5 Struggles for inclusion

The unrecognised toil of hearing-impaired students

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Between 2006 and 2009 I participated in a series of video-recorded observations of Norwegian hearing-impaired children in mainstream classrooms and kindergartens.¹ The children – aged between five and nine years – had all received state-of-the-art hearing technology in the form of cochlear implants, and we had been pointed in their direction because we had advertised our research interest in observing hearing-impaired children who ‘did really well’ in mainstream schools or kindergartens.

Indeed, the children were apparently doing well. To my naked eye, it seemed that they went along with other children as easily and naturally as those with typical² hearing would have done. When we started analysing our video recordings, however, another picture emerged. Going through the cumbersome procedures of transcribing the tapes, it became clear that the children applied a wide range of techniques designed specifically to create the general impression that they were managing as if they had typical hearing. For example, a five-year-old boy would often reply ‘yes’ when someone addressed him, be it with a question or a simple assertion. He pronounced his ‘yes’ with such a noncommittal intonation that the word could pass both as a question – ‘yes?’ – and as a confirmation – ‘yes’. His conversation partners were often satisfied with the reply, but we were left wondering: did the boy understand what the others were saying to him, or had he learned that, by giving this reply, he could save himself the embarrassment of admitting that he did not follow fully? It soon became apparent that the complexity involved exceeded this simple either/or question.

All the observed children struggled daily to manage, on a number of levels. They struggled to hear and manage the limitations of their hearing technology, especially noise. They struggled to manage in the absence of inclusive practices that accommodated children with hearing impairments. They struggled to manage the numerous situations in which they risked standing out as different, and they struggled to avoid being seen as different in a negative or shameful manner by their peers and by the responsible adults. Avoiding being seen as different was something the children mainly sought to accomplish by pretending to be like their peers: in this case, by pretending to have typical hearing. In the following sections I will analyse this behaviour,

mobilising the sociologist Erving Goffman's concepts of *stigma* and *passing* (Goffman, 1968/2005; see also David Wästerfors' chapter in this book). At this point, however, it suffices to point out that pretending to hear, and avoiding being seen as different, seemed of great importance to the children. Pretending to hear, as the five-year-old boy managed with his perfected 'yes' intonation, is an exceptionally demanding activity. Hearing-impaired people attempting to appear as typical-hearing persons must work very hard, because once they start to pretend, they must continue to do so and avoid making errors that could reveal what they are doing. They must always be on their guard, ready to repair or amend any slip-ups that might occur in what is, in essence, a constant performance, where the hearing-impaired person acts as if they were another person. This acting demands constant vigilance and a self-imposed constraint to always strive to understand, to mobilise what hearing capacity one might have, to stretch cognitive abilities to interpret and reason in order to fill the gaps of meaning when hearing becomes difficult. It is difficult to keep up such a constant pretence. None of the children we observed were completely successful in pretending to hear, so they struggled also with bottled-up frustrations and disappointments they alone knew about and which they alone cared about.³ They struggled to manage the physical and mental exhaustion caused by this daily struggle. Finally, they experienced an utter lack of recognition for their struggle.

Understanding the complex nature of hearing-impaired students' struggles is important when assessing the meaning of the concept of inclusion. The literature suggests that little has changed since our 2006 observation, and radical efforts are needed to develop and design inclusive practices that recognise student diversity and promote mutual recognition, both amongst peers, and between students and responsible adult professionals. In the Nordic countries, the majority of hearing-impaired children and adolescents attend their local mainstream schools as students in what is expected to be an inclusive setting. Little is known about the practices these students are subjected to, but there is ample general evidence that it is more difficult to be a hearing-impaired student than a typical-hearing student.⁴

Inclusion and hearing impairment

Focusing on hearing-impaired children and adolescents in inclusive educational settings calls for a brief overview of the concept of inclusion itself. The principles of inclusion and inclusive education were laid down in the 1994 Salamanca Declaration of the United Nations (UNESCO, 1994), which the Nordic countries signed along with 91 other countries. A quarter of a century later, the intention that, for example, Norwegian and Swedish public schools should be inclusive is expressed in the education acts of both countries (Opplæringslova, 1998; Skollag, 2010).

The research literature on education and inclusion is comprehensive, and inclusion is a term that can be understood and explained in different ways,

depending on the context in which it is used (Haug, 2004, 2016; Olsen, 2010). In some contexts, inclusion is used simply to describe the ‘placement’ (Haug, 2016) of disabled students in ordinary schools and classrooms, but the theoretical ambitions attached to the concept are normally more advanced. Influenced by the traditions of *disability research* and *disability studies*, the UN Convention on the Rights of Persons with Disabilities (UNCRPD, 2006) states that everyone should be able to attend the same schools and, at these schools, everyone should have the same academic and psychosocial opportunities for development and growth.

In light of these traditions, inclusion may be seen as suggesting a move away from an individual focus on the student regarded as having special needs – the traditional approach taken in special education – and instead to focus on collective educational practices. In this respect, inclusion is to education what the concept of universal design is to the principle of accessibility. Both inclusion and universal design promote the idea that human practices and attitudes have to change in order to create a society for all, and both refute the notion that individual people with impairments should be adapted or modified so that they can fit better into the community of non-impaired people. Instead, educational practices and the physical environments we design and build should be shaped in ways that enable everybody to take part and have equal access. This implies a sharp critique of traditional ways of designing teaching as an activity meant to suit the needs of the imagined average or typical student (Kermit, 2019b).

Giving up the idea of teaching the average or typical student suggests a deepened understanding of the relation between human equality and that which is unique in every individual. Here, inclusion can be framed as a concept with profound normative implications and ambitions. Inclusive education seeks to fulfil every student’s universal and equal right to education, and at the same time takes into account that every individual student must have the opportunity to develop his or her unique potential to the fullest extent possible. We owe this understanding to, among other scholars, philosophers Charles Taylor and Axel Honneth. In his essay ‘The Politics of Recognition’ (Taylor, 1992b), Taylor analyses what he sees as a tension between two fundamental recognitions, both characterising modernity and the development of modern society. On one hand, modernity is characterised by a recognition of the principles of universal human equality, dignity and rights. At the same time, it is fundamental to the modern understanding of individuality that every individual brings something unique into the world. When it comes to inclusive education, this suggests that every student must be allowed to develop self-respect as an equal possessor of inalienable rights, and must, at the same time, be given the opportunity to develop the self-esteem and self-confidence associated with having realised a unique identity (this is also central to the concept of recognition suggested by Axel Honneth, 1995). Taylor points out that even though modernity presents us with historically unprecedented freedom to choose who we want to be, identity formation has also

become more precarious and vulnerable. In the context of education and inclusion, this warning prompts the understanding that every student must be allowed to experience relations in which mutual recognition is expressed. This recognition must confirm the student's authenticity such that the student is both recognised as equal to others, and recognised for that which is particular to him or her.

Thus, inclusion can never be established where there is a tacit assumption that typical students are more authentic than students considered to have special needs. Unfortunately, this assumption lies at the root of many well-intentioned interventions in special education. Inclusion is not at odds with the idea that a student is entitled to be taught according to the level of his or her abilities. What it is opposed to are practices where some students – the ones considered 'special' – are denied the opportunity to experience the membership (Antia, Stinson, & Gaustad, 2002) in a group of peers that many typical students take for granted. In the instances where inclusion is used to signify only the placement of disabled students, as mentioned above, it is likely to only be a token recognition of equality which fails to develop practices suitable to support a society of members.

Inclusion which does develop these supportive practices requires a radical approach, with dramatic changes to historic educational practices that are designed only to suit the needs of an imagined typical student. This means that inclusive practices must resist the division between 'us' and 'them' in terms of typical and not. Further, this also implies a rejection of the notion of inclusion as a kindness extended by the typical who, propelled by good will, try to make good for other groups. On the contrary, the recognition both of that which makes everyone equal and of that which is special to each individual implies a sharp critique of such charitable ideas. Indeed, in the following, I will suggest that the idea of inclusion as a kindness might itself be seen as discrimination.

Inclusive practices in Scandinavia

Nordic kindergartens and schools in general appear to have failed to develop and establish inclusive practices where hearing-impaired children and adolescents are brought together with typical-hearing peers. This was the conclusion of a 2018 review of Nordic research on educational practices linked to hearing impairment and inclusion (Kermit, 2018). The result is in line with other reports on inclusion and disability in a Nordic context (Finnvold, 2013; Tøssebro & Wendelborg, 2014; Haug, 2016). The absence of inclusive practices strongly contrasts with the abundance of policy documents and legislation presenting inclusion as an important goal in these school systems (Olsen, 2010).

All the barriers to learning and development confronting hearing-impaired children and adolescents cannot be reduced to the one question about inclusion. Having said this, kindergartens and schools in countries like Norway and Sweden generally design their teaching and their practices to fit the typical pupil who constitutes the imagined student norm (Holmström, 2016).

Two broad and related aspects of this situation are apparent for hearing-impaired children and adolescents. First, on average, they achieve poorer academic results compared to their typical-hearing peers (Hendar, 2016). Second, they display more psychosocial problems (Laugen, 2017; Olsson, Dag & Kullberg, 2017) and more loneliness (Kermit et al., 2014) than their typical-hearing peers. It is likely that many hearing-impaired children and adolescents struggle to achieve a feeling of membership (Antia et al., 2002) in their peer groups that many typical-hearing peers take for granted. There is no sharp divide between these two aspects of inclusion, but in the following, I present them briefly and separately before turning to wider interpretations.

Psychologist Ola Hendar has conducted two large surveys in Sweden and Norway, both focusing on hearing-impaired students' academic outcomes (Hendar, 2008, 2012). It is because of his work we can state with a high degree of certainty that hearing-impaired students – as a group – achieve poorer academic results than their typical-hearing peers. Hendar applies his results to a model of development while analysing how the results can be interpreted in light of psycholinguistic theory. He finds access to language (whether spoken, signed or a combination of the two) to be a decisive factor in learning and academic development.

A study included in the 2018 review (Kermit, 2018) by applied linguist and Deaf Studies scholar Johan Hjulstad and his team (Hjulstad et al., 2015) reviews the international literature on how academic inclusion can be achieved in educational settings where hearing-impaired and typical-hearing children and adolescents are together. This study also confirms the importance of access to language, pointing out that hearing-impaired children and adolescents must be provided with the opportunity to develop language – again, spoken, signed or both – while interacting with peers. The study documents a general lack of research on how to promote inclusive practices. What research exists, more often than not, presents general assessments rather than specific examples or cases. In addition to language and peer communication, the researchers identify other ways to achieve academic inclusion, including organisation, attitudes, early intervention, use of technology, noise reduction and reduced group sizes.

Even children with minor hearing impairments have greater risk and prevalence of psychosocial problems compared to their typical-hearing peers (Laugen, 2017). A number of studies (Kermit et al., 2014; Rekkedal, 2015; Olsson et al., 2017) discuss the psychosocial situation for hearing-impaired children and adolescents in Norway and Sweden. Between them, these studies substantiate that hearing-impaired children and adolescents experience more loneliness and have weaker relations to their peers than typical-hearing children and adolescents. Many hearing-impaired adolescents do not have a single friend. Further, they are subjected to more exclusion and negative behaviour from their peers compared to other adolescents.

Studying inclusion closely: the use of the hearing loop system

Against the backdrop of the review presented in the previous section (Kermit, 2018), in the following, I discuss a secondary analysis (Heaton 2008) of selected qualitative data from a 2014 study of adolescents with sensory impairments (Kermit et al., 2014). ‘Secondary analysis involves the utilisation of existing data, generated for the purpose of one or more prior studies’, write educational researchers Andrew J. Hobson and Bronwen Maxwell (2017: 172, with reference to Janet Heaton 2008: 1). They emphasise that secondary analysis is done with the intention of pursuing research questions different from those in the original study. The secondary analysis conducted in this chapter is directed, first and foremost, at mapping the complex struggles hearing-impaired students face on a daily basis in schools that are inclusive mostly on paper. These are struggles of different, yet intertwined natures. Hearing-impaired children and adolescents struggle to hear, they struggle to bridge the gap between what is offered in terms of inclusive practices and what is needed, and they struggle to preserve their identity and sense of self in a situation where they regularly receive the tacitly conveyed message that having typical hearing is a more authentic way of being in the world than that of being hearing-impaired.⁵

The data mobilised here addresses the seemingly trivial issue of hearing loop systems. As a Nordic welfare state, Norway has a policy of fitting classrooms with hearing loop systems whenever there is a student who is entitled to have such a system due to a hearing impairment. This, however, does not mean that teachers at these schools automatically use the hearing loop systems consistently and routinely. The research of disability studies scholar Ann Mette Rekkedal (2015) suggests that neglecting to use the hearing loop systems, or using them in ways that are of little use to the hearing-impaired student, is both common and widespread.

Our informant,⁶ John, who is in his mid-teens, described to us his teachers’ use of the hearing loop system in his classroom:

They [the teachers] do not always remember to use the microphone [hearing loop system] so, in almost every lesson, I have to remind them that they must put it on. That is, after three years, my class teacher has finally started to adapt.

So I have to remind them about using the microphone and that they turn it on from time to time [...] well, it would surely be nice if they could learn a bit more and if they knew a bit more, because what they know is what I have told them...and that’s not really enough.⁷

There is reason to believe that what John describes is an everyday experience for many Norwegian hearing-impaired students (Rekkedal, 2015). John told us that he is the one who is tasked with the responsibility of reminding teachers to wear the microphone and to make sure his fellow students also use their microphones. John must attend to this ‘in almost every lesson’.

It is a reasonable interpretation that John is not happy with this responsibility. For one, no other student in his class is reported to have a similar extra responsibility in the classroom. Secondly, his teacher's behaviour constantly conveys a tacit message to all students that microphone-wearing is something one must do to be nice to the hearing-impaired student who does not meet the typical standard of hearing and thus has special needs. Using the hearing loop is not a consistent routine that teachers are bound to follow, nor is it based on the understanding that, since John is equal to his peers, and shares an equal right to education, securing his access to learning is as obligatory as securing every other student's access to learning. It must be emphasised that this latter framing must be carefully phrased: since Nordic educational models are, in general, based on the belief that students' learning processes benefit from being able to discuss and learn from each other, it is a flawed view that the typical-hearing people should accommodate John's needs because these needs are 'special' and thus call for compassion. On the contrary, as suggested in the introductory section of this chapter, there is another aspect of reciprocity in play. Neglecting the use of the hearing loop system might also be seen as a discriminatory act against John, not simply an incidence of somebody forgetting to be charitable. Indeed, the principle of universal equality suggests that when John's access to participation is impeded by teachers' practices, the classroom community misses out on the unique contributions John could have made.

Bridging the gap between what is needed and what is offered

John's experience is, on one hand, an everyday example, illustrating that his school and teachers have not adjusted their practices because there is a hearing-impaired student attending. This does not reduce the importance of addressing the underlying problem. Teaching in John's class is designed to cater to the imagined average, typical-hearing, student. Moreover, since routinely and consistently using the hearing loop system is a small and relatively simple change in practice, it is implausible that John's teachers have adopted more advanced measures to promote inclusive practises as long as they have failed to adapt this simplest of routines. The result is that it is John who must bridge the gap between what he needs and what is offered, and he must do this over and over again. John did not tell us explicitly about the psychosocial costs of what it means to be in his position, but he did remark that trying to understand his teachers and fellow students using hearing technology wears him down to the extent that he has to forego informal and social interactions with his peers and instead try to find quiet places at school where he can be alone:

Actually, I spend a good deal of time on my own, but that's really ok, because I can relax then [...] It's no problem to initiate contact with others, but I seldom feel like I want to. When I am tired I am not

interested in spending time with others. [...] I use hearing aids all the time and that makes you tired. [...] It's ok [to wear hearing aids], but it means there's this constant level of loud sound all day long, no distance, just straight in all day long, that wears me out. There's a lot of noise [at school] but yet some places I can slip away, empty rooms for smaller classes, I use to slip into them from time to time.

It is well established that using hearing aids is associated with fatigue, sometimes even chronic fatigue (Werfel & Hendricks, 2016; Camarata et al., 2018; Gustafson et al., 2018; Wang et al., 2018). My qualitative data contributes the deeper understanding that this fatigue is not only because of the use of hearing aids. John is exhausted, not only because he strives to understand what teachers and peers are saying and thus 'strains his ears' (or rather his brain). What exhausts him is also that he is on his own and left to fend for himself⁸ in a social setting where few seem to care about his need for a quieter learning environment. Attending school is not something he can choose not to do. Instead, he must seek to alleviate the strain caused by too much noise by finding solutions on his own, for example slipping away into an empty classroom. In other words, fatigue is as much the result of socially created conditions as of individual problems with hearing technology.

Passing and shame

John is on his own and has the responsibility of being the one who must always ask. What he is asking for is the fulfilment of his undisputed rights, but since the tacit message from his teachers is that using the hearing loop or securing a quieter learning environment comes second to teaching typical-hearing students, John is made to look like someone who must ask for compassion and consideration. Because the teachers have neglected to implement a consistent routine, of using the hearing loop system unprompted, they have instead instituted another routine. This is that John must, over and over, single himself out as untypical, as different from his peers. He must admit to having a need the other students can afford to forego, and is thus left in a vulnerable position by adults who fail to see that their actions create exclusion instead of inclusion because the school environment they establish is inaccessible to the hearing-impaired student.

Another informant, Fiona, was explicit when she explained how she deals with this form of inaccessibility. Her experiences are similar to John's: teachers neglect to use the hearing loop system and to structure class discussions so that one person speaks at a time:

It happens all the time [that the teachers and other students neglect to use the microphones properly] because they switch too fast from the teacher to the student who is talking [...] it's too fast for me and I have to turn around [to see who is talking]. But I never say anything, I just sit there.

However, John and Fiona handle their teachers' failures differently. Fiona does not ask the teacher to use the hearing loop system when the teacher forgets it. She also chooses not to ask the teacher to make sure she has time to identify the speaker in class discussions. 'I never say anything, I just sit there', she told us. From an adult perspective this might seem irrational and something that could have adverse effects on Fiona's future chances for further education and employment, but this misses the essential point. Fiona's behaviour is highly rational. She is dealing with another kind of struggle, the struggle of managing stigma. For this, her strategy is to lie low and not draw attention to herself. This is an example of a behaviour that sociologist Erving Goffman has dubbed 'passing' (Goffman, 1968/2005). Among hearing-impaired people, passing can take a number of forms and employ a variety of strategies, but what they all have in common is that the hearing-impaired person who is passing is trying to act as if he or she were typical-hearing (Kermit, 2019b). Passing is something hearing-impaired people can do because a hearing impairment is often hard to detect. Among the strategies Goffman describes are to '(1) sit next to someone with a strong voice; (2) choke, cough, or get hiccups, if someone [asks] a direct question; (3) take hold of the conversation [...], ask someone to tell a story [one] had already heard, ask questions the answer to which [one] already knew' (Goffman, 1968/2005: 127). Other, maybe even more familiar strategies, are – like Fiona's – to simply keep one's head down and avoid attention, or say 'yes' in a non-committal manner to questions one is unsure of having understood correctly (Kermit, 2019b).

In Goffman's theory on stigma, passing is a symptom, revealing that the person who passes experiences the particular forms of exclusion associated with stigma. In the author's words, to be stigmatised is to live under the constant tacit suspicion that one's way of being in the world is less authentic than another's:

The attitudes we normals⁹ have towards a person with a stigma [...] are well known [...] By definition, of course, we believe the person with a stigma is not quite human. On this assumption we exercise varieties of discrimination, through which we effectively, if often unthinkingly, reduce his life chances.

(Goffman, 1968/2005: 15)

There is a myriad of ways in which one can experience having one's authenticity as human questioned. I suggest that the lack of interest John and Fiona's teachers show in consistent use of the hearing loop system is an example of this questioning, as their practice sends the tacit signal that these students come second to their typical-hearing peers. The teachers would probably protest if they were to be confronted and accused of deliberate discrimination, and this is exactly the point Goffman tries to make. The exclusion of John and Fiona is not intended, but the result of unreflective practices

and attitudes. As Goffman points out, even if this is done ‘unthinkingly’, it still effectively reduces ‘life chances’ through exclusion and the constant questioning of John’s and Fiona’s authenticity as humans. To be excluded, and thus questioned, is the essence of what it means to be stigmatised.

Passing is a way of managing stigma, and this struggle is directed both outwards and towards oneself. Outwards, to try to convince others that one is, in fact, like everybody else and – in Goffman’s words – ‘quite human’. Towards oneself, to preserve one’s identity and image of self, and uphold to oneself the conviction that one is, despite all, authentic. The latter is Goffman’s central point, and coincides well with a central theme in critical theory and Charles Taylor’s theories on recognition and identity. Exclusion and stigmatisation are forms of misrecognition, and misrecognition affects a person’s sense of authenticity negatively, maybe even to the point where a person can start to believe that one is of lesser worth compared to others (Taylor, 1992a).¹⁰ Documenting that young, hearing-impaired students are passing gives cause for concern. In line with Taylor’s ideas about authenticity as well as general theories on developmental psychology, growing up and becoming an adult is the process whereby one strives to realise one’s unique potential. When one is a hearing-impaired child or adolescent who is passing, one struggles not to become the best possible version of oneself, but to appear as someone else, as the typical person. This is not an accusation of students like Fiona. On the contrary, passing is a very rational strategy when one is left with no other options. Goffman’s theory is a theory about social interaction, and at its foundation is the premise that stigma arises as a result of how people encounter and treat each other. The sociological insight is a rejection of the idea that stigma should be explained, for example, with reference to impairment. Stigma is the result of human actions, not of some kind of natural law. This point has been firmly grasped by disability scholars, who reject notions of disability as an individual tragedy caused by a person’s body, and promote the view that disability involves different forms of discrimination (Oliver, 1996; see also Eric Svanellöv & Lena Talman’s chapter in this book).

In the context of this chapter, the absence of inclusive practices is one example of such discrimination, even where it is not actively intended (Meyer, 2003). The implication of this analysis is that an inclusive school, accessible to most students, can only be realised when unquestioned exclusionary practices are articulated and openly confronted.¹¹

That stigma is socially constructed does not mean that the consequences of stigma have no physical implications. On the contrary, a central aspect of passing is that it is labour-intensive and tiring. The hearing-impaired person who is passing is faking ‘normalcy’ – in Goffman’s terms performing *as* someone whose authenticity as human is not questioned – and must be inventive in coming up with ever-new ways of improving this performance. Active passing is not something the hearing-impaired person can quit doing once he or she has started to do it: the impression of normalcy must constantly be upheld. This means that people who are passing must always be on

their guard, ready to repair or amend any slip-ups that occur in their constant performing of the passing. This demands constant vigilance and a self-imposed demand to always strive to appear like everybody else. For a person with a hearing impairment, this means striving to understand, to mobilise what hearing capacity one might have, to stretch one's cognitive abilities to interpret and infer, in order to fill gaps in meaning whenever hearing become difficult.

This suggests that the tiredness often attributed to the wearing of hearing aids or cochlear implants is not simply the strain of picking up sound, or the challenge of exposure to noise. Certainly, overcoming the limitations of technology, especially when listening conditions are sub-optimal due to the presence of many different sources of sound, is hard work in itself. However the struggle to listen and understand what other people say cannot be reduced to physical barriers. In addition to the effort of hearing is the effort of constantly mobilising one's cognitive capacities in order to make sense of whatever one can hear, and to react to it in a way that convinces others of one's competence and authenticity as a human.

These intertwined elements – of struggling to hear and struggling to manage stigma – are not well understood in current research on inclusion and hearing impairment. Nevertheless, in the context of this chapter, where the lack of inclusive practices is described as a phenomenon containing elements of discrimination, at least some of the effects of having one's authenticity as a human questioned, can be brought to light. Fiona told us that she feels vulnerable, and that being hearing-impaired is something shameful she seldom discloses. In the following extract, Fiona told us about something that happened when she attended a church weekend camp as a part of the preparatory course for confirmation (a widely celebrated event for adolescents in Norway). Fiona had noticed another girl she did not know well and decided to approach her.

I didn't tell her right away that I was hard-of-hearing, I didn't. But then I discovered that she seemed really nice and seemed to be someone who could be my friend. And so I told her...and then she just said: 'I know.' And I was very relieved that she actually wanted to be my friend. Because I have always experienced that when I tell people I'm hard-of-hearing they just go, 'Oh! Really?', and then they go away...but she just said 'I know' and remained there...she didn't go.

Friendship presupposes the kinds of mutual recognition and attractions that cannot be instilled by rights or adult intervention (Frønes, 1998; Kermit, 2012). Having said this, Fiona here expresses the expectation that being hearing-impaired is something that might disqualify her from being attractive as a friend. This is not necessarily something Fiona has learned only from experiences with peers who shun her when they understand that she is different. The absence of inclusive practices at her school may suggest to her that adults also consider her second class to her typical-hearing peers. As discussed in the introduction, when forming her identity, Fiona may already have started to wonder whether or not her way of being in the world is authentic and equal to those with typical hearing.

Passing by smoothing out and bottling up frustration

Benjamin, who is in his mid-teens, was also interviewed as part of the qualitative study in which John and Fiona participated. Benjamin combines attending his local school and attending the deaf school in the municipality, spending three days a week at the first facility and two at the second. In the interview, he described his experiences of attending both schools positively, and nothing he said hinted at problems he might experience. When we talked to Benjamin's mother, she confirmed a very good relation and cooperation with the local mainstream school. She told us that the local school, both the teachers and the management, were forthcoming and had expressed a sincere commitment to establishing inclusive practices to meet Benjamin's needs. In general, the mother told us, she thought they had achieved almost as much as one could hope for in terms of adaptations. Benjamin had typical-hearing friends and participated in a number of leisure activities in the community. Benjamin's mother continued:

He comes home and tell me he is fine and that school is ok, but at the same time I can see when he gets home that he is completely exhausted. It's about him wearing hearing aids, it's about noise, he spends an incredible amount of energy just to hang on when there is spontaneous communication...and he doesn't get it all...and then he has to ask them to repeat...and then he gets it and he understands why they laughed...only then it isn't funny anymore. So, he gets terribly tired.

[...]

There is a lot of frustration he will show only at home. He will cry even without knowing what he is crying for. He comes home very much on edge, he is tired, angry, but unable to explain why.

It is important to note that Benjamin himself did not mention his exhaustion and his frustration when interviewed. There may be a number of reasons, or combinations of reasons, for this. The point, however, is not to determine the correct reasons, but to suggest plausible hermeneutical interpretations, particularly those that can shed light on barriers to inclusion. One such interpretation is that Benjamin will routinely answer that he is fine whenever he is approached by adults outside the inner circle of the family. Keeping a straight face and assuring others that everything is fine is, of course, something many of us do from time to time. It may also be suggested that such responses are gendered and are typical of teenaged boys. However, I suggest that assuring others that everything is fine could also be classified as a form of passing, although this does not necessarily mean that Benjamin was trying to pass when he was talking to us. There is no reason to doubt that Benjamin's local school is very forthcoming and has tried to implement more inclusive practices. Benjamin has friends he spends time with, both at school and outside school. His mother's description of how he bottles up frustration and shows it

only to his close family might, nevertheless, tell us that even what Benjamin understands as ‘fine’ is not what one of his typical-hearing peers might designate by the same phrase. Even if Benjamin’s teachers try to adjust their practices, Benjamin still puts in a tremendous effort to ensure that things stay ‘fine’. In addition, whenever things turn out less than fine, it is Benjamin who has to deal with the disappointment and bottle it up until he comes home.

This suggests that it is important to ask the question: what does it mean to do well? Even if Benjamin is supported, it seems he must still struggle considerably and he still has to bridge the gap between what is offered and what he needs. To do fine in this context might as well be another way of saying ‘I am managing the things I must manage’, and this, in essence, is what John and Fiona are also doing. This, again, touches on the question of adult responsibility and whether an adult – here, a teacher – can say that the hearing-impaired student is doing well. One might claim that John, Fiona and Benjamin are all managing exceptionally well, but certainly for John and Fiona and even for Benjamin, managing is something they must themselves take responsibility for. None of these three students are recognised for the enormous and exceptional effort they put in every day and every hour just to manage the demands they face.

Recognising the struggles of hearing-impaired students

Persons with sensory impairments often find that other people make assumptions on their behalf about how life with their disability ‘is’. This can be banal even in instances where people with typical vision take for granted that they understand what it means to be blind simply because they can close their eyes for a short while and experience not seeing. Similarly, they can put their fingers in their ears and imagine how it is to have impaired hearing (Kulick & Rydström, 2015). The philosopher and feminist Iris Marion Young has analysed such reductionist attitudes where the complexity of the lives of others are reduced in a simplistic fashion. She uses the phrase ‘asymmetric reciprocity’ (Young, 1997) emphasising that humans are not mutually ‘symmetrical’. Even though we are all humans, we do not mirror each other so completely that we can easily understand how it is to walk in another’s shoes. On the contrary, since there is a multitude of ways of being human, it would be arrogant to believe that we could fully understand what it means to be another person. Young promotes a notion of equality founded on mutual respect for diversity, and a particular respect for that which in others we do not understand fully.

This point is central to this chapter. The review by Kermit (2018) surveys a number of studies that describe how adults (here mostly teachers) fail to grasp even quite simple aspects of what it means to be hearing-impaired, but still behave as if this is not a problem. Even if excuses are made on behalf of these adults, examples like the ones presented in this chapter, such as the frequent failure to use hearing loop systems routinely and consistently, cannot be so

easily brushed aside. It is exactly because neglecting to use the microphone is so frequent that it is a call for concern. If responsible teachers choose not to reflect on the importance of using the hearing loop – regardless of whether the hearing-impaired student asks for it – this is a choice that will stand in the way of that student, barring him or her from participating and experiencing equality. This is absolutely not to say that using the hearing loop system is the ultimate solution to inclusive teaching for hearing-impaired students. Rather, the failure to understand even the importance of simple measures like hearing technology render it plausible that other, deeper reflections on what inclusive practices might look like are also absent.

Having taken Young's reservations into account, the qualitative analysis developed in this chapter allows for a fairly comprehensive description of the situation of many hearing-impaired children and adolescents. An important result of this study is the qualitative analysis that allows the construction of a sketch describing the many-faceted ways in which hearing-impaired students might struggle. The enormity of the task these students are confronted with every day is under-researched, and its elements may be known to research as isolated, rather than intertwined, issues. There is need for further attempts to map out a more complex and multifaceted understanding of how these factors intertwine and how they produce a complex of struggles in the lived experiences of hearing-impaired students. The factors touched upon in this chapter comprise: (1) the struggle to hear and to manage the limitations of hearing technology, especially in noise, (2) the struggle to manage exhaustion, (3) the struggle to manage in the absence of inclusive practices,¹² (4) the struggle to manage situations where one is made to stand out as different, (5) the struggle to manage one's stigma, sometimes by undertaking (6) the struggle of passing. One must also: (7) struggle to bottle up the frustrations and disappointments one alone knows about and one alone cares about, and (8) experience an utter lack of recognition of the struggle one carries out every day.

A central aspect of the analysis is that the struggles of hearing-impaired children and adolescents could be substantially eased if responsible adults were to adopt more inclusive practices. The obstacles and barriers to equal participation facing hearing-impaired students in this study have less to do with hearing itself and the more to do with discrimination. Since discrimination is a social practice and not the consequence of some kind of natural law, we are free to decide for ourselves if we want to rid ourselves of it. This is not a naïve wish, but rather a profound sociological insight, to distinguish between social and natural reality (Berger & Luckmann, 1991: see also Slee, 2018).

Finally, it is argued that the sum of everyday trivial obstacles that hearing-impaired students encounter in accessing academic and social inclusion might be underestimated as a risk factor to their health, well-being and self-perception. Further, mobilising the ideas of critical theory, such as Axel Honneth's (1995), might help to better understand the underlying moral psychology driving hearing-impaired students in their struggle to manage their lives. Framing their toil as a struggle for recognition might be a way to combine

moral, social and psychological insights into the lives of hearing-impaired children and adolescents. The struggle for inclusion that students carry out every day is, among other things, a struggle to form and maintain a self-understanding as authentic and equal to one's peers. Practices associated with passing thus constitute a cause for alarm. A person who is passing seeks recognition, not of his or her authentic and equal self, but of the pretended 'normalcy' he or she seeks to impress on others. In other words, the reward for passing is, at best, polite recognition of the passing person's efforts, but not a recognition that confirms his or her authenticity as a human and a peer, and certainly not recognition of that which is unique to the person.

Conclusion: struggling for us, not 'them'

The qualitative analysis in this chapter allows the development of a comprehensive description of the everyday struggle of hearing-impaired students, particularly focusing on the intertwined notions of managing shame, passing and exhaustion while struggling to bridge gaps between what is offered and what is needed. These phenomena affect both the mental and the physical health of hearing-impaired students.

In both health sciences and special education, there is a long tradition of focusing mostly on individual hearing-impaired students, and less on the social factors that constitute the situations where these students struggle. A critical analysis of inadequate efforts to develop inclusive educational practices in Nordic schools and kindergartens suggest that hearing-impaired students are still mostly regarded as students with individual problems. As a result, hearing-impaired students have to fend for themselves as best they can in a situation where the general educational practices are designed to suit only the imagined, general, non-disabled, 'typical' student. This chapter implies that new and more radical efforts are needed in order to develop and design inclusive practices that recognise student diversity and promote mutual recognition, both among peers and between students and responsible adult professionals. In addition, there is need for research that combines different insights regarding hearing impairment in order to form a more complex understanding of the struggles confronting hearing-impaired children and adolescents.

In this chapter I have not addressed the underlying question of why inclusive practices seem so hard to establish. However, by focusing on the seemingly trivial case of the neglect of the hearing loop system, I have sought to demonstrate that the barriers to inclusion are not always technical or epistemological (in the sense that we do not know what to do). Routine and consistent use of the thousands of hearing loops systems already installed in schools all over Scandinavia could be achieved tomorrow. All it would take is for teachers to start using the systems consistently and routinely – without having to be prompted by a student – and to adjust classroom or group practices such that only one student speaks at a time – indeed, the latter is

probably something many teachers already strive to establish. I will not try to suggest how something this simple, yet at the same time so formidable, can be achieved. Nevertheless, I point out that the idea that teaching practice is designed to suit only an imagined ‘typical’ student probably does little to accommodate any number of students who – for a myriad of reasons other than hearing impairment – cannot identify with this imagined norm. Thus, to strike a more careful balance between that which is universally equal and that which is individual and particular, is a place to start when searching for inclusive practices focusing less on needs deemed to be special, and more on the collective task of promoting solidarity in spaces for learning and development, both collectively and individually. And, of course, starting to use the hearing loop system every day, even if no one has specifically asked for it, is probably a good way to begin creating such spaces.

Notes

- 1 I conducted this research with two colleagues, Odd Morten Mjøen and Astrid Holm (Kermit, Mjøen & Holm, 2010). The term ‘kindergarten’ is used here as the best available translation of different Nordic terms designating what are also often labelled ‘early childhood education and care facilities’.
- 2 In this text, I try to shed light on social processes whereby some children and adolescents are made to stand out as different in an unappreciated manner, and being ‘made to stand out’ is a social process, not a natural one. I thus need a term to identify those who are seldom made to stand out as different. For this latter group (if indeed they are a group), I use ‘typical’ throughout the text, knowing well that choosing such a term is fraught with difficulties since our attitudes and beliefs are embedded in our language and the words we choose. Using ‘typical’ is thus something I do while trying to avoid terms that more explicitly suggest a differentiation in moral and social status, since formulating a critique of such differentiation, in itself, is the most important objective of this text (see also the concluding paragraph of the next section).
- 3 This kind of exhausting struggle is described also for other groups, see for example the work of Ilan H. Meyer (2003).
- 4 Clinical research, for example, attests that hearing-impaired children and adolescents report a high prevalence of fatigue and health problems associated with stress (Camarata et al., 2018; Gustafson et al., 2018; Werfel & Hendricks, 2016).
- 5 This is a core aspect of what Erving Goffman (1968/2005) characterises as stigma.
- 6 The participants in the qualitative part of the study were ten sensory-impaired adolescents aged between 13 and 19 years, and seven of their parents. Written informed consent was obtained from all adult participants and from the parents or legal guardians of the non-adult participants. Observing all participants’ right to deny participation, verbal co-consent was also obtained from non-adult participants. Sensory-impaired adolescents might be regarded as potentially more vulnerable research participants compared, for example, to adults without sensory impairments. In order to prevent ethical transgressions, extra care was taken to discuss the consent form with the adolescent participants in their preferred language (spoken or signed Norwegian). Here, it was emphasised that consent should be voluntary and informed, and that it could be freely retracted. Further, the study observed the recommended guidelines for sociological empirical research involving children (Ennew, 2009) as well as recommendations from sociological childhood

studies (Morrow & Richards, 1996). Since the data presented in the following text are qualitative, quotes are fitted with fictive names and approximate ages. The original 2014 study by Kermit et al. was approved by NSD, Norwegian Centre for Research Data (<https://nsd.no/nsd/english/index.html>), the national ethics board for educational and sociological empirical research in Norway.

- 7 All the quotes presented here were originally published in Norwegian in Kermit et al. 2014. The translations are mine.
- 8 This is also addressed by Sæbø, Wie & Wold (2016).
- 9 This famous text was written more than 50 years ago. In his book on stigma, Goffman distinguishes between the stigmatised and the non-stigmatised, and refers to the latter group as 'normal'. It is worth nothing, however, that Goffman never tries to define exactly who belongs to one or the other of these two groups. His tacit message is that both the idea of stigma and of normality are socially created and thus are contingent; they can be changed by our decisions. 'Normal', in this context, might then just mean those who have never (or very seldom) experienced having their authenticity as humans questioned.
- 10 This point is also central to the understanding of what it means to be an 'other', famously analysed by Simone de Beauvoir (1949/1961).
- 11 For an insightful discussion of these issues, I recommend the 2018 book *Inclusive Education Isn't Dead, it Just Smells Funny* by Roger Slee (2018).
- 12 This chapter has focused on the use of hearing loop systems as a straightforward and common example, but it is only one of many.

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