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Disability

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ABSTRACT The chapter addresses the rights and practices towards disabled children and their families in the lights of the UN Convention of the Child and the UN Convention on the Rights of Persons with Disabilities. Although all articles in CRC apply to disabled children on equal terms with all children, a few that are of special interest in the Norwegian setting are highlighted. Drawing on longitudinal data, the chapter discusses issues related to a) growing up in a family environment b) family supports, c) inclusive education, and d) participation with peers in leisure and/or cultural activities. The analysis suggests that the outcome of current policies and practices for disabled children in these areas are out of keeping with CRC provisions and that access to services is paved with obstacles.

KEYWORDS disability | children | family support | participation | education | children's rights

12.1 INTRODUCTION

This chapter addresses the rights and practices towards disabled children and their families in the lights of the UN Convention of the Rights of the Child (CRC),¹ in particular, current practices related to supports to families, inclusive education and participation with peers. CRC was ratified by Norway in 1991 and incorporated into Norwegian legislation in 2003. The CRC was the first UN

1. Convention on the Rights of the Child, G.A. res. 44/25, annex, 44 U.N. GAOR Supp. (No. 49) at 167, U.N. Doc. A/44/49 (1989), *entered into force* Sept. 2, 1990.

Convention with a provision that explicitly addressed disabled children (Article 23) and in 2006, the Committee on the Rights of the Child published General Comment 9 on the implications of the CRC for the rights of disabled children.² Even though all convention provisions apply to disabled children on equal terms with all children, some appear to be of special interest in the current Norwegian context. The issues raised by the Committee on the Rights of the Child in their comments on periodic reports from the Norwegian government do for instance address social participation with peers;³ family support and inclusive education.⁴ Disabled children are also protected by the Convention on the Rights of Persons with Disabilities (CRPD), ratified by Norway in 2013.⁵ The dual protection is among others addressed in the General Comment 9 from the Committee on the Rights of the Child.⁶

This chapter starts out by discussing some core themes from the CRC of special current interest for disabled children and their families, and how provisions in the CRPD address those topics. The main body of the chapter is, however, a presentation of recent empirical data that illuminate to what extent current practices comply with the UN conventions.

12.2 THE UN CONVENTIONS AND DISABLED CHILDREN

Although most provisions in the CRC are of relevance to disabled children, some speak more directly to issues that have been raised by research, disabled peoples' organizations, in the public debate in Norway and by the Committee on the Rights of the Child. This chapter will in particular address the following points regarding the rights of disabled children:

1. Growing up in a family environment/ family supports
2. Inclusive education
3. Participation with peers in leisure/cultural activities

2. Committee on the Rights of the Child (2006).

3. Committee on the Rights of the Child (2000), para. 38; Committee on the Rights of the Child (2005), para. 29.

4. Committee on the Rights of the Child (2018), section F

5. International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities, G.A. Res. 61/106, Annex I, U.N. GAOR, 61st Sess., Supp. No. 49, at 65, U.N. Doc. A/61/49 (2006), *entered into force* May 3, 2008.

6. Committee on the Rights of the Child (2006).

(1) Neither the CRC nor the CRPD have provisions that directly address the right to grow up in a family setting or with their parents. On the other hand, the issue is raised in the preambles to both. The CRC maintains that State Parties are ‘... recognizing that the child, for the full and harmonious development of his or her personality, should grow up in a family environment’ and the preamble to the CRPD claim in paragraph (x) that ‘... the family is the natural and fundamental group unit in society ... and that persons with disability and their family members should receive the necessary protection and assistance...’. Article 23 (5) of the CRPD also specifies that ‘State Parties shall, where the immediate family is unable to care for a child with disabilities, undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting’ (cf. also CRC Article 9). General Comment 9 also provides an interpretation of the implications of CRC for the right to grow up in the family and family supports.⁷

The recognition of the right to grow up with the parents or in an alternative family setting was part of the background for initiatives taken by the Council of Europe to combat institutionalization of disabled children in the mid-2000s (Council of Europe 2005). In a Norwegian setting, this right may be politically self-evident and in practice, out-of-home placements appear to be rare (Tøssebro, Paulsen and Wendelborg 2014). The reason why we highlight this point is, however, not that the right to grow up in a family setting is frequently violated, but related to the preconditions for growing up at home in a normal family setting. This is among others related to the support the families need.⁸ The support system, or the “division of labour” between families and the service system, was an important dimension when the “growing up at home”-policy was implemented in Norway from the 1960s onwards and continues to be a vital part of the current debates on supports for disabled children and their families. Thus, the issue of preconditions for “growing up at home” related to family supports will be analysed in this chapter.

(2) CRC Articles 28 and 29 address the right to education in general, whereas the disability-specific Article 23 specifies that education should be provided in a way that supports social integration and individual development. The article also has a general clause on facilitation of ‘the child’s active participation in the community’. General Comment no. 9 states that ‘Inclusive education should be the goal of educating children with disabilities’.⁹ The CRPD Art. 24 addresses education and the duty for State Parties to ensure that disabled children are provided rea-

7. Committee on the Rights of the Child (2006).

8. CRC Art. 18 and 27. cf. Committee on the Rights of the Child (2018).

9. Committee on the Rights of the Child (2009), para. 66

sonably accommodated education and that disabled children are not excluded from the general education system. In the Norwegian setting, there are debates on current trends regarding segregation of disabled children from mainstream classrooms and also concerning the quality and levels of ambition in the education of disabled pupils (cf. Meld St. (white paper) no. 18, 2010–2011; NOU (public committee report) no. 17, 2016; Bachman, Haug and Nordahl 2016; Tøssebro and Wendelborg 2014; Barneombudet (Ombudsman for children) 2017). The issue of segregation also relates to the worries from the Committee on the Rights of the Child concerning participation with peers.¹⁰ Thus, we will look into recent evidence regarding segregation and quality in education.

(3) The worries from the Committee on low levels of participation among peers are not just about the education system but also related to leisure type of activities, cultural participation etc.¹¹ The rights to social participation are specifically addressed in CRPD, Article 30, and can be inferred from the general article on disabled children in the CRC on participation in society and access to ‘recreation opportunities supporting their personal development, social integration and cultural development’.¹² Social participation is also a general aim in disability policies internationally, and was one of the slogan keywords for the UN international year (1981) for persons with disabilities.

12.3 DATA SOURCES

The empirical basis for this chapter is available Norwegian research on disabled children and their families, in particular a longitudinal study of disabled children born 1993–1995 with physical disabilities, intellectual disabilities, learning difficulties and multiple disabilities: ‘Growing up with disability in Norway’. Data was gathered from parents at five points in time during the childhood and adolescence, in 1999, 2003, 2006, 2009 and 2012. About 600 families responded to questionnaires whereas qualitative in-depth interviews were conducted with 30 families in the county of Sør-Trøndelag. It was thus a mixed methods design with survey data and qualitative data covering many of the same topics. The families were recruited by the child rehabilitation units that exist in every county in Norway and the procedures were approved by the Norwegian Data Protection Authority. Details on bias, attrition and data gathering across waves are available in

10. Committee on the Rights of the Child (2005; 2018).

11. Cf. Committee on the Rights of the Child (2009), para. 70

12. CRC Art. 23

Tøssebro and Wendelborg (2014; cf. Tøssebro and Wendelborg 2017 for an English outline). The main biases are underrepresentation of families from the capital area and minority families. The children themselves responded to a brief questionnaire or were interviewed when reaching adolescence, in 2009 and 2012.

12.4 GROWING UP AT HOME AND THE DIVISION OF LABOUR BETWEEN FAMILIES AND THE PUBLIC

The policies on growing up in a family environment have a history that dates back to the 1960s. The changes that occurred at that point in time may be seen as “old days” but they also highlight why one needs to see the two issues of ‘growing up in a family environment’ and ‘family supports’ in conjunction. Briefly speaking, policies changed from ‘either-or’ to ‘both-and’ during the 1960s (cf. Tøssebro 2015).

The historical bottom line was that parents were responsible for their children and that the public provided a limited set of generic services, such as education. However, such services were not adapted to the whole range of children and those that did not fit in, were excluded. They were left in their families’ care. During the 19th century one saw the emergence of alternative services for disabled children, such as schools for deaf and blind children, and later also for children with mobility problems and intellectual disabilities. At the onset, the idea was to provide education but in the early 20th century, the arguments shifted to family protection (Kirkebæk 1993). One realized that the burdens placed on families were too extensive and that a disabled child tended to disrupt the whole family. Thus, public services were expanded in order to ‘save’ the family. This took the shape of ‘either-or’. The public supports that evolved were total in the sense that the schools were 24-hour boarding schools where the children went to school, ate, slept, and lived. The role of the family was reduced to minor or none. Sometimes parents were even told to forget their disabled child (Grunewald 2008). The last point applied in particular to the emerging long stay institutions, but even special schools were total in character. In a number of cases, schools also evolved into long stay institutions, especially schools for children with intellectual disabilities (Kirkebæk 1993; Wiking 1995).

The reasoning behind the development was of a dual nature. One intended to ‘save’ the families and also to enable parents to care adequately for their other children. The other aspect was distrust in the parents’ ability to educate and care for children with special needs. Services specialized towards specific diagnostic

groups were needed. This second argument was gradually challenged, beginning in the 1950s.

In the early 1950s there was a discussion in Sweden on boarding vs. non-boarding special schools (Grunewald 2008, p. 333). The argument was that life at boarding schools removed children from the society in which they were expected to live as adults. Thus, the schools were less likely to make the children fit for an independent adult life. In Norway, a well-known child psychiatrist, Nic Waal, argued that the family in the vast majority of cases was a better therapeutic environment: No institution could provide adequate alternatives to the care and type of stimuli that a normal family typically caters for (cited after Edlund 2010, p. 269). A typical family environment simply provides stimuli that are better suited to scaffold the psychological development of all children.

Such voices were few in the 1950s but in the early 60s a rapid change took place, and the division of labour between the public and families were rethought. The change was in part triggered by economic considerations. Waiting lists for institutions and special schools were seen as a real problem and in 1959 the Norwegian government argued that if children stayed with their parents, the costs per pupil would be a third (Tøssebro 1999). The economic arguments were, however, tuned out as the policy was strengthened. A Norwegian white paper from 1967 on disability policy claimed that to grow up at home gives a better prognosis for the children. The role of the public should thus not be to move the children from the home, but to support families in such a way that it facilitated a normal childhood and a normal family life (St. meld. (White paper) no. 88, 1966–67). This policy change echoed innovations in child protection which was codified by law fifteen years earlier, in 1953 (Hagen 2001). Support in the family came to be the preferred option and if this was impossible, the alternative should be another family. The change was thus not just about disabled children but applied to child welfare in general.

Since the mid-1960s, to grow up at home has been an uncontested principle. It is hardly discussed as a topic in disability policies at all. It is simply taken for granted. From that time few new children were admitted to institutions and the special schools/special education were based on the principle that children lived with their parents and went to school at daytime. The policy change did, however, not imply that the care simply was left to the families once again. The idea was to set up a range of services supporting the families; including day care, education (also for children earlier seen as uneducable), economic supports, respite care, assistive technology, etc. And even though there was a lack of services in the 1960s, the direction and movement was clear. A 1999 survey of disabled children

aged 4–6 years in Norway suggested that 98.5% lived with at least one of their parents and that the majority of the remaining lived with another (foster) family (Tøssebro and Lundebj 2002). The proportion living in child homes in adolescence was somewhat higher (Tøssebro et al. 2014), but basically it is taken for granted that disabled children grow up with their family – with supports from a welfare system which in Norway is mainly public.

Thus, it is uncontested that disabled children should grow up with their family, and if not possible, it should be in a family setting. It is furthermore an uncontested policy ideal that the public should provide the support needed to maintain a normal family life and a childhood as normal as possible. The public debate is to what extent this policy ideal is made real in the everyday lives of disabled children and their families, that is, to what extent the public in reality carries out its part of the ‘new’ division of labour. We will in particular address the experiences with the current division of labour from the parents’ perspective.

12.5 FAMILY EXPERIENCES WITH THE SERVICE SYSTEM

The most stressful is not having a disabled child. It is the combat with the service system. This is maintained by many parents, and we agree (our translation)

This statement is from a father of a five-year-old child, quoted from Tøssebro and Lundebj (2002, p. 190). It refers to a paradox. Since the 1960s, Norway has established a comprehensive system of supports for families of disabled children, but the interaction with this system is not only experienced as support. It also turns out to be an extra burden.

There is however also another paradox. The ‘Growing up’-surveys included a number of items on supports and satisfaction with a number of agencies in the support system. Even though there are exceptions, the satisfaction appears reasonably good. In general, two thirds to three quarters are satisfied or very satisfied, which is the level expected on this type of questions. The result is approximately the same for all waves of the data gathering (cf. Kittelsaa and Tøssebro 2014). There is some variation across type of service but that is not the main point here. The point is that during the face-to-face interviews, we were presented for a very different image. The majority of parents expressed high levels of frustration and disappointment.

There may be a number of possible explanations of the diverging results, such as geographical variation. There is however no reason to expect that the county chosen for interviews is extraordinary in this respect. Another possibility is that different research methods return different results. This may occur if frustrated parents have a high response rate for interviews and low for questionnaires or because the ticking of responses on a structured questionnaire may produce more positive responses than when people speak freely in a face-to-face setting. We will not rule out that the research method may make a difference, even though variation in response rates appears unlikely. However, it seems unlikely that methods effects are an important explanation. The case is that when speaking freely, parents did not address the same issues as the questionnaire. The questionnaire primarily asked about the services that people were provided, whereas during the interviews, the main issue was not the services as such but the process of accessing services. It was about information, applications, etc. Thus, the likely interpretation is that the paradox arises because the main problem in the current “division of labour” is not the quality of services as such, but an access process that appears like a combat from the point of view of parents.

The stories and examples told by parents vary. Some report helpful interaction and professionals taking the role of a gate opener. However, the main message is frustrations and can be summarized in the following five points (cf. Tøssebro and Lundeby 2002, Kittelsaa and Tøssebro 2014):

12.5.1 INFORMATION

Parents report that they are rarely informed about possible supports but have to find their way themselves. Some report that they have been in contact with a support agency, asking about a specific support. They are told that they do not fit the eligibility criteria, but *not* that there exists another type of support that suits their needs and for which they are eligible. Such experiences apply both to the state organized social security measures and supports from the local government. A mother claims that *You have to find out about rights and possible supports yourself. There is no one at the social security office that informs you about possible supports*, and the spouse adds: *they rather conceal the rules and regulations* (Tøssebro and Lundeby 2002, p. 211). Based on a study around 1980, Ingstad and Sommerschild (1984) claimed that social security speculated in parents' lack of information. This finding was unexpectedly replicated in our interview study. Similar criticisms were, however, directed towards many parts of the support system, including hospitals at the point in time when the child was first diagnosed. A

family report that *we were told that the child had a brain injury and was going to be severely disabled. Then their job was obviously done. We were waiting for a while. What is going to happen now? Are we going to be referred to a social worker or psychologist? What kind of supports will be triggered? Nothing happened. Absolutely nothing* (Tøssebro and Lundebry 2002, p. 201). The main exception to this type of criticisms applies to the county-based child rehabilitation units, which more often took the role of information provider and gate opener. However, it tends to take some years before parents meet this service.

12.5.2 FRAGMENTATION

The Norwegian support system comprises a number of measures and a number of agencies with responsibility for different types of support. It is not for a newcomer to understand who is responsible for what. This problem escalates the information problems, but the fragmentation problem goes beyond this. First, it is an additional burden for parents to relate to a number of public agencies and some experience that they have to take on the role of coordinating various services. Second, the fragmentation may produce “grey areas” where agencies point at each other regarding who is responsible for what. A number of parents report such experiences. An example is a worn-out family that was called to a meeting involving several agencies, in order to set up adequate support, or so they thought. The result was however a meeting where different agencies were arguing about lack of resources and who was responsible for what. The situation of the family remained unchanged (Tøssebro and Lundebry 2002, p. 220). During the progress of the ‘Growing up’-study, the government introduced a system with “individual plan” and assigned “coordinators” in order to remedy the fragmentation. Such measures were implemented for the majority of the children in this study by adolescence, but with limited impact. When children were 17–19 years old, only 11 per cent of the parents agreed that the individual plan did result in more holistic and coordinated supports. Thus, currently it appears as if individual plan is a promising measure in need of improvement.

12.5.3 THE RIGHT PERSON

Civil servants appear to take different roles. Some act like gatekeepers protecting the public purse, whereas others take the role of gate opener. The parents point to the importance of encountering the right person in the support system. Many claim that they gradually learn whom to contact in order to get the help they need. Some

report that things changed when they met the right person but also that things got more complicated when this individual quit, was pregnant or replaced after reorganization of the agency. Thus, regarding variation between civil servants, the main point is not criticisms across the board but that parents experience a kind of bureaucratic arbitrariness related to how street level bureaucrats understand and execute their role. Everyday life is dependent on meeting supporting people in the welfare system.

12.5.4 PENALTY ROUNDS

A substantial number of parents have experienced that applications for support were turned down. This applies to all kinds of services but in particular special education and social security. When the child reaches adolescence, three quarters have filed a complaint over a denial at least once. There may of course be good reasons for such denials, but this seems to be an unlikely explanation as 60–80 per cent report that the complaint was fully or partly successful. In some cases, parents report that this is frustrating but that they in the end get the support they need. In other cases of successful complaints, however, this is not the case. If one for instance complains over a denial of summer respite care, it does not help much if the decision is altered – in October. The same is also sometimes reported for special education. The main issue is, however, that there appears to be a threshold built into the system that excludes parents who give up and do not file a complaint. We cannot rule out that parents present their case more clearly and convincingly during the complaint than in the initial application. It is however unlikely that this is the full explanation and it does not change the fact that penalty rounds are part of being the parent of a disabled child. Sometimes denials lead to new strategies from parents: A mother was in October granted a week of summer respite care after filing a complaint. Next year, she changed her strategy. Instead of applying for one week of respite care, she applied for five. Then she was allocated two weeks in the first instance.

12.5.5 SUBJECT TO SUSPICION

A feeling of being subject to suspicion follows in part from the above points. Parents tend to feel discomfort in the interaction with the service system; they feel that they are met like someone trying to take advantage of or misuse the support system. This, in combination with the experience of penalty rounds, also implies that parents feel they have to describe their beloved child in the most burdensome

manner possible, in order to be regarded as eligible for the support they apply for. Thus, the interaction becomes burdensome in itself. Opting out is however not a possible choice. The families need the support and are thus stuck in the rather uncomfortable interaction.

12.5.6 VARIATION IN EXPERIENCES – TIME AND FAMILY RESOURCES?

There is reason to expect that the above descriptions fit better during the first years of the childhood. As time goes by, parents will be more familiar with the system, better informed, the fragmentation appears less chaotic and many have found ‘the right person’ in the service system. Furthermore, some types of support will run more or less automatically when allocated, such as the basic and supplementary benefits (grunn- og hjelpestønad). This expected trajectory is however only partly the case. Parents argue that it helps to become familiar with the system and the criticisms are less severe when the children are adolescents. But on the other hand, the pattern and types of frustrations are unexpectedly stable. Some relate this to new milestones. Needs change, transitions from day care to school and later to secondary school produces new rounds of access processes, the ‘right person’ in the service system gets pregnant, has quit or is replaced due to reorganization of the agency. Even though the economic support from social security is based on long-term decisions, supports like special education and respite care are short term – some social services for no more than three months. Thus, access processes are not only about the entry into the support system during early childhood, they are permanent facts of life for families with disabled children.

A number of the critical points above are likely to be associated with the families’ ability to master an unfamiliar and bureaucratic system. One would thus expect variation according to family resources, for instance related to their level of education. Our data hardly confirms such an expectation. This may be because the frustrations are mainly evident in the qualitative interview data, and not the survey data. Thus, we were not able to systematically analyse experiences by socio-economic variables in the medium-sized sample, only based on the rather small qualitative sample. And in the qualitative sample, frustrations apply both to families with high and low socioeconomic status.

There is one qualification concerning the unexpected missing association with family characteristics which relates to one of the biases in our data: the underrepresentation of minority families. In order to partly correct for this, some colleagues did a series of qualitative studies specifically on minority families with disabled children (Berg 2012). One of the main conclusions was that frustrations

and problems were escalated in minority families, but also that cultural differences (such as understanding of disability) and misunderstandings appears to play a limited role in this escalation. The point is rather that the frustrations outlined above, such as information problems and fragmentation, are even more severe in minority families due to language problems, less information about the welfare system and fewer resources in the social network (knowing someone who knows whom to contact). Thus, the source of the escalation appears to be issues related to the minority status rather than cultural difference. But the group as such is nevertheless more vulnerable.

In short, the narratives of parents suggest that the gap between policy ideals and the realities experienced by the families of disabled children is wide, and that this in particular relates to peoples' encounters with the service system and the process of accessing services rather than the quality of services as such. This does not imply that disabled children are deprived of a childhood in a family setting but it causes stress and frustrations among parents. Thus, the road to 'necessary protection and assistance' (cf. the preamble to CRPD) is paved with thresholds and is experienced as a combat with what is intended to be a support system.

A number of the above points suggest that many street-level-bureaucrats act like gatekeepers. This applies at least to information, penalty rounds and suspicion. The intriguing question is why civil servants encountering families with disabled children appear to be more eager to protect the public purse than to support them. We cannot answer this, but their dual role is likely to be relevant. Their job is to serve the eligible but also to reject people who intend to misuse the system. This duality is inherent in social services. The problem is that thresholds intended to keep the ineligible out has a pervasive effect on the everyday lives of people that need and are eligible for the supports.

12.6 INCLUSIVE EDUCATION?

Articles 28 and 29 of the CRC address the right to education in general, whereas the disability-specific Article 23 specifies that it should be provided in a way that supports social integration.¹³ There is furthermore a general clause on societal participation. The CRPD also addresses education and the duty for state parties to ensure that disabled children are not excluded from the general education system.¹⁴ In Norway, every child has the right and access to education, disabled or

13. Cf. Committee on the Rights of the Child (2009), para. 66

14. CRPD Art. 24.

not. The question is, however, to what extent disabled children are included in regular educational settings.¹⁵ Education in inclusive settings is seen as important for social integration of disabled children and the possibility to participate in educational and leisure time settings on same terms as other children.

Inclusive practices appear to be affected by the age of the child. Disabled children had a legal right to be prioritized for admission to preschools (day care centres) since the first act on preschools in 1975. At that time, and up to 2005, preschools were defined as care- and family-supporting services. By the new preschools act (Lov om barnehager 2005) these institutions changed from being care- and family-supportive services to become pedagogical services preparing children for school. Furthermore, all children in Norway gained the legal right to admission to preschools in 2009 and in 2011, about 97 per cent of the children aged 3–5 years attended (Statistics Norway 2012). However, because of the early right to be prioritized, preschools have a long tradition of providing care to all children, including disabled children.

As suggested by data shown in Figure 12.1, most disabled children attend regular preschool units; only about 12 per cent of children did not. The vast majority of children with physical or intellectual disabilities aged 4–6 years attended regular preschool groups in 1999. However, about a quarter of the children with multiple disabilities attended special preschools or special groups in regular preschools.

In the compulsory primary school, achieving a ‘school for all’, or one that is fully inclusive, is an important policy goal and part of the official aims behind the system of education for all children in Norway (Haug 1999). Before 1975, the state ran special schools, whereas municipalities were responsible for general primary education, that is, all other children. In 1975, a legal and administrative integration took place. The Special School Act was embodied into the general Education Act, and municipalities became responsible for the education of all children. However, special schools did not disappear. Some were transferred to municipalities whereas others continued to be run by the state, providing education that was purchased by municipalities. However, inclusion policies and ideology were gradually strengthened. In the late 1980s, legislative changes gave every child the right to attend their local school and to belong to a regular class together with their peers, but parents could apply for or accept other options. In 1992, all state-run special schools were closed with the exception of schools for sign language students. The ideology was that special education should take place in a classroom setting together with peers at the local school.

15. Cf. Committee on the Rights of the Child (2018).

Given such a core value base of inclusion, one would expect that schools make substantial efforts to accommodate disabled children in regular schools and classrooms throughout their primary school years – even and perhaps especially when relations between disabled children and their environment change as they grow older. However, as Haug (1999, p. 238) points out, the belief that Norway has put the goal of the inclusive school into practice have to be questioned. The use of special schools or special units at regular schools was fairly stable from the 1960s to 2005. About 0.8 per cent of the total pupil population attended special schools in the 1960–70s, and subsequently reduced to 0.6–0.5 per cent in the late 1990s and up to 2005 (NOS 1994; Skårbrevik 1996; Tøssebro 2006; Wendelborg 2006). Compared to other European countries, there was less use of segregated educational provisions (special schools/special classes) in the Norwegian school system in the mid-1990s (Vislie 2003). However, the use of segregated educational provisions increased in Norway to about 1 per cent in 2006–07 and to 1.3 per cent in 2008–09 (Wendelborg 2010). The proportion seems to be reduced since then, but there is some uncertainty about how schools define segregated provisions after 2011 (Wendelborg 2017).

These general figures on segregation in the education system provide information about the system at large, but are less informative as to the proportion of disabled children that are provided segregated schooling. As shown in Figure 12.1 the inclusive practices of preschools appear gradually to be replaced by segregation as children grows older. The segregation of an increasing number of disabled children takes place particularly during the transitions from one type of school to another (preschool to primary school, primary to lower secondary school, lower secondary to higher secondary school).

Thus, in the transition from preschool to primary school, there is a substantial increase in the proportion of children who do not attend regular educational settings. About one third of the children attend educational settings separately from peers without disabilities in early primary school. This proportion remains stable until the transition to lower secondary school, when it further increases to half of the pupils with disabilities. In upper secondary school only a third remains in regular educational settings. These results suggest that schooling for children with disabilities is a trajectory out of the general peer group.

Figure 12.1 shows that segregation from regular educational settings is not only related to age, but also type of disability. The separation from peers takes place rather early for children with multiple disabilities, somewhat later for children with intellectual disabilities, but as children reach adolescence it also applies to children with physical impairments.

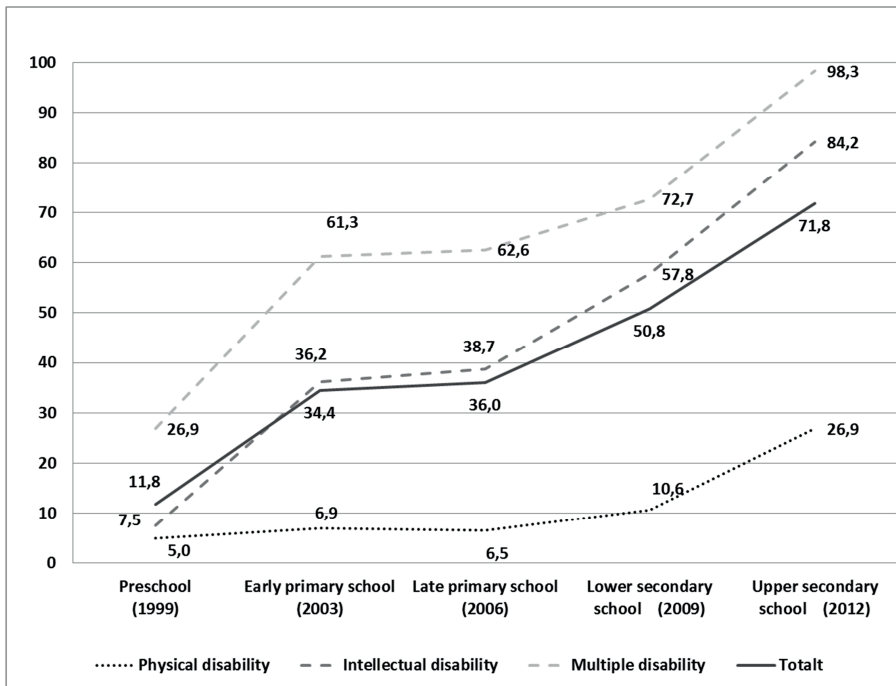


FIGURE 12.1 The development of the proportion of pupils getting their education outside regular class by age and type of disability (longitudinal data 1999–2012).¹⁶

Source: Wendelborg (2014).

Marginalization from regular class depends on more factors than age and type of disability. Some findings were expected, for instance that pupils with more severe impairments participate less in regular classes. However, the story of marginalization also comes with surprises. The number of inhabitants in the municipality is for instance of great importance for the proportion outside regular classrooms. Municipalities with many residents and in urban areas use segregated solutions to a greater extent than municipalities with smaller population size and density. This difference between municipalities (local governments) has probably both practical and ideological explanations. The practical explanation is in line with what Meijer and De Jager (2001) have pointed out; to set up a separate school system for children in sparsely populated areas is inconvenient, both because of an insufficient number of pupils with disabilities and because children would have to be transported substantially longer distances to a special school unit. Thus, the solution is more likely to be educational provisions within the local regular school.

16. $n=558$ (1999), $n=448$ (2003), $n=392$ (2006), $n=364$ (2009), $n=241$ (2012).

However, this does not explain why Oslo, the capital of Norway, uses segregated solutions more than other major cities. Neither can it explain why more children attend regular classes in municipalities with about 20–40 thousand inhabitants compared to the larger cities. Thus, local policies or ideologies also appear to play a role. There may even be an interaction between practical and ideological issues. If it is impractical to set up a segregated measure, or none exists, the school authorities are likely to put more effort into making inclusive settings work. This will in turn affect ideology and future practices. On the other hand, if there exist options of segregated measures, schools are more likely to see that as an easy way out and are less motivated to put much effort into making inclusion work. In short, the supply of educational provisions is likely to affect policies, ideology and the experienced need for segregated options, that is, demand.

The proportion of disabled children who are attending regular schools is not the full picture of the inclusiveness of education. Another element is that some pupils formally belong to a regular class, but scarcely participate in classroom activity. In primary school about a quarter of the disabled children who attend regular schools, participate less than half the time in class. This proportion increases with age. In secondary school, well over 40 per cent is more than half the time outside of the regular classroom. This segregation within an “inclusive” setting appears to be correlated with special education. When controlling for degree and type of disability, the number of hours with special education has a relatively strong effect on number of hours out of class. This suggests that the special education practice may in reality be a barrier to participation among peers, in particular the practice of taking the child out of class for special education lessons instead of developing strategies for special education within class (such as two teacher systems).

This practice may reflect the regular schools’ adaptation to the tension between the ideology of inclusion and their maintenance of existing traditional practices. It may also be a result of how schools manoeuvre in waters with contradictory pressures from different parts of the educational policies and ideologies. The Norwegian school system aspires to bring about a truly inclusive school, in which all children have access to the same facilities without segregation. However, there are other educational aims and ideologies that counteract this, such as the focus on performance, achievements and competition. In the everyday teaching, such diverging ideologies are not easily managed by teachers and there is reason to note that the increase in the total number of segregated children followed the shock-waves due to mediocre results on the 2001 PISA tests and subsequent reforms with focus on achievements.

After the transition to upper secondary school, the practice of taking pupils belonging to regular classes out of the classroom is reduced. The reason is not that there has been an inclusive turn in upper secondary school, but rather that few disabled pupils are attending regular educational settings at all. At the age of 17–19 years of age, less than 10 per cent of the children/youth in the ‘growing up’-study were attending a regular classroom where they participated more than half their time together with peers. Education for disabled children is thus a trajectory out of the general peer group, rather than social integration.

This pattern of segregation from peers obviously deviates from the national policy ideals of inclusive education. Some argue that it takes place because it is more convenient for the general school system – that it is a safety valve for traditional teaching methods. Teachers need to put less effort into accommodation for the full variation among pupils if disabled children are excluded. However, there are also voices that claim that the provision of segregated measures is in the best interest of the child. Such voices tend to refer to three types of arguments: (1) that disabled children will learn more in a more specialized educational setting, (2) that parents and children should have the opportunity to choose among options, including segregated options, and (3) that inclusion very often in reality leads to isolation and loneliness. We will discuss the first two points briefly here and address the “loneliness issue” in the next section on participation among peers in leisure and cultural activities.

There is limited research on learning outcomes for disabled children in different educational settings in Norway, but internationally there is a substantial body of research including a number of literature reviews. Such reviews tend to find that the evidence is inconclusive. Some studies show an advantage of inclusive settings but also the other way around. In general, the reported effects are vague, and the most reasonable conclusion is that it is not the issue of inclusion vs. segregation that matters when it comes to learning outcomes (cf. Hegarty 1993, Baker, Wang and Walberg 1995, Lindsay 2007, Dyssegaard and Larsen 2013). The argument for segregated solutions because of improved learning outcomes is thus not supported by existing evidence.

In this context, it is also relevant to note that the educational provisions for pupils with disabilities, and in particular with intellectual disabilities, has been criticized for low expectations and low ambitions regarding learning, thus not preparing them for an ‘ordinary’ or ‘independent’ life (cf. NOU (Norwegian public committee report) no 17, 2016). This criticism is supported by parents of children with disabilities who claim that individual education plans (mandatory if the child receive special education) tend to be “copy and paste” of learning goals of other

children and not according to the level of competence of their children (Wendelborg, Kittelsaa & Wik 2017). Major concerns about the process of referral for special needs education, as well as the quality and content of the training, have also recently been raised by the Norwegian Ombudsman for Children (Barneombudet, 2017). The concerns include worries about the use of teachers without formal qualifications for this group of pupils. Thus, in addition to the issue of segregation, even official voices like the Ombudsman for children and a public committee report also in practice question if educational provisions for all groups of disabled children are in keeping with Article 29 (a) of the CRC, specifying the right to education directed to the development of 'the child's personality, talents and mental and physical abilities to their *fullest* potential'.

The issue of the opportunity to choose segregated options is both related to the Education law and the CRC. According to the Education law only parents can decide that their child shall attend a school other than the neighbourhood school. One could therefore argue that the increasing segregation with age is due to parental choice, probably because they find inclusive education unsatisfactory. The CRC, Article 12, addresses the child's right to be heard – to express their views and that the view is given due weight in accordance with the age and maturity of the child.¹⁷ The increasing proportion in segregated setting by age could thus be in respect for the views of the children. The question is however what empirical evidence exists concerning the views of children and parents, and how this should be interpreted.

The children taking part in the 'Growing up'-study were interviewed or responded to a questionnaire in 2009 and 2012, when they were 14–19 years old. When asked what type of school they prefer, a vast majority of the adolescents reported that they preferred a school together with their general peers (Wendelborg 2014). However, there are some nuances. First, priorities appear to depend on the current type of school. Close to 100 per cent of disabled children in regular schools prefer this option, whereas there is more variation among children in special schools or classrooms. The majority responds that they prefer a regular school with more children with a similar type of impairment. Second, during interviews both children and parents report relief after the transition from regular school to a special school or unit. It is thus reason not to simplify this matter. We will shortly come back to interpretations but let us first have a look at the parents' attitudes and choice.

In the international literature, the views of parents have been found to vary according to the characteristics of the child (Lundeby 2006), including, for

17. Committee on the Rights of the Child (2009).

instance, diagnosis (type of disability) and age (Kasari et al. 1999). Parents' opinions also appear to be affected by current educational placement (Jenkinson 1998; Kasari et al. 1999) and worries about inadequate training and attitudes of teachers in regular schools, lack of resources and specialized instruction, and concerns about the social integration and academic progress of their child (Jenkinson 1998; Leyser and Kirk 2004; Palmer et al. 2001; Roll-Pettersson 2001). Parents' perceptions about regular placement are also influenced by parental characteristics such as educational level and income (Stoiber, Gettinger and Goetz 1998).

The attitude of the parents taking part in the 'Growing up'-study appears to reflect the type of school the child attends. This can be an indication that the increasing number in segregated settings reflects parents' choice. However, longitudinal studies on deinstitutionalization and choice of school suggest that it may be the other way around, that current placement has a strong impact on attitudes. Many parents change their view after involuntary relocations. Therefore, the 'Growing up'-study focused on the parents' reasoning and experience of the choice setting rather than ideological opinions. This analysis (Lundeby 2006) suggested that some parents chose a segregated setting because they either feared or had experience of inadequate accommodation in inclusive settings. However, it was equally important that choice in reality was very restricted. The headmaster of the local school could for instance claim that the school had no experience with disability and really nothing to offer, or (s)he could point to lack of resources in the regular school. In the case of parents who had experienced unsatisfactory accommodation, one could also argue that the choice is not about inclusive or segregated education, but a response to a regular school that is not sufficiently adapted to the full variety among pupils. Thus, children were integrated in a non-inclusive regular school. If the school does not develop inclusive practices, there is no reason to be surprised that it does not work well. The point is therefore that the parental choice is taken in a context that discourages certain choices. The fact that there is a strong correlation between municipal population size and proportion in segregated settings also suggests that structural drivers are playing a part.

We will thus argue that even though parents sometimes chose or accept a proposed segregated option, this cannot be seen as the driver of segregation. This does not imply that we argue that the parental choice is uninformed. It is likely to be informed, but that abstract preferences are likely to play a minor role compared to contextual and situational factors. Consequently, there is a need to be clear about the distinction between parents' choice at the individual and situational level and the obligations of the state and local governments. At the individual level, the choice of parents and the opinions and experiences of children should be

respected. At the policy and school owner level, however, the question is priorities for future development of the educational system. The current state of affairs suggests that there is a need for the development of educational provisions that are really inclusive, that is, accommodated to the needs of the full variety of children. And as for the obligations according to the CRC, it is the obligation of the state to develop inclusive settings that are the issue. The restricted and contextually based choices of parents cannot be used as an argument to disregard this obligation.

The issue of loneliness will be addressed in the wider perspective of social participation with peers in general, to which we now turn.

12.7 PARTICIPATION IN SOCIAL AND CULTURAL ACTIVITIES

Schools are an important point of departure for social and cultural activities not only during school hours. There are organized after school activities such as brass bands, school choir, sports activities, school plays and activities around public holidays. School may also be the starting point for unorganized activities. Thus, if you don't participate together with your classmates in school time, chances are that you neither do so in "after school activities". In the Growing up study there were several examples of children with disabilities who watched the class perform at school plays while they themselves sat in the audience. Parents also told stories of linked lives in which the child's experiences and marginalization influence the parent's role and position in the local community. The father of a boy with disabilities attending a regular school reported that he never was invited to the common parents' meetings in his son's class (Wendelborg and Tøssebro 2010). He described how this had a negative impact on his role as an ordinary parent in the local community: the parents of children in the 7th grade – the grade his son attended – always organized the celebration of the Norwegian national day on the 17th of May. All the parents were assigned tasks, except for him: *But it is like you are kept ... outside, you see. It became very clear just then when it came to the 17th of May.*

Disabled children and youth participate less in leisure activities as such and are often grouped together with others with disabilities (Kunnskapsdepartementet [Department of Education] 2008). However, they report to a higher degree compared to their general peers that they are members of organizations, except for sports clubs (Ødegård 2006). At the same time, they report that participating in organized leisure activities was not an important part of their everyday life (Løvgren 2009). This 'devaluation' may, however, be an adaptation to missing inclusion in such activities, an interpretation that is supported by the fact that the

disabled children in the referred study reported the experience of prejudices and negative stereotypes (Løvgren, 2009). In the ‘Growing up’-study, disabled children participated less with their general peers as they grew older. This applied to both organized and general leisure activities. However, their participation with other children with disabilities increased. Thus, disabled children experience an increasing encapsulation together with other disabled children in leisure time – a parallel development as seen in the education system. This development is influenced of type of disability and degree of impairment.

Thus, the image of low participation by peers, as commented upon by the Committee on the Rights of the Child in 2005,¹⁸ is sustained. It is, however, also important to address to what extent the parallel developments in school and leisure time are linked or not, which is related to the issue of loneliness. As noted in the previous section, it is frequently claimed that integration in reality leads to isolation and loneliness, whereas segregation provides the opportunity for inclusion among disabled peers. The data from the ‘Growing up’-study does not support such arguments. Controlled for type and degree of impairment, pupils attending and taking part in classroom activities score better on measures like having friends, social participation in school and leisure time, perceived social acceptance, peer intimacy and quality of life (Wendelborg and Paulsen 2014; Wendelborg and Tøssebro 2010; 2011; Wendelborg and Kvello 2010; Wendelborg 2017). But on the other hand, pupils attending regular class but with low participation in the classroom, score lower on the same measures than children attending special schools or units. Thus, attending regular classes is not a sufficient condition for integration, more friends and participation with peers. It is also necessary that the disabled pupils have sufficient anchorage in the regular class. A special education practice that takes pupils out of class for individual training appears to be a risky strategy for social participation with general peers. In short, the argument that integration leads to isolation is not supported by the data, but this is in part dependent on how the integration in the regular classroom is organized.

12.8 CONCLUSIONS

The main data source of this chapter was the longitudinal study ‘Growing up with disabilities in Norway’. The study collected data from families with disabled children born 1993–95. This cohort was chosen for a particular reason. The children were born after the implementation of a set of reforms intending to move the real-

18. Committee on the Rights of the Child, 2005, *Concluding Observations on Norway*.

ization of inclusion ideals a quantum leap forward. This included the dissolution of institutions for intellectually disabled people in 1991 and the transformation of state special schools into resource centres without children on a long-term basis in 1992. Thus, the children of this study were the first generation born into a system that was intended to make inclusive policies real. The aim of the study was thus to analyse what it was like to grow up with impairment in the emerging inclusion era.

The results show that disabled children in general are included in preschools but as they grow older, an increasing proportion is segregated from their peers. National statistics also show that in general, the proportion of all pupils that do not attend regular classes increased substantially during the first decade after year 2000. It is not quite clear what went wrong, but there is no doubt that the 1990s was the golden age of inclusion policies. This was replaced by political silence after year 2000, and the focus in education policy was certainly dominated by other issues, not least the shock in the aftermath of relatively mediocre results of Norwegian pupils on the PISA tests (2001). Thus, the results of this study can hardly be seen as an analysis of growing up in the inclusion era, but rather during the subsequent silence.

The analysis of this chapter suggests that the outcome of current policies and practices for disabled children are out of keeping with CRC provisions. This applies to the worries earlier noted by the Committee on the Rights of the Child concerning participation with peers, and the recent comments on inclusive education.¹⁹ Furthermore, the recent criticisms from the Ombudsman for Children (2017) and a public committee report (NOU no 17, 2016) suggests that the quality of education for some groups of disabled children falls short of the requirements of CRC Article 29 (a) on support for the development of their full potential.

Disabled children do in general grow up with their parents or in a family setting in Norway, and this is as such in keeping with the CRC and the CRPD. However, the data on the interaction between the families and the support system suggests substantial challenges. The results suggest that the main problem may not be the absence or poor quality of services as such, but an access process that is paved with thresholds which raises the question whether this is in keeping with the CRPD preamble's reference to 'that persons with disability and their family members should receive the necessary protection and assistance'.

This chapter has focused on issues related to inclusion and family supports, partly because those are important issues but also because of available data. There

19. Committee on the Rights of the Child (2018).

are, however, also debates on a number of other issues related to the CRC, such as the risk of bullying or abuse. Some reports suggest increased risk, such as a report by Ipsos (2016) on visually impaired children. This suggests that two out of three have experienced bullying in school. This is an alarming finding, but in general the state of the art in this area is more uncertain. The same goes for child poverty. Thus, in such areas the conclusion is not necessarily problems related to the CRC, but that there is an urgent need for a more solid knowledge base.

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