

Inclusive practice for students with neurodevelopmental disorders in Sweden

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Abstract

'Inclusion' aims to achieve adaptation of the environment to the diverse prerequisites and needs of individuals, instead of demanding of individuals to cope with the challenges of a given context themselves exclusively. All Scandinavian countries have made formal decisions to enhance inclusive practice for children and adolescents with disabilities in educational settings, seeking to implement international conventions. We investigated current inclusive practice for students with neurodevelopmental disorders (NDDs) in Swedish primary, secondary and high-schools using the 61-item INCLUSIO scale among N=4778 school staff with educational responsibilities in 68 public and private schools across 11 municipalities. Overall, school staff reported not to be well prepared to teach students with NDDs and that their school's implementation of concrete inclusive practice was limited. Findings indicate a gap between inclusive educational ambitions and current practice for students with NDDs. Enriched teacher education and supervision for NDDs, a shift in pedagogical views of NDDs and better collaboration between community services, as well as systematic evidence-based implementation plans driven by policy makers and educational authorities may help improve inclusive practice.

Keywords: inclusion; school; education; autism; ADHD; neurodevelopmental disorders

Introduction

Neurodevelopmental Disorders (NDDs) arise from alterations of the maturation, architecture or functioning of the developing brain. In DSM-5, NDDs comprise attention-deficit hyperactivity disorder (ADHD), autism spectrum disorder (ASD), communication disorders, specific learning disorder, motor disorders and intellectual disability. NDDs are common with an estimated prevalence of 16.2% to 17.8% (1). Child and adolescent psychiatry has a pivotal role in the clinical assessment and treatment of NDDs. However, as NDDs are currently incurable, not necessarily pathological, but often cause lifelong challenges, they are a societal responsibility and a multimodal approach to NDDs is recommended with players in diverse arenas of society being decisive for individual outcomes (2, 3).

This is particularly true for educational settings, where scholastic failure, exclusion and absenteeism is a widespread concern (4-6).

A pivotal concept to achieve equity of opportunities and better outcomes for children and adolescents with NDDs in school is educational *inclusion*. It aims to achieve adaptation of the environment to the diverse prerequisites and needs of individuals, instead of demanding of individuals to cope with the challenges of a given context themselves exclusively (7). While many countries have transformed from a perspective that children with NDDs cannot be educated adequately in regular schools and require special school settings to that almost all children with NDDs should be able to succeed in mainstream schools, simply placing children with disabilities in regular classrooms is not

inclusion and potentially harmful. Instead, inclusion means to establish a rich, accessible learning environment that is adapted to all pupils' prerequisites (8). Scandinavian countries have in recent years taken political decisions towards implementing inclusion of youth with NDDs in education (9), seeking to operationalize the United Nations convention on the rights of persons with disabilities and the Salamanca Statement and Framework for Action on Special Needs Education, a document signed by 92 nations, aiming to lead the progress towards inclusive education.^{1,2}

The concept of inclusion is viewed somewhat differently depending on history, social factors and culture (10). For example, while a recent study showed that in France inclusion of autistic children and adolescents in regular classes depended on the presence of challenging behaviors, sensory processing, anxiety, adaptive and cognitive deficits (11), in Sweden, by school law, only pupils with intellectual disabilities can be excluded from mainstream schools. Inclusion is typically seen as education provided as a part of mainstream education that is put into practice by regular school staff, possibly supervised by specialists (12). It is also viewed as an approach that should focus on improving the learning environment, routines, procedures, pedagogy, staff behaviors and attitudes, not manipulating students, which would follow the concept of "integration". However, the literature on specific inclusive educational actions is rather scarce (13), and what inclusion should entail in practice for teachers and other school staff is often not specified and followed-up, or a matter of debate (14). Therefore, it is largely unknown, if and which concrete actions are currently implemented in mainstream schools by staff which could be subsumed as inclusive, although it has been hypothesized that inclusive practice remains poor for students with NDDs (15). The same is true for the status-quo of inclusion in educational settings in Scandinavian countries (16).³

Therefore, the purpose of this study was to examine inclusive education practice for students with NDDs in Swedish schools, where the Swedish School Act that came into effect 2011 strictly reinforces inclusion by highlighting the rights of all students to receive a safe, supportive and motivating education that is characterized by individualization, inspiration and curiosity of learning and development of skills⁴.

Methods

Sample

N=4778 school staff (76% female) aged between 19 and 77 years (M= 46.0) with an average of 16 years in service participated in the study between February 2015 and June 2016. School staff consisted of principals/leaders, primary/secondary and high-school teachers, special educators, special education teachers, youth workers, personal assistants, and school health team members (Table 1), with about 60% of the participants working as regular teachers in primary, secondary or high school. The staff worked at 64 public and four private schools in six Region Stockholm municipalities ($n = 3870$), and the municipalities (Hudiksvall, Lerum, Mora, Strängnäs, Sundsvall, Östersund) in other central and northern regions of Sweden ($n = 908$). The size of the schools varied between ~90 and ~1200 students. Within a collaboration between the Center of Neurodevelopmental Disorders at Karolinska Institutet (KIND) and the City of Stockholm, staff at schools in Stockholm municipalities had been obliged to take part in the study as part of the city's effort to inventorize inclusive practice at its schools. Other schools were recruited by snowball sampling after respective principals had expressed interest to participate and receive data on their individual school's inclusive practice.

Measure

School staff completed the INCLUSIO questionnaire (17), composed of 61 Likert-scaled items on inclusion plus background items on prior NDD education, to map how schools work actively and systematically towards inclusion of students with NDDs. The questionnaire is a face and content valid scale, derived from long-term experience of KIND clinicians working with schools in Sweden on educational inclusion and avoidance of school absenteeism and based on a Delphi process and several revisions following piloting in collaborating schools. In the current sample, INCLUSIO had a Cronbach's alpha of $r_\alpha = .87$; its subscales had internal consistencies of $r_\alpha = .70-.89$. INCLUSIO usually requires 25 minutes to fill-in and inquires about: being prepared to conduct inclusive practice/previous education in NDD inclusive praxis (background items), and eight subscales: *Assessment of support needs* (7 items), *Use of individualized support* (10 items), *Implementation of a structured learning environment* (8 items), *Individual changes applied to schedule/teaching* (7 items), *Functional response to behavioral characteristics* (6 items), *Cooperation with parents* (6 items), *Consideration of*

¹ <https://www.european-agency.org/sites/default/files/salamanca-statement-and-framework.pdf>

² <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

³ https://www.autism.se/rfa/uploads/nedladningsbara%20filer/skolenkat_autismforbundet_2018.pdf

⁴ http://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/skollag-2010800_sfs-2010-800

peer-relations (8 items), and *Staff education/professionalism* (9 items). Items can be responded to with “yes” (indicating inclusive practice), “rather yes” (indicating moderate inclusive practice), “rather no” (indicating doubtful inclusive practice), “no” (indicating no inclusive practice), and “don’t know” (indicating no knowledge of inclusive practice). While items are directed to include all NDDs, it is important to note that in Swedish school context NDD is nowadays predominantly understood as a label summarizing ADHD and ASD, which also form by far the largest subgroup of NDDs diagnosed in Sweden (18). INCLUSIO is conceptualized as a criterion-based instrument, expecting that in case of “good enough” inclusive practice, a large majority of items are responded to with “yes”. The INCLUSIO questionnaire was completed online and

anonymously following informed consent and in collaboration with municipality and school authorities.

Analyses

Descriptive statistics (%) for all 61 INCLUSIO item response frequencies (yes, rather yes, rather no, no, don’t know) and medians (Md) and ranges (%) for its subscales are provided for the whole sample. In addition, χ^2 inference statistics were run on descriptive response differences for each item to examine Bonferroni corrected (5%/63) statistical significance levels applying an alpha of .00079. Differences in reply patterns between types of school staff are reported, too, if statistically significant.

TABLE 1. School staff characteristics

Professions	All	Women	Men	Age	Years working in school
	4778	3650	1128		
	N (%)	n (%)	n (%)	Mean (SD)	Mean (SD)
Primary school teacher	1646 (34.4)	1393 (29.2)	253 (5.2)	44.4 (11.0)	15.3 (10.6)
Secondary school teacher	1219 (25.5)	839 (17.6)	380 (7.9)	46.3 (10.3)	16.7 (9.8)
High school teacher	19 (0.4)	11 (0.2)	8 (0.2)	45.1 (10.7)	14.0 (8.6)
Principal/school leaders	202 (4.2)	142 (3.0)	60 (1.2)	51.0 (8.5)	23.0 (9.3)
Special educator	204 (4.3)	190 (4.0)	14 (0.3)	53.3 (8.4)	23.1 (10.3)
Special education teacher	174 (3.6)	151 (3.2)	23 (0.4)	51.9 (9.9)	23.8 (11.5)
Youth worker	527 (11.0)	344 (7.2)	183 (3.8)	43.0 (11.9)	15.0 (10.9)
Personal assistant	199 (4.2)	108 (2.3)	91 (1.9)	39.9 (13.6)	10.4 (9.2)
School health team	161 (3.4)	138 (2.9)	23 (0.5)	48.7 (10.5)	12.4 (8.3)
Other/not specified	435 (9.0)	334 (7.0)	93 (2.0)	47.8 (11.8)	16.8 (11.1)

Results

Overall, 5.8% replied “yes” to the background item asking staff if their education had sufficiently prepared them for teaching students with NDDs; 13.5% replied “rather yes”, 36.9% “rather no”, 32.3% “no” and “8.4% “don’t know” ($p < .0001$). Responses varied for different professionals. “Yes” responses were highest for members of the school health team (nurses, social workers, psychologists, physicians) with 19.9% and lowest for primary/secondary school teachers with 3.4% (n.s.). In the whole sample, 14.2% indicated that they had received complementary education with focus on NDDs, and 82.3% that they had not ($p < .00001$). This figure was highest for special education teachers (53%) and lowest for primary/secondary school teachers (5%) ($p < .0001$). Regarding the subscale ‘Assessment of support needs’, the percentages of “yes” answers/item varied between 24.6 and 47.8% (Md = 29.7%). These values were 10.9 to 47.4% (Md

= 16.1%) for ‘Use of individualized support’; 15.5 to 50.5% (Md = 30.8%) for ‘Implementation of a structured learning environment’; 16.2 to 37.1% (Md = 27.6) for ‘Individual changes applied to schedule/teaching’; 15.1 to 47.1% (Md = 22.6%) for ‘Functional response to behavioral characteristics’; 31.4 to 46.6% (Md = 42.7%) for ‘Cooperation with parents’, 3.4 to 47.1% (Md = 26.6 %) for ‘Consideration of peer relations’, and 8.9 to 65.9% (Md = 24.0 %) for ‘Staff education/professionalism’ (see Table 2 for a summary of findings). Principals/school leaders responded more positively than other professionals on the subscales ‘Assessment of support needs’, ‘Cooperation with parents’, and ‘Staff education/professionalism’ ($p < .0003$), while high-school teachers typically gave the least positive answers for ‘Functional response to behavioral characteristics’, ‘Cooperation with parents’, and ‘Staff education/professionalism’ ($p < .0002$).

TABLE 2. INCLUSIO results by subscale/item in % in the whole sample (N=4778)

Subscale/item^a	Yes	Rather yes	Rather no	No	Don't know
Assessment of support needs					
Support plans are followed-up and evaluated*	31.5	41.0	14.5	2.6	10.4
There is a specific and accessible support plan document*	37.7	36.8	12.1	3.1	10.3
Staff involved in support plans meet regularly*	24.6	37.2	20.8	6.3	11.1
It is clear who is responsible for the student's support plan*	28.0	37.6	18.8	7.1	8.5
School applies formal assessments of NDD ^b -difficulties ^c *	29.7	33.1	10.2	4.1	22.9
In case NDD suspicion, the school health team refers to clinical services*	47.8	34.7	5.9	1.8	9.8
Recommendations from clinical services are used for support planning*	27.9	41.1	9.3	2.3	19.4
Use of individualized support					
Transitions are prepared for with student's participation*	16.1	30.2	15.5	5.2	33.0
Transitions are prepared for individually and specifically*	24.8	35.1	13.3	3.3	23.5
When a student with NDD starts in the school, prerequisites for adequate support are evaluated*	12.1	25.4	20.6	12.3	29.6
Everyday individual adaptations in the classroom and schedule are provided*	27.0	45.7	15.8	3.6	7.9
Support from of personal assistants/supervisors is provided	10.9	29.9	26.7	13.8	18.7
Students receive the individual special education support needed ^d	18.3	38.9	24.7	12.8	5.3
Teachers that fit the student are selected for teaching*	10.7	27.7	19.5	29.1	13.0
School rules are adapted to student's needs ^d *	37.2	35.3	14.7	4.3	8.5
Students are offered alternative options to demonstrate knowledge ^e *	47.4	33.8	5.7	1.1	12.0
School offers certain case management ^f *	14.2	26.7	19.3	8.4	31.4
Implementation of a structured learning environment					
Rules are communicated clearly so that student with NDD understands	41.2	42.1	6.3	1.2	9.2
Routines are an essential part of teaching	50.5	39.3	5.4	1.0	3.8
Clarity and repetition are used in the communication with NDD students	33.9	47.5	7.3	1.9	9.4
Changes to procedures are communicated to NDD student as early as possible	30.5	44.4	10.3	2.3	12.5
School has distraction-free work stations	15.8	25.9	32.7	18.8	6.8
Instructions are short, concrete and stepwise	30.8	49.0	9.9	1.9	8.4
Students are offered organizational aids ^g	25.7	43.6	13.2	3.3	14.2
School uses visualization of schedules and time ^h	37.3	42.1	10.2	2.9	7.5
Individual changes applied to schedule/teaching					
Individual support is integrated into whole class teaching*	24.1	43.1	12.4	3.8	16.6
Strategies for handling stressful situations are provided*	16.2	40.3	19.7	3.7	20.1
Students' interests are integrated in teaching*	17.1	38.8	21.9	4.0	18.2
Development of students' communication skills in individual and group context*	31.3	39.9	10.0	2.7	16.1
Development of language/communication is always part of the support for students with NDD*	27.6	41.1	11.5	2.8	17.0
Training of students' social skills in individual and group context*	37.1	36.9	9.8	3.7	12.5
Training of social signals and rules are part of the support for the NDD student*	29.5	39.5	14.1	3.3	13.6
Functional response to behavioral characteristics					
Staffs get time to discuss NDD student's behavior and support plans*	22.1	36.4	24.9	8.1	8.5
NDDs student's needs are known even outside of the classroom, in the rest of the school ⁱ *	18.5	33.9	22.3	7.5	17,8
School offers space for rest and withdrawal*	24.5	35.5	23.3	8.8	7.9
There are individual crisis plans for challenging situations*	15.1	29.2	22.3	13.2	20.2
Staff discusses how to avoid minor signs of difficulties*	47.1	1.9	39.8	5.4	5.8
Self-regulation techniques, such as reward systems are used in the work with the student*	22.6	37.5	17.3	5.6	17.0
Cooperation with parents					
There is mutual exchange of knowledge about the student with NDD between home and school ^j *	38.9	40.4	6.1	1.1	13.5
School uses caregiver's knowledge to optimize support*	43.1	36.9	5.4	0.6	14.0
Caregivers have access to a specific responsible contact person*	45.6	28.1	6.1	2.9	17.3
There are regular exchanges between caregivers are responsible staff around the student with NDD*	46.4	35.6	5.9	2.2	9.9
Decisions taken around the student are taken together by parents and school*	42.7	37.5	4.4	0.3	15.1
Parents are viewed as experts of their child*	31.4	38.2	9.8	2.5	18.1
Consideration of peer-relations					
The school applies programs to develop peer relations	14.8	28.5	22.9	15.4	18.4
NDD students are prepared for unstructured social situations*	26.6	40.2	15.5	4.0	13.7
In case of group-work, the composition of the group takes into account knowledge of the student with NDD*	43.7	36.3	5.1	2.9	12.0
Peers are involved in the social support development for students with NDD*	16.2	31.2	20.5	12.5	19.6
There are selected peers who students with NDD can refer to for help/advice (e.g. mentor systems)*	3.4	8.0	24.1	46.2	18.3
Peers who regularly interact with NDD students are aware of their needs*	29.0	46.2	10.3	1.5	13.0

(table continues)

The student with NDD is viewed an individual with strengths and weaknesses, not merely problems*	46.9	37.1	9.5	0.9	6.5
Students at the school are used to handle diversity*	47.0	41.4	8.0	0.8	2.8
<i>Staff education/professionalism</i>					
A support oriented view for students with NDDs is natural in our school*	42.1	36.3	11.5	4.0	6.1
Staff understands that individualized support might be necessary for a given student with NDD*	65.9	25.2	4.0	1.4	3.5
There is regular exchange with external NDD experts*	17.4	29.0	20.2	10.1	23.3
School can provide information about support and treatment of NDDs outside of the school*	8.9	17.0	16.9	15.5	41.7
Responsibilities around the support of NDD students are clear among the personnel*	19.4	37.8	20.9	7.9	14.0
Based on the planned support for NDD students there is regular exchange with other involved professionals*	18.1	32.0	16.9	5.5	27.5
The school staff has basic knowledge of NDDs*	24.0	42.3	13.9	3.5	16.3
Various school staff has advanced knowledge of NDDs*	28.1	31.5	16.1	4.3	20.0
A special education view and related support means are part of the school philosophy for NDD students*	28.3	41.7	16.1	3.9	10.0

Note. *significant differences between item response frequencies ($p < .00079$); ^aItems are translated from Swedish and shortened for reader's ease and summary presentation; ^bNDD = Neurodevelopmental Disorder; ^cReading/spelling tests, Psychoeducational Profile; ^de.g., can spend breaks in classroom; ^ee.g., allowed to present orally instead of in written form, or vice versa; ^fe.g., helps with support outside of school; ^ge.g., provide time-timers, visualized schemes; ^he.g., checklists, planning aids; ⁱe.g., sensory overload reaction in crowded/noisy places, such as canteen.

Discussion

While inclusion of students with NDDs in school is an explicit goal of Scandinavian educational authorities and policies (9), its contemporary concrete implementation in mainstream school practice is basically unknown. It has been argued that “true” inclusion of pupils with ASD, ADHD and other NDDs, which is adaptation of the learning environment to their needs beyond just placing them in regular schools, is still far from being a reality (15). Unfortunately, our data investigating actions taken that are consistent with inclusion or a prerequisite for inclusion in a large sample of school staff in Sweden are mostly consistent with this claim. Generally, school staff reported that they were not well educated to teach students with NDDs and that their own actions or their schools implementation of inclusive practice was limited. Especially regular teachers, being the largest group of respondents and at the same time working most closely with students, reported restricted skills and inclusive practice applied. The largest gaps were observed for the absence of mentor systems, and information of and the coordination with outside school services. There was also a substantial minority of “don't know” answers, indicating a lack of communication or orientation about inclusive practice strategies. As the survey collected data from the perspective of service providers (school staff) not receivers (students, caregivers), we hypothesize that the current results are rather optimistic, and voices of parents and students themselves might have led to a different, perhaps even less encouraging pattern of results. Findings may also vary depending on the

operationalization of inclusion, of which possibly a multitude are legitimate owing to the shortage of a widely agreed-on definition in practice (16). We used INCLUSIO, a questionnaire derived from development and supervision of school staff performed by NDD clinicians, not a genuine educational or teaching perspective. Our data are not brand-new, and despite public service routines usually being slow in introducing change, some dimensions of inclusion assessed in our study (e.g. staff education/professionalism) might have improved to the better meanwhile.

In order to achieve implementation of inclusion in education, we presume that several actions are recommendable. First, evidence-based education of NDDs, both basic science and applied practice, should be included in teacher and other school staffs' mandatory education. Recently, the Swedish government has launched an educational bill that makes five full-time weeks NDD education mandatory for school teachers during their university education, which will hopefully serve this recommendation⁵. However, the contents, quality and effect of such teacher upskilling efforts needs to be followed-up and completed by hands-on supervision on the spot in classrooms on case-basis. Second, anti-psychiatry or anti-diagnoses attitudes may still be strong in some parts of university education in Scandinavia, why a paradigm-shift at pedagogical faculties is required, accepting NDDs both as existing entities and as an own research and education responsibility. Currently, a lack of adequate NDD awareness and knowledge in schools is still hampering fruitful collaboration between

⁵ <https://www.regeringen.se/rattsliga-dokument/departementsserien-och-promemorior/2020/01/okad-kompetens-om-neuropsykiatriska-svarigheter-och-sex-och-samlevnad-i-lararutbildningarna/>

education, health care on other services as pointed out previously by the Swedish National Audit Office and the Swedish School Inspectorate^{6,7}. Third, politically endorsed and resourced scientifically-based implementation plans in order to bring the notion of inclusion from an abstract and ideological level to a actionable and pragmatic level. For the time being, it appears that commonly systematic inclusive actions in schools beyond placement of children and adolescent in mainstream school remain the exception, not the rule. Recently, in Sweden, political initiatives have been initiated that might also affect positively students with NDDs, especially those with learning disabilities, such as the so called “reading, writing and basic math guarantee”⁸. Still, they are largely driven by the idea of reaching educational targets, not inclusion.

In summary, to the best of our knowledge, we have for the first time and on a micro action level of inclusive practice shown that the majority of different school staff professionals in Sweden experience a great deal of potential to improve inclusive practice, as operationalized by the INCLUSIO questionnaire. The authors are not aware of any comparable study from Scandinavia or internationally examining inclusion implementation in NDDs in a comparable manner. We suggest several mostly top-down policy actions on state and municipality level to adequately address and develop mainstream school inclusion culture for this group. We think that for all of the proposed actions, child and adolescent psychiatric expertise and liaison will be important (19).

Conflict of interest/competing interests

The authors declare no direct conflict of interest related to this article. Sven Bölte discloses that he has in the last 3 years acted as an author, consultant or lecturer for Medice and Roche. He receives royalties for textbooks and diagnostic tools from Hogrefe, Kohlhammer and UTB.

Funding

No specific funding source to declare.

Ethics approval

Data collection was part of the municipalities' organizational evaluation. Participants provided informed consent, but data collection from the author's side was fully anonymous and did not include sensitive personal information, not necessarily requiring ethical approval according to Swedish law.

Acknowledgements

We thank all involved municipalities, schools and school staff for their participation. In addition, we acknowledge Frida Bartonek and Martin Hammar for their support in data collection and analyses.

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⁶ <https://www.riksrevisionen.se/en/audit-reports/audit-reports/2011/coordination-of-aid-for-children-and-young-people-with-functional-impairments.html>

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