A Psychosocial Follow up Study of Children with Cochlear Implants in Different School Settings

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In order to study the psychosocial and communicative consequences of cochlear implants (CI) in deaf children in Sweden, a longitudinal study of 22 preschool children with cochlear implants was carried out. When the children had started school a continued longitudinal follow up study of the same group of children was initiated in order to follow their development in different school settings. Twenty of the 22 children took part in the school study and a short overview of some of the main results of the school study is presented here.

Background and educational context

The educational goal for deaf children in Sweden is a development towards bilingualism in Swedish Sign Language and Swedish. In early intervention programs parents of deaf children are encouraged to learn sign language as soon as possible after diagnosis and Sign language education is provided free of charge. The goal of habilitation is to ensure a well functioning communication in the family, in pre-school and school, and on into adult life. According to the recommendations of The Swedish National Board of Health and Welfare issued in 2000, the family must have acknowledged the role of Sign language and started to use it in communication with their child in order for the child to be considered for a CI. The goal stated for children with CI is early communication in Sign language and a bilingual development in Sign language and spoken Swedish. Studies carried out in more orally oriented settings have shown that some of the most important factors motivating parents to let their child have a CI operation are the wish that the child would function as a hearing child, the children’s communicative difficulties and the parents’ frustration about their lack of communicative ability (Kluwin and Stewart, 2000; Perold, 2001). None of the parents in the Swedish longitudinal study mentioned communicative difficulties as a reason for the operation. Rather, the Swedish parents stressed the wish to open as many roads to development as possible, not denying their children any options (Tvingstedt, Preisler and Ahlström,
This difference in attitude is probably a result of the way early parental guidance and habilitation is administered.

The children in the study were among the first to be operated with a CI in Sweden and the recommended age of operation at the time, was from two years of age. Today more than 80% of the children diagnosed as deaf are operated and operations are conducted on children from the age of 12 months, occasionally even earlier. The information to parents has also changed. Originally the CI-teams only guaranteed that the children would be able to hear environmental sounds, which was the information given to the parents in the study. Today the CI-teams forecast a development oral language on most children. Although the parents in the study of course hoped that their children would be able to hear and speak, parents today anticipate such a development to a much greater extent. This may have consequences for their motivation to learn sign language and to use signs in communication with their child.

Theoretical framework

The study is based in relational developmental psychology. The importance of interaction and close relationships is seen as crucial, not only for the development of language and communication but also for the psychosocial and cognitive development of the child.

Children are seen as active co-creators in their own development, which takes place in close relationships with important others in the environment. Children are regarded as competent and already from birth equipped with the capacity to enter into interaction and communication with their caregivers (Trevarthen 2004, Stern 2000). In order to develop their ability to communicate, children need caring partners who respond to their signals and they need to be engaged in repeated habitual social exchanges where child and caregiver are involved in constructing reality through finely tuned relationships (MacDonald and Carroll, 1994). In encounters with others - at first with caregivers and members of the family and later on with other adults and peers - the child gradually develops a sense of self in relation to the psychosocial as well as the physical world (Stern, 2000).

Children also acquire important developmental skills in interaction with peers, like the capacity for reflection and self-reflection, the ability to take the perspective of others, and the ability to interpret and understand social situations (File, 1994; Frønes, 1995). They also learn how to negotiate and how to handle conflicts. Studies have shown that well functioning peer relations are related, not only to the children’s social situation in school, but also to their school achievements (Zettergren, 2001).
With a sociocultural perspective on learning originally based on the theories of Vygotsky (1978, 1986), communication and interaction also become central processes in the development of knowledge and in the cognitive development of children. Knowledge is seen neither as external objects nor as inner thoughts, but rather as embedded in the activity of knowing – as something that is jointly constructed, through language, in cooperation, in activities situated in a social context. Hence learning presupposes language, communication and interaction. (Wells, 1999).

Most studies on the effect of cochlear implants in children have been concerned with speech production and speech perception (e.g. Geers and Moog, 1994; Gantz, et al., 1994; Waltzman et al., 1994, 1997; Allen et al., 1998; Waltzman and Cohen, 1998; Moog and Geers, 1999; Svirsky et al., 2000; Blamey et al., 2001). These studies often give a very positive picture of the implant use and tests show that the children make significant progress in production as well as perception of words in laboratory settings. But although pronunciation and discrimination of words is related to development of spoken language (O’Donoghue, 1999; Geers et al., 2003) it is not the same as being able to hear, understand and communicate in everyday settings. In a review of a large number of studies in this field Spencer and Marschark (2003) reached the conclusion that children with CI after a couple of years will obtain a functional hearing capacity in parity with that of a hard-of-hearing child.

The aim and method of the study

The main objectives of the school study were:

- to explore the parents’ motives and considerations when choosing school placement for their child, as well as the parents’ and the teachers’ experiences of the adequacy of the school placement
- to describe the language environment in which the children were living, the patterns of communication in the classroom, the children’s school performances, primarily in reading, as well as their peer interactions
- to give words to the children’s own experiences of wearing a cochlear implant.

The parents of the 20 children were interviewed about their opinion of the school placement and about the situation in the school setting. Eighteen of the children were video-observed in everyday interaction at school, during lessons and breaks. Their teachers and personal assistants have also been
interviewed about the school situation. Reading tests have been administered
to the children and the 11 oldest children were interviewed themselves, when
they were between 8.5 and 10.5 years old, about their opinion of wearing a
CI.

The following overview focuses on some central issues brought up by
parents, teachers and assistants in the interviews, underpinned with
corresponding findings in the interviews with the children and the
observations from the video-recordings in the classrooms. More
comprehensive accounts of the results are given in the reports from the study

The group of children

The group of children taking part in the school study consisted of 11 boys
and 9 girls. Fifteen of the 20 children were pre-lingually deaf. Twelve of
them were born deaf, while 3 became deaf before 1½ years of age, due to
meningitis. Five children became deaf between 2 and 4 years of age - after
they had started using oral language - 4 of them due to progressive hearing
loss and 1 due to meningitis.

Table 1. The child's sex related to time and cause of deafness

<table>
<thead>
<tr>
<th>Deafness</th>
<th>Boys</th>
<th>Girls</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 2 years of age</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pre-lingual meningitis</td>
<td>2</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Pre-lingual deafness, cause generally</td>
<td>6</td>
<td>6</td>
<td>12</td>
</tr>
<tr>
<td>unknown</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 – 4 years of age</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pre-lingual meningitis</td>
<td>3</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Pre-lingual progressive hearing loss</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>11</td>
<td>9</td>
<td>20</td>
</tr>
</tbody>
</table>

The children were operated when they were between 1 year and 11 months and 4
years and 10 months old. All of the children used Nucleus/Cochlear mini 22/20+2
implants.
Table 2. Age at operation (in years and months) related to time of deafness

<table>
<thead>
<tr>
<th>Age at operation/Deafness</th>
<th>1:11-2:11</th>
<th>3:0-3:11</th>
<th>4:0-4:11</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 2 years of age</td>
<td>6</td>
<td>4</td>
<td>5</td>
<td>15</td>
</tr>
<tr>
<td>2 – 4 years</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Total</td>
<td>6</td>
<td>7</td>
<td>7</td>
<td>20</td>
</tr>
</tbody>
</table>

During the preschool period 7 children attended preschools for deaf children using sign language and 9 attended preschools for deaf and hard of hearing children where both signs and speech were used. Four children were mainstreamed in ordinary preschools for hearing children - 3 with and 1 without a personal assistant using sign language.

Table 3. Pre-school placement

<table>
<thead>
<tr>
<th>Pre-school placement</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-school for deaf children using sign language</td>
<td>7</td>
</tr>
<tr>
<td>Pre-school for deaf and hard-of-hearing children where sign language and spoken language were used</td>
<td>9</td>
</tr>
<tr>
<td>Mainstreamed in an ordinary pre-school</td>
<td>4</td>
</tr>
<tr>
<td>Total</td>
<td>20</td>
</tr>
</tbody>
</table>

At the end of the school study half of the children were mainstreamed in ordinary classes, with a personal assistant using sign language, and half of them attended sign language classes at a school for the deaf. The proportion of children in mainstream schools is on a par with what has been found in studies from other countries (Archbold et al., 2002; Dayas et al., 2000).

Table 4. School placement related to time of deafness

<table>
<thead>
<tr>
<th>School placement Deafness</th>
<th>Sign-language class for the deaf</th>
<th>Ordinary class</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 2 years of age</td>
<td>9</td>
<td>6</td>
<td>15</td>
</tr>
<tr>
<td>2 – 4 years</td>
<td>1</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Total</td>
<td>10</td>
<td>10</td>
<td>20</td>
</tr>
</tbody>
</table>

At the end of the study the children had been using their implants for between 5 and 7.5 years.
Table 5. School placement related to time with implant at the end of the study

<table>
<thead>
<tr>
<th>School placement</th>
<th>Sign-language class for the deaf</th>
<th>Ordinary class</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>5 – 6 years</td>
<td>4</td>
<td>5</td>
<td>9</td>
</tr>
<tr>
<td>6 – 7 years</td>
<td>5</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>7 – 8 years</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td>10</td>
<td>10</td>
<td>20</td>
</tr>
</tbody>
</table>

Results

Although the child's ability to perceive, understand and use spoken language naturally affected the parents' choice of educational placement, other factors were also of importance.

The background factors most strongly related to school placement were the distance to the school for the deaf and the children's preschool placement. Nine out of 10 children living too far away from a school for the deaf to allow daily commuting attended ordinary classes, while 9 out of 10 children living close enough to commute attended a school for the deaf. The distance to the school for the deaf and the consequences for family and child if the family should have to move or the child should have to live away from home during the school weeks was also a prominent theme in the interviews with the parents. There were cases when staying together as a family at home was seen as the main advantage of the implant operation.

All of the children who had attended preschools for the deaf using sign language continued to schools for the deaf and all of the children with experience of mainstreaming in ordinary preschools continued to ordinary classes with hearing children in mainstream schools. The children attending preschools for deaf and hard-of-hearing children went on to both kinds of education.

Four out of five post-lingually deaf children attended ordinary classes and almost two thirds, or 9 out of 15, of the pre-lingually deaf children attended schools for the deaf. However no clear relations could be established between school placement and other background variables, such as age at operation or time with implant (Tvingstedt, et al. 2003). As the group is small, conclusions should of course be drawn with caution and the results cannot be generalized. They do however point to the complexity of the question – something that has also been pointed out in other studies (e.g. Archbold et al. 2000).
In the interviews the parents explained that sign language was more sparsely used at home now, than during the preschool period. Most of the children using their implants could take part in everyday conversations in the home settings. Sign language was occasionally used but most of the communication at home was in spoken language. But it was also clear from the interviews that most of the parents experienced difficulties when discussing complicated matters with the children as their vocabulary as well as their understanding of concepts was limited. Several of the children had deficiencies in their articulation, which could make it difficult for adults outside the family to understand what was expressed. All of the parents, independently of which school the children attended, stressed the importance of sign language when complicated, abstract or particularly important new concepts should be explained.

In the interviews all of the parents expressed that they were content with their choice of school for their child irrespective of school placement. The children enjoyed school, which the parents took as an indication that the placement was adequate. This did not mean however that they could not also be critical.

The parents of the children in the schools for the deaf considered sign language to be the children’s first language and maintained that their child received a qualified education that the child could profit from. But they were not content with the status of speech in the special schools and wanted more exposure to oral language than the children were offered.

Although the parents of the mainstreamed children were content with the school placement they believed that the situation could be improved, if the child had received more support and if the educational setting had been better adapted to the child’s needs. They were aware that their children had difficulties in discriminating speech in noisy environments and also in understanding words and concepts, which could make it hard for them to understand information given by the teacher in class. But at present they preferred this form of school education rather than a school for the deaf. However most of the parents viewed the school placement in a short-term perspective and were prepared to reconsider if it should not work. Some of them had also established contact with a special class for the hard of hearing or a school for the deaf in order to facilitate in the event of a future change of placement.

The teachers in the schools for the deaf maintained that the school placement was adequate as the children's perception of speech as well as their speech production was too limited for them to be able to take profit from being educated in spoken Swedish. In three cases there was no doubt about the adequacy of the school placement, as the children no longer used the implant. In one case this was due to deficiencies in the implant. In the other two it was probably related to behavior problems and deficits in
concentration and attention, as the children had an ADHD diagnosis – a relationship that has been found in other studies as well (Knutson et al. 2000). In the schools for the deaf there was an ongoing discussion of how the exposure to spoken language could be increased for children with CI and when and how the two languages should be used.

The teachers in the ordinary classes felt that the school placement was adequate. But as their experience of having a child with CI in the class increased, they became more aware of the difficulties in giving educational support for the child. Lack of resources and many pupils in the classroom made for a demanding work situation for the teachers. Many of them maintained that the child had to adapt to the conditions in a class with hearing pupils and some pointed out that they “could not perform miracles.” The support provided for the mainstreamed children in the study was to engage an assistant using sign language, for the child.

During the first school years most of the children could take part in classroom activities with all the pupils. But as the children grew older and the content of the teaching became more abstract, some of them spent an increasing amount of time alone with their assistant for individual education and less time in the classroom.

The results from the analyses of the video recordings were in accordance with the descriptions in the interviews.

In the ordinary classes, communication was based on spoken language. The assistants tried to interpret what the teacher said, but as some of them had limited sign language competence and as the child with CI did not look continuously at the assistant, it was difficult to assess what the child understood. According to the way the children acted and the way they asked questions after the lesson, it was obvious that information was missed. A lot of the information that was given to the hearing children, in small talk, or in comments from the teachers, was seldom or never translated to the children with CI and therefore not attainable for them.

The children seldom made utterances in the classroom setting. But when they did speak it was often difficult to understand what they said, as they had difficulties in pronunciation and their tone of voice was often different from those of the hearing children. Their vocabulary was in many cases restricted and they had problems in taking part in oral classroom dialogues. Some of them used sign language with their assistants while others understood sign language to a varying extent, but never used it themselves.

In one-to-one settings with the teacher or the assistant the children could take part in the communication, pose questions, answer the teacher’s questions and also communicate about everyday matters in spoken language.

In the interviews the parents stressed that the children needed to look at the person speaking in order to hear what was said. However, in several
classes the children with CI were seated so that they had a good view of the teacher and the assistant but not of the other children, who were seated beside or behind them. This made it difficult for the children with CI to see and hear what the other children said and what answers they gave to the teachers’ questions, which of course affected their ability to follow the teaching.

In the schools for the deaf the children took part in the lessons in a different way. The number of children was small - between 6 and 12 pupils compared to between 18-30 in ordinary classes. They were generally attentive in class, as you would expect a small group to be. Sign language was the language used and the children did not seem to have difficulties in understanding what was signed in the classroom. In one-to-one situations spoken language was sometimes used between teachers and children with CI and in some of the classes in the study spoken language supported by signs was used during specific lessons.

The interviews with the children gave a similar picture of the situation as the one presented by the parents and the teachers. The implant had advantages in certain situations. The children could profit from it in the home situation when communicating with parents and siblings and in the school situation in one-to-one situations with teachers and assistants. But they had difficulties in understanding what was said in the classroom, something that they attributed either to teachers’ and other pupils’ way of speaking – they spoke too low or too indistinctly – or to the sound level in the classroom with many pupils being too high. The difficulty of taking part in classroom conversations is a problem the children with CI share with other hard-of-hearing children (Preisler & Ahlström 1997, Tvingstedt, 1998; Antia & Kriemeyer, 2003). In a Norwegian study of older children with CI in mainstream schools Christophersen (2001) draws the conclusion that smaller classes are a prerequisite for taking part in classroom interaction - a conclusion that is corroborated by the present study.

Conclusions

The children in mainstream classes could, according to their parents, teachers and assistants, manage quite well in the school situation during the first 2-3 years of school, under the condition that the educational setting was adjusted to their needs and that the assistant could translate much of the information given by the teacher. The necessity of sign language was expressed in most of the interviews. The problem was that the sign language proficiency of assistants as well of children was limited in several cases.

The adults maintained that there was interaction between the children with CI and their classmates. The means of communication was primarily
based on single signs, single spoken words, nonverbal means and actions. Similar results are reported from other studies of peer interaction (see e.g. Bat-Chava and Deignan, 2001). Several of the adults, primarily among the assistants, envisaged problems to do with knowledge acquisition and peer relations, as the children grew older. Many of them were hesitant as to whether the children would be able to cope in regular class in higher grades.

The children in the schools for the deaf managed well academically but the parents wanted more exposure to speech for their children in the school setting. Peer interaction was usually no problem for the children in the school, although they had no or few friends at home in the neighborhood.

The opportunities for language development in different school settings are of course dependent on the capacities of the children as well as on the stimulation offered. The official goal for children with CI is bilingual development in Swedish and Sign language. However, the parents often felt that they had to waive one or the other. Parents who had chosen the school for the deaf wanted more spoken language and parents who had chosen mainstream schools were aware that this was not an environment where the children could develop their sign language. This was a choice the parents felt that they had been forced to make and someone said: “you can’t both eat the cake and have it too”.

Most of the parents irrespective of choice of school placement advocated an increased contact and cooperation between the different types of schools. Opportunities for the children to be exposed to, and also choose different modes of communication in different educational and communicative situations as well as increased contacts with hearing, hard-of-hearing and deaf, peers was sought.

The children in the study appreciated their implants but they were well aware that they were still deaf – an awareness that they shared with their parents (Preisler et al., 2002). In a study of deaf adolescents with CI as well as without CI, Wald and Knutson (2000) showed that the two groups had strikingly similar identity beliefs and both favored a bicultural identity. The question is to what extent children and young people with CI are afforded the possibility of developing such an identity.
References


Blamey, Peter; Sarant, Julia; Paatsch, Louise; Barry, Johanna; Bow, Catherine; Wales, Roger; Wright, Maree; Psarros, Collen; Rattigan, Kylie & Tooher, Rebecca (2001). Relationships among speech perception, production, language, hearing loss and age in children with impaired hearing. Journal of Speech Language and Hearing Research, 44(2), 264-285.


Preisler, Gunilla; Tvingstedt, Anna-Lena & Ahlström, Margareta (2003). Skolsituationen för barn med cochlea implantat - ur föräldrars, lärare och assistenters perspektiv. (The school situation of children with cochlear implants – from the perspective of parents, teachers and


