When inclusive structures become social barriers:
Disabled children’s participation in childhood

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(A full text version is sent directly to the opponent)

Astrid is a girl with Down’s syndrome who attends a regular school in a rural part of Norway. She was seven years old in 2002, when her mother spoke quite happily about Astrid’s relations with her classmates ‘Oh yes. They ring and ask if they can come along home with her and …so it seems like she is well accepted. I don’t have to do anything, it seems to happen automatically’. Four years later Astrid’s mother was more discouraged, explaining: ‘But you notice as they grow older, she isn’t their first priority to be with. It was totally different in the first and second grades, because then they are children in a completely different way.’

In spite of a strong inclusion ideology where all children are supposed to have the same opportunity to be at the same arena as other kids, the story of disabled children’s childhood often become a story of increased marginalisation and decreased participation with peers. This story is not static and as Astrid’s story illustrate; children’s behaviour change during childhood and the changes can be connected to different, but coincident social and structural processes. This paper focus on children with either mobility difficulties, intellectual difficulties or multiple impairments and these children’s social position and participation with peers in childhood institutions and in leisure activities. Childhood institutions are here defined to be day care centres, primary school and school-leisure arrangements. The ambition with this paper is two-folded: (1) First we want to describe how structures in childhood institutions change during childhood, i.e. we want to describe were the disabled child become physical placed compared to their peers and how this placement influence social life in other arenas. (2) Second we will illustrate how the social interaction logic change during childhood and affect disable children’s social participation with peers. The chapter illustrate how children’s different childhood arenas influence each other reciprocally, and that participation at school influence children’s possibility to participation in other social arenas.

The social part of inclusion seems to be most difficult to achieve. Much of the research concerning disable children and the social dimension of inclusion have point of departure in non-disabled children’s friend preferences and sociometric tests where impairments become a category (Harper et al 1986, Richardson 1983, Guralnick et al 1996) and attitudes children in general have towards disabled peers (Bunch & Valeo 2004). Furthermore, there are experimental studies with ambitions to manipulate single variables to gain social interaction between disable children and their peers (Goldstein & Cisar 1992), and to identify how to regulate individual’s impairments, characteristics and/or behaviour to promote interaction. Research focusing on the circumstances, living conditions, quality of life and identity constructions have become more frequent (Grue 1998, 2001; Pivik et al 2002). Additionally there is an increased focus on children’s social positions, roles and presentation of self in relation to peers (Ytterhus 2000, 2004, Ytterhus & Tøssebro 2006, Ottosen & Bengstsson 2002, Egilson 2005, Wendelborg & Kvello in press).

1 School-leisure arrangements is a public service to children from 1 – 4th (6 – 10 years) grade at primary school. It is placed at school localities, is ran by the school, but it is not defined within the Act of education. For children with disabilities have a legal right to enter these leisure activiteis until the age of 12.
The empirical base
This paper built on both quantitative- and qualitative longitudinal data from two projects. In this paper we use data from:
- Qualitative interviews from the parents of 31 children
- Participant observation of face-to-face interaction between children with and without disabilities in public municipal day-care-centres and primary schools. More than 100 children were involved and 11 were disabled, 9 in day-care-centres and seven of those in primary school. Data collected in 1996/97 and 2002/03. The children are born in 1990 – 1993.
- Qualitative interviews with parents of disabled children.
The disabled children in both studies were either mobility disabled, intellectual disabled or had multiple impairments.

Theoretical point of departure
- a relational model of disabilities are focusing on the complex and situational interaction between the individual and the surroundings → impossible to categorise the individual with learning difficulties but make a better understanding of the interaction between the child’s qualifications and the school’s demand which together create difficulties (Emanuelsson 1994)

Legal point of departure
- One common act of education in compulsory schools from 1975 in Norway
- The Educational Act (17th of July 1998 with last changes Dec 14th 2007)

Findings
Where are disabled children physical placed during childhood?

Day-care-centres
- 95 % of the disabled children entered day-care-centres while 62 % of children in general did in 1999 (SSB 2007)
- Of these 95% we did find 81 in ordinary day-care-centres, 2 % in family-based-day-care units and 12 % i special day-care-centres for disabled children

Schools
- Different statistics make different pictures, but it seems like there has been few changes in the period 1960 – 2005- Approximately 0, 5 – 0.8 % of pupils went to special schools (NOS 1994, Skårbrevik 1996, Vislie 2003, Tossebro 2006, Wendelborg 2006) which is among the lowest rate of special school rates in Europe.
- However, a change occurs in 2006 and 2007 and the number of children attending special schools increased to 1,2 and 1,1 %, which implies a movement towards the average in Europe (Vislie 2003).
- While 12 % enter special day-care-centres, the share of disable children in segregated settings increased to 35 % when starting school ( 75 % of multiple impairments, 40 – 45 with intellectual disabilities and less than 10 % of those with mobility disabilities)
- Wendelborg & Tossebro (2008) found no major changes in school placement during primary school years, which is contrary to earlier findings. However, the amount of time children with disability are absent from regular classes does increase significantly as the children become older!
Leisure activities
- Children with mobility difficulties participate less than children in general and have fewer friends (Law et al 2007, Stevens et al 1996)
- Children with intellectual disabilities who attend special schools participate less in leisure activities and in birthday-parties with peers (Ytterhus & Tossebro 2005)
- There are significant correlation between degree of classroom participation in regular schools and participation in leisure activities (Wendelborg & Kvello in press)
- The turning-point in social activities seems to find place in the transition from 4th to 5th grade (±/+/- ten)

Parallel marginalisation processes
1) Special education
   a. Increases within ordinary schools during childhood (GSI 2007-08, 3,4 % - 3,8% - 4,6 % - 5,4 % in first to fourth graders, while 6,3 % - 7,3 % - 7,8 % of fifth to seventh graders)
   b. The amount of special education hours increase proportional with increase in grades and is mostly given individually or in small groups.
2) Changes in social interaction
   a. When you are physically placed mostly in other settings than your peers you did get less time to interact with them (ref special education, transport to and from school)
   b. Two phases:
      - at 3 – 8 years the interaction logic are situational and you have to be "playable" (Ytterhus 2000, 2002, 2004), non-disabled peers try to adjust their behaviour to make the play going on, most non-organised activities in leisure time
      - at 9 – 11 years the interaction turn into more focus-driven-activities, the leisure time activities become more organised by adults and according to interests, adjusted behaviour does find place only when it does not hamper the non-disabled peers
3) Decreased access to public social services for the families with disabled children (Ytterhus et al 2008)
   - lose/lack of public support workers
   - decreased involvements from private network members
4) The normative norms of majority invade childhood at school

Conclusion
Multiple parallel reinforced processes make disabled children marginalised from peers. The identified processes especially involve children with intellectual disabilities and multi-impaired children. On the one hand childhood institutions marginalise children with impairments by their organisation of their offerings to disable children. If they are placed at other location than their peers it affects their possibility for social interaction with peers also in other arenas. “Time” becomes an important variable in social interaction for both mobility and intellectually disabled children, even though in different manner. On the other hand change in content of relations combined with changes in interaction logics makes it more difficult for disabled children to participate in peer relations when they reach the age of +/- ten years and even earlier for intellectual disabled children.

Social relations and friendship in childhood will probably always become secondary in education and we do not claim that education must only focus on social interaction or that special education is not necessary. However, when the organisation of childhood institutions...
“accidentally” increase segregation and we have knowledge about relational aspects in childhood, it might be possible to remove this extra burden for disabled children.

**Litteratur**


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Nettsteder:

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