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Children with Down Syndrome in Finland and Italy: Comparing Adaptive Behaviour and
Services

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Abstract

Objectives. The aim of this study was to compare a sample of Italian (n = 29) and Finnish children (n = 32) with Down syndrome for possible differences emerging from diverse educational surroundings. Besides the level of adaptive and challenging behaviours, some other issues were compared, including teacher satisfaction.

Methods. We used the children's teachers as informants. They were interviewed using standardized scales.

Results. No differences in adaptive behaviour or challenging behaviour were observed between the samples. All children from the Italian sample were fully included in mainstream classes, while in the Finnish sample, 92% of all the school years were spent in self-contained special education classes. The Italian sample received physiotherapy and speech therapy more often than the Finnish sample. Satisfaction concerning the resources and organization of the children's education was high among the Finnish informants but rather low among the Italian informants.

Conclusion. The results illustrated some differences in the organization of special education of children with Down syndrome in Finland and Italy. The interpretation of the level of adaptive and challenging behaviour scores was hampered by the high standard deviations, indicating the inner heterogeneity of the samples.

Keywords: Inclusion; Inclusive education; Finland; Italy; Down syndrome; Adaptive behaviour; Disabilities; School

Children with Down Syndrome in Finland and Italy: Comparing Adaptive Behaviour and Services

The level of adaptive behaviour of children with intellectual disabilities is affected by several factors, including the age of the child and their access to education. A comprehensive model of these factors was presented by the World Health Organization (2001).

Environmental factors, such as services, are considered an influential element in this model. A well-known example from the near past is the detrimental effect of institutional care on the behaviour of persons with intellectual disabilities (see for review: Kim, Larson & Lakin, 1999). Alongside the slow disappearance of institutional care, the comparative studies on institutions have now almost vanished. A new environmental factor awakening attention is the effect of school environment, especially inclusion, on the learning of children with disabilities.

Finland and Italy constitute two opposites in Western Europe with respect to the educational integration of children with disabilities. While, in Italy, full inclusion has been the rule since the year 1977 (Associazione TreeLLe et al., 2011), segregated special education classrooms have continued to dominate in Finland (Saloviita, 2009). It is naturally too daring to conclude that possible differences between the outcomes of children in different countries could be explained on the basis of one single variable. These kinds of explanations have often been presented to explain the PISA results, as described by Sahlgren (2015). However, even if the national environments differ in numerous ways, several studies have identified the level of educational integration as a factor affecting the educational outcomes of children with disabilities.

Comparative Studies on Educational Inclusion

Several studies have attempted to evaluate the effects of educational integration on children with disabilities by comparing the outcomes obtained in integrated settings with

those obtained in separate special education classrooms. Hattie (2009) presented an extensive meta-analysis of 150 studies with Cohen's $d = .28$, which indicated that inclusive environments demonstrated a small positive effect when compared with segregated settings. Earlier meta-analyses have shown parallel results, pointing out small to medium advantages in favour of mainstream classrooms over segregated education (Baker et al. 1994/1995; Carlberg et al., 1980; Dunn, 1968; Heller, 1982; Wang et al., 1985). The better educational and social outcomes observed in mainstream settings have been attributed to various factors, including higher educational expectations and more advanced role models in mainstream classrooms compared with special education classrooms (National Down Syndrome Society, 2014). However, no controlled studies are available conforming these hypothetical factors.

Individual studies differ with respect to their internal validity or their ability to attribute observed outcomes to the variable of interest—in this case, classroom type. A few experimental studies in the past have favoured mainstream educational placements (Budoff et al., 1976; Calhoun et al., 1977; Österling, 1967). However, experimental studies in which students are randomly distributed into segregated or mainstream classrooms are no longer considered ethically acceptable.

Children with special educational needs differ greatly from each other, which creates a challenge for studies trying to compare the effects of diverse environments on learning. However, the variance associated with individual characteristics can be partly controlled for when similar children are compared. Because Down syndrome is a common cause for special educational needs, several studies have specifically studied children with Down syndrome. A research review by de Graaf et al. (2012) identified 26 studies in which regular and special placed children with Down syndrome were compared across various outcome variables. However, the methodological quality of the studies varied greatly.

The overall results of the review indicated that mainstream placement yielded a better

development of language and academic skills (de Graaf et al., 2012). For self-help skills, no such differences were found, and the results were mixed for social functioning. For behaviours, social networks, and self-competence, at most, small positive differences in favour of mainstream placement were found. The reviewers concluded that mainstream placement in education produced more academic and language attainment for children with Down syndrome. The differences could not be explained only by the selective placement of higher functioning children in mainstream classes (de Graaf et al., 2012). The effect of various modifiers has been controlled for in some studies using statistical methods (Casey et al., 1988; Sloper et al., 1990; Turner et al., 2008). Another approach has been to utilize natural experiments in which school placement is not determined by the children's characteristics but by geographic area (Buckley et al., 2006; Casey, et al. 1988; Laws et al., 2000).

Some examples of the studies reviewed by de Graaf et al. (2012) include four studies from the UK. In the first of them, Casey et al. (1988) compared 18 children with Down syndrome with 18 children educated in special classes over the course of two years. The ages of the children varied from 3 to 10 years. The mainstream children made significantly greater progress in numeracy, language comprehension and Stanford-Binet mental age scores and also compared favourably on all other measures used. The school placement of the children was not determined by the characteristics of the children or their families but by the differences in educational policies in different areas. Moreover, some important background variables were statistically controlled for.

A second study investigated 117 children with Down syndrome aged 6 to 14 with regard to attainment in reading, writing and numeracy skills using checklists completed by their teachers (Sloper et al., 1990). Using multiple regression analysis, a strong positive relationship was found between academic attainment and the integrated placement of the

child.

A third study compared the language and memory development of 22 children with Down syndrome attending a special school matched for age with 22 children with Down syndrome in mainstream education (Laws et al., 2000). The results showed that children in mainstream classrooms achieved significantly higher scores for vocabulary, grammar and digit span measures.

A fourth UK study followed 71 young people with Down syndrome at the ages of 9, 14 and 21 years (Turner et al., 2008). Using path analysis, it was shown that mainstream school attendance had a modest beneficial effect on reading, writing and numeracy skills in every age group.

Two studies published after the appearance of the de Graaf et al. (2012) review give additional support to its conclusions. An Australian study of Couzens et al. (2012) analysed the results of 89 participants with Down syndrome between the ages 4 to 30 years in multilevel models of age-related change. Stanford-Binet subtest scores were used as dependent variables. Students who attended a regular school demonstrated the highest scores across all subtests, providing support for the hypothesis that regular school placement results in higher cognitive outcomes and more rapid development of cognitive abilities. However, the study was not able to separate the effect of different school environments from the selective factors associated with the initial cognitive level of the child and the education of the mothers.

A recent Dutch study represents an extensive investigation of 121 children with Down syndrome of whom 67 were placed in mainstream classrooms and 54 in special education classrooms (de Graaf et al., 2013). Children in mainstream classrooms had higher scores in reading ($d = 0.63$), writing ($d = 0.28$) and mathematics ($d = 0.45$). However, part of the greater attainments in mainstream classrooms was due to selective factors such as cognitive

functioning, parental educational level and the extent to which parents helped the children at home with their studies.

Finland and Italy Compared

Finland and Italy resemble each other in many respects. Both are European welfare states with developed disability services and school systems. In the UN Human Development Index, Finland occupies position 21 and Italy position 25 in the international comparison (United Nations, 2013). The efficacy of the school systems in different countries has been measured by several international comparisons. Finnish 15-year-old school children have performed well in the Programme for International Student Assessment (PISA) organized by the Organisation for Economic Cooperation and Development (OECD), occupying several top or near top places, while the success of Italy has been more modest. For example, in 2012, Finnish children placed 12th, 5th and 6th in math, science and reading, respectively, among 65 countries. Italy placed 32nd, 32nd and 27th, respectively (OECD, 2014).

Children with Down syndrome in Italy start their education in day care centres at the age of 0 to 3. Preschool is for children from 3 to 6. At the age of 6, children enter comprehensive school, which lasts 10 years (Gruppo scuola coordown onlus, 2010). In Finland, children attend day care from the age 0 to 5 or 6. Children with Down syndrome start preschool at the age of 5 and comprehensive school at the age of 7. In both countries, compulsory education terminates at the age of 16.

In Italy, children with Down syndrome enter classes with usually no more than 20 children. They always receive additional support from the special education teacher, called the 'support teacher', a variable number of hours every week. Each support teacher has, at most, four children to supervise, who are all typically in different classrooms (Gruppo scuola coordown onlus, 2010). In Finland, the size of special education classrooms is normally about six children. Besides the special education teachers, the staff consists of one or more teaching

assistants.

The number of weekly school hours is higher in Italy than in Finland. The length of the school week in Finland is 19 hours in the first grade and 30 hours in the final ninth grade. In Italy, school starts at 40 weekly hours, which reduces to 30–36 hours in upper grades.

The educational level of classroom teachers has been higher in Finland than in Italy. In Finland, classroom teachers have a master's degree, which requires five years of study in university. In Italy, this level has been achieved only recently. Special education teachers generally have a higher level of education in Italy, where they are experienced classroom teachers with one additional year of training in special education. In Finland, special education teachers of children with Down syndrome have suitable background qualifications (not necessarily as a teacher), with one year of additional training in special education.

The biggest difference in the school environment for children with Down syndrome between Italy and Finland is the level of school integration. In Italy, all children with Down syndrome have attended mainstream classes since 1977. The Italian school system is thus based on the principle of full inclusion, as confirmed by law 571/1977 (Archivio Pubblica Istruzione, 2014). Finland, on the contrary, has one of the most segregated school systems in the world, with approximately 5% of children placed in special education classrooms for more than 50% of the weekly hours (Statistics Finland, 2014). While in Italy all children with Down syndrome attended mainstream classes since the seventies, in Finland, children with moderate or mild disabilities only attended training schools organized by social service authorities, while children with severe disabilities did not receive any education provided by teachers. In Finland, the education of children with Down syndrome started in comprehensive schools only in 1997, and it has been continually carried out in separate classrooms or special schools.

On the basis of general findings concerning the slight supremacy of inclusive

education over segregated schooling with respect to scholastic achievement (Hattie, 2009), it has been hypothesized that Italian children with disabilities would display higher levels of achievement than students with disabilities from other countries. This hypothesis has received some support from the findings of Vianello et al. (2009). They found that Italian children with genetic syndromes (Down, Fragile-X, Cornelia de Lange and Prader-Willi) displayed greater development, especially in reading and writing, than could be predicted on the basis of intelligence tests. They supposed that the crucial variable might have been the inclusion of almost all pupils with intellectual disabilities in mainstreaming. Based on this study, it was hypothesized that Italian children with Down syndrome would have higher adaptive behaviour scores than Finnish children, at least on academic tasks. However, several other factors, such as various differences in school systems, lifestyle values, family cultures and public services are intertwined in this comparison.

Methods

Participants

The participants of this study were 61 children with Down syndrome: 29 coming from Rome, Italy, and 32 coming from various parts of Finland. Of them, 62% were boys and 38% were girls. All the participants were native citizens of their home countries and all lived with their parents. Initially, the aim was to select only participants between 13 and 15 years of age. Because it was difficult to find participants inside these limits in Finland, the following exceptions were accepted: In the Finnish sample, there were three 16-year-old participants, four 17-year-old participants and one participant who had just turned 18 years old. The final Italian sample contained one 16-year-old participant. The mean age in the Italian sample was 14.7 years, and in the Finnish sample, 15.4 years. In sum, the Finnish participants were somewhat older than the Italian participants, $t = -2.64$ ($df = 47.4$), $P = .011$.

The children's levels of intelligence were measured by asking informants, using the

ICD-10 categories of mild, moderate, severe and profound disabilities. In both countries, the level of intelligence was measured by psychologists, using intelligence tests and ICD-10 classifications. The diagnoses were formally given by physicians. This information was not used in the study because, in the Finnish sample, no association was observed between the scores of adaptive behaviour and the reported level of intellectual disability. This indicated that the information obtained from the Finnish teachers concerning the intelligence was not reliable. The participants did not have any other significant disabilities, except two persons who had heart problems.

Sampling and Data Collection

The data was collected through structured interviews with the teachers working with children with Down syndrome. The Italian sample was obtained from the city of Rome, which has 2.8 million inhabitants. Those selected for the study, included children whose families had participated in activities provided by the Italian Parents' Association of Persons with Down Syndrome (AIPD Roma). The parents were first contacted for permission. Then, the data collection was performed by interviewing the children's teachers. The interviews were performed by the second author. There were no refusals from either the families or the teachers. Those interviewed were special education teachers (75%), class teachers (14%) or educators working with the child in the school (11%).

The Finnish sample was collected from all over the country, which has 5.5 million inhabitants. Special education teachers were contacted through a nationwide in-service training and research project, VETURI, which operates in the entire country. Schools with large numbers of special education students were contacted separately. Moreover, a letter was published on the Finnish Association of the Parents of Children with Intellectual Disability website in order to find families to volunteer. Only one special school refused to participate. The children with Down syndrome in Finland were dispersed across hundreds of local

schools. No systematic bias was observed from this way of collecting participants.

After permission was obtained from the families, the interviews were performed either over the phone or in person. The interviews were performed by four persons, two of whom were authors of this study and two other master students of special education, who were supervised and trained by the authors to perform the interviews. The person interviewed was always a special education teacher. All the families and teachers contacted agreed to participate in the study. During the study, the ethical standards of the National Advisory Board on Research Ethics in Finland (2009) were followed.

Data Collection Instrument

For the data collection, the two scales used in this study were translated from English into Finnish and Italian. In the case of the ABI Scale, we used a ready-made translation in Italian which was commercially available (Brown et al., 2004). First, some background information was collected. Background information on the children with Down syndrome contained the usual demographic data, including questions about their disabilities. Some questions on the schooling and various services used by the children were also asked.

ABI Scale. The level of adaptive behaviour was measured by using, with slight modifications, the Adaptive Behavior Inventory Short Form (ABI-SF) by Brown and Leigh (1986). A short form of 50 items was constructed from the original scale of 150 items by selecting every third item from a list in which the items were ordered according to their observed level of difficulty (Brown et al., 2004). The long form was divided into five parts: self-care skills, communication skills, social skills, academic skills and occupational skills.

For this study, four changes to the original short form were made. The item “Makes long distance telephone calls without assistance” was considered outdated and was replaced with the adjacent next item in the long form, “Arranges own transportation to school”. In a similar way, “Completes a job application” was replaced by “Handles money, makes change

in a responsible manner” because it was considered more age appropriate for the children in this study. Further, “Is aware of other’s perceptions of her/himself” was replaced by “Refrains from inappropriate talking” because this was considered easier to answer, and “Writes a business letter” was replaced by “Performs work requiring at least sixth grade reading ability”, which was thought to be more age appropriate. All these replacements used strictly adjacent items from the original full scale in order not to compromise the reliability and validity of the scale.

The psychometric properties of the original ABI Short Form indicate good or excellent qualities (Brown et al., 2004). Reliability, measured as Cronbach’s alpha, was $\alpha = .93$ for a sample of intellectually disabled children with an age of 13 to 14. Test–retest reliability was $r = .95$. The criterion validity of the scale was confirmed through its high correlations with all domains in the AAMD Adaptive Behavior Scale Part I (Brown et al, 2004, 96). The construct validity of the scale was confirmed through its high correlations with IQ, school success and age (Brown et al, 2004, 97-98). In the present sample, the reliability of the scale was $\alpha = 0.96$.

Problem Behavior Inventory (PBI). In order to measure the challenging behaviour of the participants, we used a modified Finnish version (Saloviita, 2002) of the SIB Problem Behavior Inventory (Bruininks et al., 1985; Bruininks et al., 1986). Modifications consisted, first, of adding one new item: “Hyperactive behaviour”. The items constituting the scale were the following nine: “Hurtful to self”, “Hurtful to others”, “Destructive to property”, “Unusual or repetitive behaviour”, “Withdrawal”, “Hyperactive behaviour”, “Disruptive behaviour”, “Socially offensive behaviour” and “Uncooperative behaviour”. Examples of each type of behaviour were given in the questionnaire.

Second, the measurement of the frequency of challenging behaviour was changed to a scale from 0 to 3. A value of 0 indicated that the behaviour was never observed. A value of 1

was used if the behaviour occurred, at most, three times a month. A value of 2 was selected for the occurrence of behaviour one to six times a week, and a value of 3 for the occurrence of behaviour on a daily basis or at least seven times a week. The sum score was counted across all nine items to indicate the sum total.

Third, the severity of the behaviour was assessed using the scale from 0 to 2. A value of 0 indicated a mild problem or no problem at all; a value of 1 was scored for behaviour that was harmful or disturbing, and a value of 2 was used if the behaviour posed a danger for the health of the person or others, or if it was life-threatening to the person or others. The sum total was counted across all nine items.

According to Saloviita (2002), the inter-rater agreement of the modified PBI was $r = 0.72$, the test-retest reliability was $r = 0.84$ and the equivalence was $r = 0.67$ when the scale was compared with the ABS Part Two (Nihira et al, 1974). His version, however, contained an additional item, "Sleep disturbance", which we removed from the present study because many of the respondents were not able to evaluate it. The reliability of the PBI as counted from the present data was $\alpha = 0.78$.

Results

The comparison of adaptive behaviour and challenging behaviour between the Italian and Finnish samples is presented in Table 1. The samples did not differ from each other, as confirmed by t-tests. Ten items from the original 30-item ABI academic skills scale were included in the short form. Similarly, there were no differences found between countries in this 10-item scale. Because age correlates with adaptive behaviour and the Italian and Finnish samples differed by age, the result was controlled by analysing covariance with age in days as a covariate. The difference between sample means in the ABI scores was not statistically significant, even in this case, $F(1) = .232$, $P = .632$. It was also observed that age measured in days did not have a significant correlation with adaptive behaviour ($r = .083$) or challenging

behaviour ($r = -.250$).

Because the level of both adaptive behaviour (Brown et al., 2004, 102; Saloviita, 1990) and challenging behaviour correlates with the level of intellectual disability (Saloviita, 1990), the sample distributions were compared using this dimension. In the Italian sample, the level of intellectual disability varied from mild (21%) to moderate (31%) and severe (48%) disabilities. In the Finnish sample, the corresponding percentages were 25%, 63% and 13%, respectively, indicating a lower portion of children with severe disabilities compared with Italy and an overall result indicating statistically significant difference in distributions, $X^2 = 9.89(2)$, $P = .007$. In the Italian sample, the three levels of intellectual disabilities differed from each other with respect to ABI scores in the Kruskal-Wallis test, $X^2(2) = 17.39$, $P = .000$. In contrast, this test was not significant in the Finnish sample, $X^2(2) = 2.89$, $P = .235$. This finding will be discussed later.

Over the prior six months, speech therapy was received more often by the Italian sample than the Finnish sample. The same was true of physiotherapy (see Table 1). Between the countries, while there were no differences in the number of non-disabled friends, the Italian children were reported to have more disabled friends outside of school. The percentage of children without any friends with whom they contacted outside of school hours was, in the Finnish sample, 34% and, in the Italian sample, 14%.

The major difference between Italian and Finnish children was their schooling history. In the Italian sample, 100% of the participants' school years were spent in mainstream classes, while this number in the Finnish sample was 8%. The Finnish children with Down syndrome were typically taught in self-contained special education classrooms.

The informants were asked if they were satisfied with the way the teaching of the children was organized. Of the Finnish informants, 84% agreed or fully agreed, while only 19% of the Italian informants agreed or fully agreed with this statement. The informants were also

asked what kind of changes they hoped to see in the way the children were taught. Eight alternatives were given. The results are presented in Table 2.

Discussion

No differences were observed in the adaptive behaviour or challenging behaviour between Finnish and Italian children with Down syndrome. Neither were there any differences in academic skills or the severity of the challenging behaviour. However, the sample sizes were low and the standard deviations in these measures were high. Therefore, firm conclusions could not be made. High standard deviations also probably explain why no positive correlation was found between the age and adaptive behaviour of the children. This was in contrast to previous knowledge concerning their relationship (e.g., Turner & Alborz, 2003).

Despite the shared diagnosis, the children with Down syndrome are not a homogenous group because their level of intellectual disability varies considerably. In a recent Finnish total population study, it was observed that the intellectual level of people with Down syndrome was dispersed between mild (19%), moderate (30%), severe (33%) and profound (18%) levels (Määttä et al, 2006). In order to control for this effect, a much larger sample would have been needed in the present study. Controlling the level of intellectual disability was not considered possible because no association was observed between the adaptive behaviour scores and the level of intellectual disability in the Finnish sample, indicating the information's lack of reliability concerning the level of disability.

The comparison between countries confirmed that inclusive education of children with Down syndrome was the norm in the Italian sample, while in Finland, the inclusion of a child with Down syndrome in a mainstream classroom was exceptional. In the Italian sample, the participants had more frequently received speech therapy and physiotherapy than the Finnish sample. The children from the Italian sample had more friends than in the Finnish sample, but

in both countries, several participants had no friends at all outside the school environment. The relative lack of friends among people with Down syndrome was also confirmed in a total population study from the city of Rome (Bertoli, et al., 2011).

There were differences in satisfaction between the Finnish and Italian informants concerning the organization of the children's education. While the general level of satisfaction was high among Finnish special education teachers, the Italian informants, comprising of special education teachers, classroom teachers and educators, expressed several unfulfilled needs (see Table 2). These differences may indicate the divergences in the financing and resources of the school systems in both countries. The only wish that the Finnish teachers presented more often than their Italian colleagues was the wish to move the children from their classroom to some other classroom. This may reflect the Finnish situation in which the placement of a child with educational problems may awaken a tug-of-war between teachers. In Italy, the placement of the child seems not to be an issue for discussion.

A limitation of this study is the small sample size. It was relatively easy to collect 29 cases from the city of Rome through the database of the Down Syndrome Association. In Finland, similar databases were not available. Between the years 1998–2007, an average of 75 children with Down syndrome were born every year in Finland (Official Statistics of Finland, 2014). On the basis of this number, we succeeded in contacting no more than 10% of the Finnish children (13–15 years old) with Down syndrome. Despite the low number, no systematic selection bias was observed. The participants were obtained randomly from the numerous Finnish basic education mainstream schools and from the few existing special education schools. Because of the small sample sizes and the unreliable information from Finland concerning the level of disability, it was impossible to match the samples to make them more similar with each other on the basis of IQ or some other variable.

The results of this study highlight some differences in the services provided to children

with Down syndrome in the two countries. While the Italian teachers felt that there were more shortages in the services, their commitment to the inclusive placement of the child was not compromised. This can be concluded from the observation that no Italian teacher wished to remove any of the children from their classes. The Italian teachers' commitment to inclusive education has been observed in previous research as well (Cornoldi et al., 1998). Because of the heterogeneity of the samples, no conclusions can be made on the possible differences in the adaptive behaviour of the children in the compared countries. Thus, any conclusions concerning the possible effects of inclusive education cannot be presented. Future studies would need larger sample sizes to judge whether any differences exist in behavioural outcomes between the countries.

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Table 1

Comparison of adaptive and challenging behaviour among children with Down syndrome in Italy and Finland

	N	Mean	SD	<i>t</i>	df	<i>p</i>
Adaptive behaviour (ABI)						
Finland	32	70.8	30.0	.257	59	.798
Italy	29	72.8	31.2			
ABI Academic skills						
Finland	32	12.72	7.2	.343	59	.733
Italy	29	13.38	7.8			
Challenging behaviour						
Finland	32	5.2	4.5	.607	59	.546
Italy	29	5.8	4.1			
Severity of challenging behaviour						
Finland	32	1.3	1.8	1.398	59	.167
Italy	29	2.0	2.0			

Table 2

Comparison of some variables between children with Down syndrome in Italy and Finland

	N	Yes %	No %	Sum %	X2	df	<i>p</i>
Speech therapy							
Finland	32	28	72	100	6.26	2	.044*
Italy	29	38	62	100			
Physiotherapy							
Finland	32	6	94	100	8.79	2	.012*
Italy	29	17	83	100			
Friends with disabilities							
Finland	32	53	47	100	4.62	1	.032*
Italy	29	79	21	100			
Friends without disabilities							
Finland	32	38	62	100	.338	1	.561
Italy	29	45	55	100			

Table 3

Informants' answers to the question "What kind of changes would you like to see in the organization of the child's education?"

	Item	Agree or fully agree %	
		Italy (N = 29)	Finland (N = 32)
1.	More help from the special education teacher	69	7
2.	More help from the classroom assistant	59	27
3.	More help from the classroom teacher	48	3
4.	More planning time	48	7
5.	More help from the therapists or psychologists	45	10
6.	Smaller classroom size	31	7
7.	More support from the families	24	7
8.	Removal of the child to some other classroom	0	23