had most troubles in using the MSN Messenger website because it was difficult for them to use the Internet, remember passwords and initiate communication.

If we look at how parents and teachers evaluate the outcome of networking alone, we see a comparatively small effect. However, when asked if they would participate in a similar, permanent project, the majority of the respondents said they would do that. We can thus conclude that the desire to form networks was intact, however, provided that we improve and develop the contents and organization of the project. The importance of ensuring social interaction for the purpose of experience exchange and sharing of innovative ideas has also been pointed out in a Norwegian study (Skogen 2004).

Discussion of results

Knowledge

The number of teachers who said they lacked knowledge about DMD was reduced considerably. We believe that in giving teachers more knowledge, they have become aware that easy access to information is important for their role as a teacher. Participation in SKUD (interviews/questionnaires and networks) seems to have made the participants more aware of the many-faceted problems, thus making their assessments at project end more well considered and reliable.

Choice of school

Results in our study clearly show how the two school types differ in respect of opportunities and expectations. Mainstream schools were characterized by a higher academic level and greater expectations in terms of writing papers, taking the final exams, further education and future career opportunities. This emphasizes the importance of enrolling the student in the right type of school. And it shows that testing the cognitive skills of students with DMD before they begin school makes good sense.

Friendships

Friendships are important for most people and sometimes crucial for young people including children and youths with functional impairment (Høgsbro et al. 1999). A large portion of the students in the study have a relatively small social network and their friendships are, to a great extent, related to school – especially at SEN schools – and thereby of great importance as an integrating factor for these students. The possibility to form friendships is experienced very differently at the two types of schools. At mainstream schools, students with muscular dystrophy rarely have other students they can identify with and the risk of feeling different is imminent. But it is possible to build friendships at school and continue them outside school. At SEN schools, the presence of several other students with a physical impairment minimizes the risk of the boys feeling stigmatized. At SEN schools, a larger portion of the students with DMD are also involved in planning recess activities than in mainstream schools. In contrast, the students at SEN schools have fewer friends outside school, typically because the schools are not located in their neighbourhoods

and having friends over requires some planning. According to Norwegian research, a child's place of residence is decisive for the size and composition of his network (Bø and Schiefloe 2007), and when long transport times prevent daily contact with friends, this becomes an important issue and makes high demands on the teachers' and parents' ability to create the necessary space and framework for establishing friendships.

Network

In the following, we will discuss the SKUD network in relation to aim, organization and effect (Gielen and McDonald 1997).

Participants in the networks were informed about the importance of having direct access to knowledge. They said this was very rewarding and would recommend it for future use. Many teachers, parents and students had joint access to information which would otherwise have been given to each of them individually and they had rich possibilities for exchanging experience. This was much appreciated at seminars.

By allowing employees from both types of school to share experience, their mutual insight in the other type of school increased.

The balancing of teachers' and parents' expectations to one another was strengthened through the increased access to information. Parents often expect more from the school than it is able to honour and by participating in networks, the teachers have shown an interest in the student's specific problems which is appreciated by the parents.

The lack of financial resources at the individual schools was an obstacle as the project budget only covered seminars and could not reimburse the schools for the costs of having teachers out of house.

Conclusion and perspectives

The focus of this study was to examine networking among students with DMD, their class teachers and parents as a method to gather knowledge about the factors hindering or promoting the best possible schooling and school experience. The participants in the study were students with DMD in mainstream and SEN schools, their parents and teachers. In their assessment of the project's effect, the majority of parents and teachers said they would participate in SKUD if it was a permanent offer. We can thereby conclude that the project apparently met a widespread demand for more information.

At project start, both parents and teachers said that the teachers needed more information about DMD. Teachers found that having a student with muscular dystrophy in their class was a great challenge, and many of the teachers in mainstream classes had experienced significant problems with having a personal assistant present during class periods. The project aim of ensuring access to much needed relevant, specialized knowledge increased the awareness of a variety of problems associated with students with functional impairment. The majority of respondents said they had obtained more knowledge and this resulted in more competent evaluations of the students' competences and difficulties.

On the basis of the project results, we recommend that schools which accept children with functional impairments be given access to expert knowledge about special conditions related to the individual student.

The study proved a need for establishing networks – especially those formed at seminars and especially for teachers. Participation in the networks varied for the different types of respondent groups and especially teachers at mainstream schools found it difficult to participate because they were pressed for time. The need for more knowledge, on the other hand, was pronounced and parents expressed a wish that the teachers had more knowledge.

Participation in networks does not alter the students' academic skills but exchange of experience might help prompt qualified solutions to complicated problems.

The choice of school type will greatly influence the individual student. He will be exposed to very different opportunities, expectations and conditions in a SEN environment than in a mainstream school and vice versa. Whether the existing school system offers adequate physical and academic environments for students with a combination of physical and cognitive impairment has not been the main focus of this study, but the study shows that students in mainstream schools are given more academic challenges and have better opportunities for establishing friendships outside school. On the other hand, the risk of stigmatization is less pronounced at SEN schools. Because social and cognitive competences vary considerably in children with DMD, we also recommend that children with DMD take a child neuropsychological test before starting school. This may help qualify the choice of school type.

Students with DMD generally have fewer friends than students without muscular dystrophy. Especially SEN school students see fewer friends outside school than their peers. This emphasizes the importance of taking relevant and viable initiatives and ensuring that teachers are able to create the necessary space and framework for retaining friendships.

Results from SKUD can be generalized to other diagnoses for students with special needs, for example, students with progressing functional types of impairment who depend heavily on other people and whose perspective on life have changed due to new treatments. Experience gathered from the SKUD network will also be relevant for other teachers of children with special educational needs and for establishing networks for those teachers.

The long-term aim for students with a functional impairment is to enable continuation to upper secondary education and to support them in living an independent youth and adult life at their own terms. Half of the teachers and parents of students at mainstream schools and more than half of the parents of students at SEN schools found that an extra preparatory year after ninth grade would improve the student's qualifications to complete an upper secondary education. This emphasizes the importance of setting up initiatives that take the student's cognitive as well as physical needs into account.

The interest in specialized information combined with a pronounced indication that the project has increased the knowledge of DMD clearly shows that the networks had the desired effect. The teachers' need for specialized information and general knowledge about DMD was met and parents unequivocally say that the teachers now are more knowledgeable about DMD. The study group which benefited most from the study and notably from the physical networks was teachers at mainstream schools. In conclusion, the authors of this article therefore greatly recommend networks as a forum for dissemination of information and as a platform for experience exchange.

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