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Uniting Divided Worlds: Identity, Family and Education in the Life Projects of Deaf and Hard of Hearing Young People

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Abstract

The article is based on a study of living conditions among Deaf and hard of hearing people 16-20 years old. Identification, family relations and education are discussed. This is the first generation of Norwegian Deaf and hard of hearing people whose parents have been offered real opportunity to learn sign language. Unlike earlier generations of sign language users, many of these youths have experienced personal as well as linguistic acceptance at home. They perceive themselves as obvious participators at a variety of local and global scenes and contexts both in hearing and Deaf worlds. They are uniting worlds that traditionally have been divided by language barriers. Among those who have not experienced the same degree of inclusion and acceptance as deaf or hard of hearing at home, questions of belonging to Deaf or hearing worlds seem to add pressure to the anxiety often connected to the teenage years.

Children of the normalising ideology

> I feel that I am becoming more and more Deaf. But to be honest, I must admit that I miss hearing people. I belong to both worlds, but I also fall between two stools. I am concerned to find my place, to learn who I am... (Helene, 16)

Helene alternates between describing herself as Deaf or hard of hearing. She has received her elementary education in a public school with hearing peers, but is now enrolled in an upper secondary school for the Deaf. In this quote she says that she is in a process of moving between two worlds. Senses of belonging or questions about self-identity might be more pressing during the teenage years than any time earlier or later in life. To many young people, crafting a sound identity as young adults and as Deaf or hard of hearing is an ambiguous task.

Questions of belonging to Deaf or hearing worlds seem to add pressure to the anxiety often connected to the teenage years. The identification process that many go through before reaching adulthood might also be obscured or delayed due to the more or less subtle normalizing pressure from a majority in the society, following a dissociation of many of the same values from the Deaf world (Breivik 2001). People will have to find their own trajectories, and the options available to, and choices made by, Deaf and hard of hearing young people will be related to their personal, material, social and linguistic resources and living conditions. However, as will be shown thorough this article, the young people have an individualistic approach to their own life career, and perceive themselves as stakeholders in their own life course.

This article is based on a study of living conditions among Deaf and hard of hearing young people. Topics related to identification, family relationships and belonging as well as education and ambitions are discussed. A survey was sent out to the entire population of those defined as Deaf and hard of hearing pupils aged 16-20 years old in the special education support system in Norway. The questionnaire was sent to 152 pupils, with 77 replies, which gives a response rate of 52%. The questionnaire covered issues related to living conditions as well as Deaf and minority issues, networks-integration-marginalisation, society and community activities, and use of media. The survey was followed by 15 qualitative interviews, centered on topics related to education, language, family relationships, peers and expectations for future life. The informants were recruited through the survey and were interviewed in a language of their own choice - Norwegian Sign Language (NTS), signed Norwegian or Norwegian.

Self-identification

Thirty nine per cent of the respondents said they identified themselves as 'Deaf' and 60% said they identified themselves as 'hard of hearing' or 'hearing impaired'. Language competence appeared to be strongly connected with self-identification. Of those identifying as hard of hearing/hearing impaired, 91% said they had Norwegian as their best language, while 80% of those saying they were Deaf had NTS as their best language. Approximately 80% of all respondents know both NTS and both-either written and spoken Norwegian. We chose to ask 'Which language do you know the best?' instead of using more scientific terms like mother

tongue, first language, primary language etc. for two reasons. First, we were not sure if the respondents would understand these concepts. Second, we wanted to know which language the young people were most comfortable with, not which language they had learned first.

All but one checked one of the options regarding identity, while 37% were unsure about their own hearing loss. The identity label therefore seems to be more important to the young people in the survey than the hearing loss. Compared to hearing loss, the replies to other questions in the survey did not show the consequent patterns that were observable when compared to self-identification. The large group uncertain about their own hearing loss strengthened our decision to use self-identification as a point of departure for analysis, not reported hearing loss. Personal and linguistic resources as well as material and social conditions heavily influence the consequences of a hearing loss.

Among those who identified themselves as 'Deaf', 66% disagreed that they were disabled, while 53% of those identifying themselves as 'hard of hearing' or 'hearing impaired' disagreed that they were disabled. This slight difference is in accordance with an otherwise observed pattern:

> More generally, we can observe that late deafening and moderate hearing loss tend to be associated with the disability construction of deafness, while early and profound deafness involve an entire organisation of the person's language, culture and thought around vision and tend to be associated with the linguistic minority construction. (Lane 1997:155)

It might seem as though the young people questioned in this survey have adopted a similar pattern of identification. However, what is more important to observe is that the majority of the respondents distance themselves from an identity as 'disabled', despite the traditional status of deafness/hearing loss as a classical 'handicap'. Both groups also seem to give solid support to the minority group discourse in the Deaf movement. Almost 90% of those labeling themselves Deaf, and 80% of those labeling themselves as hard of hearing, agree with a statement saying that Deaf people belong to a linguistic and cultural minority.

Families and belonging

A little more than 60% have no other Deaf or hard of hearing family members; 19% report that they have Deaf or hard of hearing siblings, while about 10% have Deaf or hard of hearing parents. The latter coincides well with the rule of the thumb that approximately 90% of all hearing impaired children are born into families who neither have much insight into the consequences of a hearing loss nor know any sign language. Parents of Deaf and hard of hearing children have traditionally been given few opportunities to learn sign

language. The results from this project indicate that changes have occurred - 42% of those who only have hearing family members report that sign language is used at home. Of those who state that NTS is their best language, 76% say that sign language is a home language.

Insiders in the Deaf community and employees at the county college, which has offered family courses in sign language and Deaf culture for three decades, report a gradually increasing social pressure since the 1980s for parents to learn sign language if a child is Deaf or hard of hearing. In 1996, one of the world's most thorough sign language education programs for parents of sign language using, hearing impaired children was launched in Norway. All parents of sign language using children born after 1992 are entitled to receive at least 40 weeks of free instruction in sign language and Deaf culture before the child reaches 16 years old (Liltved 2002). To ensure sign language education for parents with children born earlier than 1992, too, parents of these children have been offered two weeks of sign language education annually until the child becomes 16 years old.

Hanne (17), Trine (16) and Maja (16) belong to the new generation of young Deaf people who have grown up in a hearing, sign language using family. The signing milieu at home, gives Hanne a sense of equality and belonging:

> I know I am very lucky to have such a supportive family as mine. They have all learned sign language, and I have never got any special treatment at home because I am Deaf. (Hanne, 17)

When Hanne was a little girl, her parents, siblings and grandparents went to a county college for the Deaf for six months to learn sign language. The story Hanne tells about herself is one of inclusion and participation through sign language. She has a hearing boyfriend, whom she has taught sign language to. When her Deaf friends from school go home for the weekends, she hangs out with him and his hearing friends.

Trine (16) and Maja (16) also spoke of their deafness and family relationships as a matter of course. During the interviews, they could not remember any incidence at home marking them off as deviant or 'special' in the family setting. These girls say they feel like any of the other family members.

This seems to reflect their subject position in general - related to both Deaf and hearing people. The 'normal' family bonds appear to have influenced their world views. They have not been put under pressure to be 'integrated' in a structure where they do not readily fit in. Instead, their closest surroundings have transformed to fit the prerequisites of the child. Several of the young people did not question their own position, identity or rights, and are in a position in which they can change the consciousness of their hearing surroundings. They are aware of differences, but also discuss

the differences as a matter of varieties. A Deaf world or a hearing world is not rendered more 'normal' than the other, as Marianne, who has Deaf parents, formulates:

> Deaf people are a cultural minority, but also a part of something larger. It is a bit provocative when people who claim they are 'normal' say that we are special, when we really are like them. (Marianne 16)

It is as if these girls take their identity as Deaf for granted. Their parents have accepted them for what they are, through learning sign language, and in this way contributed to a high Deaf confidence. Yet, other interviews revealed that family communication is still is a source of personal frustrations and intra-familiar conflicts, especially among the hard of hearing young people. Some parents may have felt that the child heard so well that sign language was not considered necessary for family communication, while others may not have had the opportunity to learn sign language. Parents of hearing impaired children, who do not have sign language as their first language, are not entitled to the same courses as parents of sign language using children.

Frode (20), who identifies himself as hard of hearing, provides an example of being left out in own family:

> I am not very close to my siblings. They were all talking at once. Even tough I asked them again and again what they were talking about. I often ran away and walked out for hours. Or I sat in my room listening to music. (Frode, 20).

Helene (16) conveys a message of being the different child, the child who does not feel she is like the other even tough she admits she likes her family and also feels like a part of her family.

> I am also quite left out, compared to my sisters. I am in one sense one of them, but there have always been problems with me who am hard of hearing. I do not understand what they are talking about when we are eating dinner. I appreciate my mom using voice and signs, and that she shows me some consideration. Still, I feel left out, and I am quarrelling a lot with my little sister since there are so many misunderstandings. I have always been the bad girl at home, while my big sister is so calm and I look up to her. I have always felt left out at home, indeed. (Helene, 16)

During the interview, she repeatedly talked about her need to find her own place. She expresses how she does not really feel at home anywhere. She feels content about being hard of hearing, but that she will have to find her own place. Frode however, conveys a negative message about the hearing loss itself.

> I do not like to be hard of hearing. It is better to be hearing. I do not understand what people are talking about. If the physicians find a cure, I want to become hearing. I do not feel well with Deaf people, it is better to be with hearies. (Frode, 20)

Anne (18), however, is very clear about not wanting to use sign language, even though she has a profound hearing loss and her parents and teachers have encouraged her use sign language. During the interview (which was conducted in spoken Norwegian, after her preference), both she and the hearing researcher had to repeat questions and answers in order to make themselves understood. Despite the obvious communication problems, she insists that she neither wants to use, nor needs, sign language.

> My parents thought that I was dependent of sign language. They gave in, but the school was more difficult. I had to fight. The school wanted me to change my decision. I have no regrets with regard to the choices I've made. (Anne, 18)

Anne speaks of an opposite struggle vis-a-vis her parents than Frode and Helene. She insists on being identified as hard of hearing, not Deaf. Keeping aloof from sign language - despite the communication problems in her surroundings - seems to be a part of her identity construction. By this she also reveals that she (like many of her age peers) is a strong agent in her own identification development, a process in which language seems to be a crucial factor.

The young people, who have experienced their parents learning sign language, seem to be confident in their identity as Deaf. They do not convey the same messages of searching for an identity or a place to belong as those who have experienced more family communication struggles. Compared to the stories told by older generations, the experiences of this generation seem to be different. Those with parents who have learned sign language, have been included in the intimate family life to a degree rarely seen before. Following a general increase in accepting Deaf ways of life and sign language, the youth participate at more arenas in the society than earlier generations of Deaf people. This may eventually imply a generational transformation of the Deaf identity experience.

Transnational activities

Participation in the intimate and close communication often taken for granted in a family setting has rarely been an available option to Deaf people born into hearing families. Belonging has, to many Deaf and hard of hearing people, been of a translocal nature (e.g. in schools for the Deaf or at the Deaf Club) and transnational activities have long-standing traditions in the Deaf community (Fjord 1996, Breivik 2001, Haualand 2003). Mia (20) and Simone (17), who have Deaf

parents, tell about transnational family activities since they were young children. As a result of this, both are multilingual and know several sign languages. They have an excellent literacy in both Norwegian and English, and understand at least one more written language, too. Mia says:

> I have been to several Nordic camps for Deaf children or youths. I have been traveling a lot with my parents, for example at Nordic Deaf Culture Festivals and handball championships since my father played handball at the Deaf national team. Just a few weeks ago, I went to Sweden for a gathering for pupils in upper secondary schools for the Deaf. I have a lot of friends abroad. Only this winter, I have visited my sister in the USA and I have been in Rome. When I am traveling, I always live with someone I know, or at a friend of a friend's house. (Mia, 20)

Mia and Simone are perhaps more experienced travelers than many of their age peers, but they are not exactly unusual if comparing their experiences of transnational activity with the replies from the survey.

The survey showed a gap in degree of international interaction between the sign language users and the young people preferring spoken Norwegian. Sign language users were more likely to have traveled abroad to meet Deaf or hard of hearing people from other countries, and more likely to have done this more than once (over 70% of our sample of sign language users had traveled abroad for this purpose, compared to under 40% of the Norwegian speakers). Comparing transnational Deaf/hard of hearing activities to other variables, like identity or language of instruction in school, shows the same pattern. Use of sign language and identification as Deaf increase the chance for transnational contact with other Deaf or hard of hearing people. Those identifying themselves as Deaf also reported more contact with other people through e-mails and chatting, and also had more Deaf or hard of hearing friends abroad than those identifying themselves as hard of hearing.

However, not only the Deaf interviewees tell about international activities. Tone (18) who has a slight hearing loss plans to go to a university in Scotland after graduating from upper secondary school for a bachelor and eventually honors degree in marketing or education. Tone is confident that she will manage to study and communicate in a foreign language, despite of her hearing loss. People with a hearing loss will in general have more problems communicating verbally in foreign spoken languages, since lip-reading a foreign language is significantly more difficult than lip-reading a native language. Sign languages are also more easily adapted to a mode of communication comprehensible by other signers. One might therefore expect that knowledge in one or more sign languages increase the possibility for transnational activities.

For successful agency in the accelerating globalizing

processes, linguistic competence is a resource, but professional participation also requires education. Teaching families of Deaf and hard of hearing children sign language strengthens personal confidence and the basis for participation. However, there are signals from the young people that the schools for the Deaf have not adopted a similar attitude towards participation and abilities yet.

Education and ambitions

Language(s) of instruction is one central aspect in the education of young Deaf and hard of hearing people, but attitudes and expectations toward linguistic and theoretical skills and achievements should be given some consideration. Most of the respondents are undertaking upper secondary education along with other Deaf or hard of hearing pupils, either in a school for the Deaf or hard of hearing (55%) or through a mainstream program (16%), while one fourth (27%) receive education in a all hearing environment, but have contact with the support system at a school for Deaf or hard of hearing.

The respondents are following a variety of courses, with a majority following general studies (47%) or vocational education (43%). The number of Deaf and hard of hearing pupils in the special education support system is quite small compared to the total number of pupils undertaking upper secondary education in Norway. The interviews reveal that many have experienced structural limitations in their choices, and not all have been able to take the classes they wanted to in the first instance, due to lack of teachers or low numbers of pupils. The portion of pupils on the different courses thus gives an impression of which are offered by those schools that are a part of the special education support system, in addition to providing a rough picture of the preferences of the young people themselves.

Structural constraints had been a problem to a few of the interviewees. But many were far more concerned with what they had experienced as low expectations and low levels of instruction. Maja is not very satisfied with the counselor from lower secondary school:

> Entering general studies was my own decision. But the counselor was not very positive. She asked me persistently if I was sure, if I would follow normal progression and not use four or five years instead of the regular three years. She was so skeptical and had a lot of prejudices. (Maja, 16)

The prejudices Maja experienced from her counselor at the school for the Deaf may not be unique. General studies are more theoretically advanced than the vocational courses. Expectancies towards academic achievements of Deaf pupils have in general been low (Lane 1992). Maja's counselor reflects this tradition in her attitude towards Maja's plans, despite her excellent marks and Norwegian literacy. Comments from

almost all Deaf interviewees and the table below make it reasonable to conclude that low expectations are still prevalent in several schools for the Deaf.

Oline (20) went to a school for the hearing impaired from first to seventh grade, and shifted to a school for the Deaf when she entered lower secondary school, and quickly noticed the difference in level of education:

> The teachers were too protective and 'understanding' at the new school. If we had not done homework, they said 'oh poor you, this must be too difficult for you'. When they treated us that way, they did not get much respect from us. But when I protested and told them to quit threatening us as if we were stupid, I was thrown right out of the classroom. (Oline, 20)

None of the others tell they have been expelled from class, but Oline's familiarity with low-level education is not unique to her. Trine, who went to another school for the Deaf also experienced low levels of instruction:

> Some teachers put really high demands on us, while others did not expect anything from us. One example of the latter is when we had a quick test, and the answers were enclosed. (Trine, 16)

Low expectations seem to be familiar and expected. Some of the young people who feel they have received an adequate education underline that they had been lucky, like Simone:

> It's thanks to my teacher in Norwegian, who was Deaf, that I know Norwegian so well. The teachers at my school were continuously comparing us to the hearing pupils at the school at the other side of the schoolyard, and the education level was adequate. (Simone, 16)

Helene (16) was the only hard of hearing pupil in her local lower secondary school, and had an interpreter during the lessons. When she entered upper secondary school, she noticed a difference between herself and her classmates who had attended a school for the Deaf, and she feels that she can relax a bit in class. However, she also says that she was all done at the end of the day when she was in lower secondary school. Her sense of being able to relax in class may also be connected with the strenuous effort she was used to mobilize to follow the instructions in lower secondary school. At the upper secondary school she did not have to make much effort to grasp the messages from the teachers and classmates. Hence, the sense of ease may influence her evaluation of the instructions as well as the level of the education itself.

A most striking difference in ambition level can be seen when considering major language(s) of instruction in elementary school. While nine of the 14 Norwegian speakers (64%) planned to go on to college or university, only two of

the 18 sign language users were committed to this goal (the majority of them, 56%, remained undecided). Those who were educated bilingually, or who used sign supported Norwegian, fell somewhere between the two language groups (with 39% desiring to go on to college or university and 41% undecided). At the time the respondents received their elementary education, only the regional or central schools for the Deaf had sign language as the main instructional language, albeit that the teachers' sign language qualifications varied.

The schools for the Deaf have been and are crucial language and cultural shelters, but the reverse side of this system might be what one can see here. 11% of the respondents who have received their education in sign language only (and thus have only attended a school for the Deaf), plan to undertake more education after leaving upper secondary school, while 64% of those who have received their education in only Norwegian (and have been following a mainstream education progress) are heading for further education.

The schools for the Deaf have gone through major changes the past ten to 20 years, but the interviews reveal that low academic expectancies and prejudices still is experienced by the pupils in these schools. The young people we have interviewed seem to have found ways to overcome this, and have not allowed the attitudes of their teachers or counselors to influence their future ambitions. When we asked about future plans during the interviews, occupations like oceanologist, sign language researcher, lawyer/advocate, TV journalist, estate agent/manager, teacher, midwife, designer and business manager were mentioned. Furthermore, those who identified themselves as 'Deaf' were slightly more ambitious than those labeling themselves 'hard of hearing'.

The interviewees seem to talk about the schools with some ambiguity. The positive side is that the schools for the Deaf are offering milieus of peers and teachers who enable them to communicate spontaneously. What some have surrendered is freedom to chose subjects or courses after own interest, and theoretically advanced instructions.

Authoring selves, uniting worlds

It stands to reason to expect that this generation will not accept limited access to society in their adult life. Many have experienced being insiders in their families, and expect to be treated as insiders in a hearing society, too. Differences can still be seen between those who have experienced relatively seamless communication at home and those who have had to struggle to be included.

The still internalized low expectations towards academic results in some of the schools are in contrast to the move towards inclusion inherent in teaching parents sign language. To the extent that the pupils in the schools for the Deaf have experienced systematic discrimination, discrimination seems to have occurred in educational settings. The schools are an arena where 'the relationship between discrimination on the basis of both perceived impairment and discrimination on the

basis of perceived generational location' (Priestley 2001, p246) is highlighted in the case of Deaf and hard of hearing youth and children. The low expectations that the young people experience may, in part, be a result of a traditional failure in teaching Deaf children to read, speak and write, partly due to the underestimation of sign languages (Lane 1992). Even if the status of NTS has altered, the testimonies of pupils reveal that century-old internalized pathological attitudes toward Deaf and hard of hearing children still prevail in the schools. But the optimism about the future and their own possibilities, indicate that many of the interviewees seem to have built mental ballast in family and among peers to oppose this suppression.

The opposition also indicates that the interviewed young people, to a large degree, perceive themselves as the key stakeholders in their own life project(s). The post-modern life approach is a very striking and common feature. John (18) captures the life strategy of many of the informants:

> I turned the whole thing upside down. I had to get new friends. I found a new style of clothing, a little more grown up than the others. I wanted to be different in my way. It felt good to walk with a straight back. I wanted to change, and I did. (John 18)

He carefully selects the style and friends he wants to be associated with, and chose an identity as hard of hearing rather than Deaf, and thereby is reminiscent of an identity 'shopper'. In Bauman's (2001) words, personal qualifications, images, social milieu and romantic partners have been commodified, and the code that formulates personal life strategies has been transferred from the pragmatics of shopping. Welfare services seem to be approached in a similar way, as branches of a state that is there to serve its consumers. Basically, the young people seem to approach the welfare system in the same way as most other young people in the Norwegian society - they take it for granted. If they can benefit from the offers of the welfare state, they do. But they do not necessarily adopt the categories the entitlements it is based upon, like Marianne when she discusses whether she should apply for rehabilitation support when she enters college:

> If I accept rehabilitation support, does that mean that I accept I am disabled? In one way, we are perhaps disabled, since we don't hear. I can understand the concept, but I do not feel that I am disabled. (Marianne 16).

The ambiguity and discussions related to belonging and identity also reveal that collective representations or beliefs are not inevitably becoming personal beliefs. The data from young people in the project '...belies any simplistic notion that identities are internalized in a sort of fixing

process that unproblematically reproduces the collective upon the individual, the social upon the body' (Holland et al. 1998:169). Ambiguity is a characteristic of the teenage years, but as they are defined as disabled people in a welfare context, this ambiguity is also a critique of the definite categories of the welfare state.

Discussing normality as a relative concept, as Marianne does, challenges basic structures of the welfare bureaucratic system, and is thus challenging the power of the welfare system itself. At the same time, they do not convey the same distance from a majority world as previous generations of Deaf people have done traditionally. Teaching parents of Deaf and hard of hearing children sign language seems to have reduced barriers within families and between worlds. But not all parents or families have the opportunity to learn to communicate with their Deaf or hard of hearing children. Increase in uncertainty about identification and belonging seem to be the price some of the young people of these families pay. Offering courses for parents of hard of hearing children, too, may be a reasonable step to decrease the identity anxiety of hard of hearing youth.

There has been a change of policy from unilaterally trying to teach Deaf and hard of hearing children to speak their parents' language to teaching the parents their children's language. Increased acceptance and visibility of sign language in public life have also reduced the traditional stigma attached to Deaf people. This has given this generation of youth quite another experience of growing up Deaf or hard of hearing than the generations before them. They have been included in their early years and expect to be included in their adult lives, too. The Deaf and hard of hearing young people in this survey perceive themselves as obvious participants in a variety of scenes and contexts, both in hearing and Deaf worlds. In practice, many of them are uniting worlds that traditionally have been divided by language barriers.

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