# School refusal behaviour in students with autism spectrum disorder.

An exploratory study of frequency and associated factors.

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CONTENT

**Abbreviations**

| | |
|---|---|
| ADHD | Attention Deficit Hyperactivity Disorder |
| ASD | Autism Spectrum Disorder |
| ASEBA | Achenbach System of Empirically Based Assessment |
| BRIEF | Behavior Rating Inventory of Executive Functions |
| BRI | Behavioral Regulation Index |
| CBCL | Child Behavior Check List |
| DSM-IV | The Diagnostic and Statistical Manual of the American Psychiatric Association, Fourth edition |
| DSM-5 | The Diagnostic and Statistical Manual of the American Psychiatric Association, Fifth edition |
| e.g. | for example |
| GEC | Global Executive Composite |
| ICD-10 | The International Classification of Disorders, 10th edition, World Health Organization |
| ICD-11 | The International Classification of Disorders, 11th edition, World Health Organization |
| i.e. | that is |
| IQ | Intelligence Quotient |
| MI | Metacognition Index |
| PDD | Pervasive Developmental Disorder |
| PDD-NOS | Pervasive Developmental Disorder- Not Otherwise Specified |
| SMT | Social Motivation Theory |
| SRS | Social Responsiveness Scale |
| SRB | School Refusal Behaviour |
| TD | Typically Developing |
| TRF | Teacher`s Report Form |
| UN | United Nations |

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**Summary**

School refusal behaviour (SRB) in students with Autism Spectrum Disorder (ASD) is a serious condition as reported by parents, clinicians and teachers, but scarcely elucidated by research. In recent years, there has been an increasing number of papers concerning SRB in clinical and in general child and adolescent populations. However, the relevance of these findings as applied to students with ASD remains unknown. The overall aim for this study was to advance the understanding regarding SRB in students with ASD without intellectual disability who attend inclusive primary and secondary schools.

In a population of 78 students with ASD without intellectual disability and 127 typically developing (TD) students aged 9 – 16 years who attended inclusive schools, we assessed the frequency, duration and expression of SRB in a period of 20 school days. Socio-demographic variables were assessed in the students with ASD. A questionnaire comprised six categories: 0) attendance, 1) pleas for not attending school, 2) misbehaviour in the morning to avoid school, 3) tardiness followed by attendance, 4) pleas to not attend classes during the day, 5) did not attend classes, or 6) did not attend school. The questionnaire answered by teachers showed that 42.6% of the students with ASD and 7.1% of the TD students displayed one or more days with SRB. Furthermore, 58.6% of the students with ASD displayed SRB in 20% or more of the assessment period. Parent reports revealed SRB in 53.2% of the students with ASD. No significant difference was found in the frequency of SRB between primary and secondary school students. However, students in primary school displayed SRB mainly as physical or verbal refusal (84.6%) compared to 35% of secondary school students. Parents of students with ASD answered a socio-demographic questionnaire, showing the association between illness in family members and SRB in the child.

In a sample of 62 students with ASD with (33) and without (29) SRB, we assessed social and executive functioning, and emotional and behavioural problems. We utilized the parent

rated questionnaires Social Responsiveness Scale (SRS), Behavior Rating Inventory of Executive Functions (BRIEF) and the Child Behavior Check List (CBCL). The findings demonstrated overall higher rates of social and executive deficits and emotional problems in students with ASD and SRB. Furthermore, associations between SRB and the subscales Social motivation (SRS), Initiate (BRIEF) and the Depressed/Withdrawn (CBCL) were identified.

Thirty-five pairs of parents and teachers of students with ASD with (17) and without (18) SRB answered questionnaires regarding teachers' competence in ASD, school – home collaboration, and emotional and behavioural problems reported on the CBCL and the Teacher`s Report Form (TRF). The parents tended to rate teachers' competence in ASD and school-home collaboration less satisfactorily than the teachers, and the discrepancy increased when the student displayed SRB. However, a significant modifying effect of SRB was found on the agreement between parents and teachers on the subscales Depressed/Withdrawn, Thought problems and Aggressive behaviour (CBCL and TRF).

The high rates of SRB in this study emphasize the importance of awareness of SRB in students with ASD among clinicians, teachers and parents. The findings are in line with studies conducted in the general child and adolescent population, and indicate that general recommendations for assessment and treatment could be relevant for students with ASD. However, an assessment of executive functioning and a more thorough assessment of social functioning should be given to students with ASD. Furthermore, the limited competence in ASD in more than half of the teachers, and less satisfaction with school – home collaboration, in addition to the high level of burden on the parents because of illness in the family, calls for clinicians to support teachers and parents in the assessment and treatment phases.

**List of papers**

Munkhaugen, E. K., Gjevik, E., Pripp, A. H., Sponheim, E., & Diseth, T. H. (2017). School refusal behaviour: Are children and adolescents with autism spectrum disorder at a higher risk? *Research in Autism Spectrum Disorders*, *41*, 31-38. DOI: 10.1016/j.rasd.2017.07.001

Munkhaugen, E. K., Torske, T., Gjevik, E., Nærland, T., Pripp, A. H., & Diseth, T. H. (2017). Individual characteristics of students with autism spectrum disorders and school refusal behavior. *Autism*, 1362361317748619. DOI: 10.1177/1362361317748619 https://doi.org/10.1177/136236131774861

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# 1. INTRODUCTION

## 1.1 School refusal behaviour

### 1.1.1 *History and definitions*

School refusal behaviour (SRB) is defined as child-motivated refusal to attend school or a child having difficulties remaining in classes for an entire day (1). SRB was first described as truancy characterized as a form of delinquency displayed by students who show a wilful and illegal absenteeism from school without their parents' knowledge (2, 3). Child psychiatric disorders such as oppositional defiant disorder and conduct disorder were frequently reported in students with truancy behaviour (4-6). However, these characteristics did not cover the students with anxiety-related refusal to attend school, as first reported by Broadwin (7). These

students want to go to school but are not able to do so, and the absenteeism is known of by the parents (8). They often display symptoms of anxiety, depression and psychosomatic complaints (4, 5, 8). This group of students is often referred to as students with anxious school refusal, school phobia or separation anxiety. Commonly, anxious school refusal, school phobia and truancy were perceived as conditions best understood separately concerning both individual characteristics and interventions (4-6). However, in some cases students display a range of emotional and behavioural problems associated with both anxious school refusal and truancy; these are referred to as mixed school refusers (4). Although psychiatric diagnoses are commonly linked to these conditions, they are not synonymous with them, and a proportion of students with SRB do not meet the criteria for any psychiatric diagnosis (4, 9, 10).

Introducing SRB as a term that covers both students with anxiety-based school refusal and truancy behaviour represented a shift in the taxonomy of the phenomenon (1). SRB

> *'includes youth aged 5 – 17 years who, to a substantial extent, (a) are completely absent from school, and/or (b) initially attend then leave school during school days, and/or (c) go to school following behaviour problems such as morning temper tantrums, and/or (d)display unusual distress during school days that precipitates pleas for future nonattendance'* (1).

This broader definition of the term was also justified by clinical experience that showed that categorizing students with psychiatric conditions was not sufficient to cover the heterogeneity in individual characteristics. Furthermore, categorical and dimensional aspects of classification were added to strengthen the link between assessment and treatment (1). The categorical classification of SRB consists of: a) non-problematic (temporary) versus problematic (extended) absence, b) parent-motivated or primary familial/societal causes versus child-motivated, and c) self-corrective versus acute (2 – 52 weeks) versus chronic (>

52 weeks). SRB is defined by problematic, child-motivated and acute or chronic absenteeism. If the student fulfils these categories, Kearney and colleagues argue to add a dimensional approach, utilizing functional analyses to collect information concerning the eliciting and maintaining conditions of SRB (1). Four different conditions for why the students do not attend school were proposed: a) to avoid specific or general stimuli provoking negative affectivity in the school environment, b) to escape from aversive social/evaluative situations in the school environment, c) to gain verbal/physical attention from caregivers at home, and/or d) to pursue positive tangible reinforcement outside the school environment (1).

The diversity of the definitions of SRB used by researchers presents a blurry picture, making the field a challenging one to study and potentially presenting an obstacle for a shared understanding among researchers and practitioners (6, 11). However, the term SRB describes the behaviour neutrally and broadly, thus it can be regarded as appropriate for exploring the phenomenon in students with ASD.

### *1.1.2 Prevalence of SRB*

The prevalence of SRB is difficult to establish because the condition covers both physical and verbal refusal, tardiness, and partial and complete absenteeism. However, rates between 5 – 28% in the general child and adolescent population are proposed as an estimate based on registers that assess different aspects of SRB (12). Furthermore, the prevalence of anxiety-based school refusal and truancy is found to be 2% and 6.2% respectively (4). Norway lacks a national register of absenteeism in $1^{th}$-$10^{th}$ grades, and since SRB is not classified as a diagnostic category in the International Classification of Diseases Tenth Revision (ICD-10) patient register data are not useful for establishing prevalence rates (13). However, self-reported anxiety-based school refusal or truancy was found in 6.2% of a sample of students in

6th-10th grades (5). Kurita (14) found that 27.3% of students with ASD with and without intellectual disability exhibited anxiety-based school refusal, while 40% of a subsample of students with ASD without intellectual disability did so. Additionally, of interest for this study are the findings that 28.1% of all students with ASD and 45% in a clinical referred sample of students with anxiety disorders displayed a reluctance to go to school (14, 15).

SRB is found to occur at all ages; however, periods involving changes, such as starting at school or transitions between schools, represent peaks (5, 6, 16). SRB is regarded as equally common in females and males, but the distributions may be somewhat different for different expressions of SRB (5, 6, 16, 17).

### 1.1.3 *Consequences of SRB*

SRB is a serious condition not only for the student but for the whole family. Furthermore, education is one of the most important factors for equalizing living conditions and providing welfare and democracy in society, thus it is of great interest to politicians. In the short-term, SRB can hamper the students' academic and social development, and their attitude towards school, and lead to a vicious cycle. Furthermore, SRB can lead to severe distress and conflicting relationships with parents and teachers (6, 12, 18, 19). School absenteeism of more than 10% of a school year (authorized and unauthorized) is considered to be serious both academically, socially and emotionally, and a risk factor for chronic SRB (20). Long-term consequences of SRB are school drop-out and related problems, e.g. isolation, psychological problems, substance abuse and criminality. These problems could be prolonged into adulthood and lead to, for example, psychiatric disorders, occupational difficulties, unemployment, poverty and martial problems (6, 8, 12, 19).

Approximately one-third of students who receive treatment for SRB have serious adaptive difficulties later in life (6). Better prognosis is related to less severe SRB, fewer symptoms of psychopathology, younger age, early interventions and good functioning at the end of treatment (8, 19).

## 1.2 Individual characteristics associated with SRB

### *1.2.1 Emotional and behavioural problems*

Emotional and behavioural problems and psychiatric disorders are often examined in studies of SRB. The conditions most commonly reported are depression, generalized anxiety disorders, oppositional defiant disorder, conduct disorder and attention deficit hyperactivity disorder (ADHD) (4, 8, 9, 17, 21-23). Studies also show that students with SRB often have more than one psychiatric disorder and co-occurring conditions, e.g. negative personality traits, relational problems and academic difficulties (4, 5, 21, 24, 25). Furthermore, studies of students who attend school with reluctance show symptoms of depression, interpersonal maladaptation and anxiety. Typical statements from these students include ‘There’s nothing fun at school even if I go’ or ‘Sunday night, thinking of school the next day gets me down’ (15, 26). Symptoms of depression likely impact school performance through the student’s lack of energy, reduced capacity for thought, concentration and decisiveness (23). Thus, symptoms of depression should be recognized early by teachers and parents and steps should be taken to relieve distress for the student. However, differentiating between SRB and co-occurring emotional and behavioural problems could be complicated, which implies that collaboration with clinicians from mental health services is necessary (23).

Emotional and behavioural problems in students with ASD and SRB are scarcely studied. However, obsessive behaviour, anxiety and lack of engagement in formal education have been reported in students with ASD and SRB (14, 27).

### *1.2.2 Somatic complaints*

Somatic complaints and sleep problems are closely related to SRB, especially in those who display symptoms of anxiety and depression (4-6, 15, 17, 28). Considering somatic complaints (e.g. headache, stomach ache, nausea or vomiting, fatigue, sweating etc.) as symptoms of physical illness or psychosomatic complaints could be difficult for parents and teachers and should be examined by a physician (6). However, related to SRB, these symptoms are often relieved when the students stay home from school or during the holidays and weekends. Furthermore, during the school day somatic complaints are often the reason for visiting school health personnel, and are then caused by another reason other than illness, i.e. not wanting to be in a particular class (29).

## 1.3 Family factors associated with SRB

The most consistent family factors associated with SRB are mental health problems or medical conditions in the parents, and an unsafe home environment with a lack of parental involvement and support (4, 6, 17, 21, 30, 31). This therefore emphasizes the importance of providing support to the parents when the students display SRB.

### 1.4 School factors associated with SRB

Difficulties establishing and maintaining positive relationships with peers are commonly reported as risk factors for SRB (4, 6, 21, 32). Students may fail to establish friendships either because they behave in a shy or aggressive way, the relationship is conflicting or unstable, or the students are exposed to teasing or bulling (4, 6, 14, 21, 32). Knowledge regarding the negative impact a poor relationship between peers has on school attendance calls for school professionals to be aware and take proactive steps. Havik, Bru (32) found an indirect association between SRB and the teachers' classroom management, suggesting that teachers showing supportive behaviour could have a positive modelling effect on the students. Furthermore, harsh discipline and unsupportive teachers both academically and emotionally are associated with SRB (14, 32, 33).

### 1.5 Autism spectrum disorder and diagnostic criteria

Autism Spectrum Disorder (ASD) is a pervasive neurodevelopmental disorder, defined by symptoms of persistent deficits in social communication, social interaction, and restrictive and repetitive patterns of behaviour, activities or interests (13, 34, 35). ASD most often manifests in later childhood, when the social demands exceed the child's capacity. However, behaviour markers have been recognized in children less than 12 months of age and subtle developmental delays are found within motor, communication and social domains from six months (36, 37). Nevertheless, the average age for the diagnosis is between four to five years (36). Children and adolescents with ASD show a large heterogeneity and display a range of intellectual and language abilities. The condition impacts everyday living and is observable across all arenas of life (13, 34, 35). However, the severity of the symptoms varies depending on the context, e.g. irregular days in school may be stressful and increase the symptoms. The

limited ability to initiate and maintain reciprocity in conversation and play, such as sharing interest and emotions, seriously impacts the establishing of friendships and relationships with others (38). Furthermore, a profound problem with changes and the insistence on sameness in routines and activities commonly creates distress for individuals with ASD.

The term ASD has been used by professionals and parents in everyday language in the past few decades and is formally stated in the fifth revision of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) and the International Classification of Diseases, eleventh revision (ICD-11) (34, 35). ASD replaces the term Pervasive Developmental Disorder (PDD) which included the main ASD subgroups of autistic disorder, Asperger`s syndrome and pervasive developmental disorder not otherwise specified (PDD-NOS) (13, 39). The ICD-10 criteria are used for diagnostic purposes in Norway, and are the criteria used in this study. Changes in diagnostic criteria and the new labelling of the condition have raised considerable debate. Some have argued that the stigma is more largely related to autism than to Asperger`s syndrome, and that the new criteria could exclude individuals from a diagnosis within the spectrum compared to the DSM-IV. The use of the term ASD, in the DSM-5 and ICD-11, is based on low or no evidence for differentiation into subgroups. The dimensional approach is assumed to embrace the heterogeneity that characterizes the condition and thus guide the treatment and adaptation of the environment more appropriately (40-42). However, some studies have shown that the rates of children diagnosed with ASD are lower when using the DSM-5 rather than the DSM-IV, and that a lack of understanding of the dimensional construct might lead to poorer services for people with ASD (43-45). Clearly, it is too early to conclude whether the change will represent an improvement or reduce the quality of life for people with ASD, especially regarding the ICD-11 that has recently been released but not implemented.

The symptoms of ASD have been described as early as in the 18th century (46). However, most commonly ASD is related to the work of Leo Kanner (1894-1981), a child psychiatrist, and Hans Asperger (1906-1980), a paediatrician in the early 1940s. Despite not knowing each other, they both described behaviours in some boys that displayed symptoms later known as autistic disorder and Asperger`s syndrome. Childhood autism was first defined as a diagnostic entity under the schizophrenia grouping in the ICD-8 (1967), and Asperger`s syndrome was first defined in the ICD-10 (1993) (47). In 1981, Lorna Wing (1928-2014), a psychiatrist, introduced the idea of a broad spectrum of disorders rather than extinct entities, which presumable is a more proper way to understand the symptoms according to the DSM-5 and ICD-11 (34, 35, 48).

### 1.5.1 *Aetiology and prevalence*

The aetiology of ASD is best understood as a complex interaction between genetic and environmental factors (49, 50). Twin and family studies indicate that the contributions from genetic factors are strong, with estimated heritability of > 80 % and a concordance rate for monozygotic twins of approximately 45%, versus 16% for dizygotic twins (49, 50). The genetic architecture, however, is found to be extremely complex and heterogeneous. One estimate is that nearly a thousand genes, both rare genetic variants with large effect and common variants with smaller effect, may be involved (50-52). Additionally, many of the identified genetic findings are not specific to ASD but are also related to other neurodevelopmental disorders, e.g. ADHD and schizophrenia (51, 53). Environmental factors with an association to ASD are also found; e.g. infections in pregnancy, maternal malnutrition, exposure to toxins and drugs, and parents' reproductive age (50, 54). However, the knowledge of environmental impact is limited and no single or major factor has been

discovered. It is agreed upon that advances in the understanding of the aetiology of ASD lie in the further study of the complex interplay between genes, and environmental factors which most likely have their effect during foetal life (51, 52).

ASD is one of the most common neurodevelopmental disorders, with onset in childhood having an estimated prevalence of 0.6 – 1.5 % (36, 50, 55). Boys are diagnosed four – five times more frequently than girls; however, it is increasingly accepted that girls may be under recognized (50). The prevalence rates of ASD have increased over the past few decades, most likely due to a broadening of the diagnostic concept, and an increased awareness of ASD in the public and in the educational and health services, as well as better access to services (36).

## 1.6 Co-occurring conditions

ASD and co-occurring conditions have received increasing attention (50, 56). Findings show that more than 70% of individuals with ASD have one co-occurring condition, rating intellectual disability, gastro intestinal problems, epilepsy, ADHD, and anxiety and sleep problems as the most common (50). The high frequency of co-occurring conditions likely underlies a combination of shared pathophysiology, the environmental effects of growing up with ASD, shared symptoms or overlapping diagnostic criteria (50). Emotional and behavioural problems in individuals with ASD are within the scope of this study.

### *1.6.1 Emotional and behavioural problems*

Emotional and behavioural problems are frequent in individuals with ASD and are commonly reported to be higher than 70%, which exceeds the rates in typically developing (TD) students (7-13.3%). Furthermore, 40% had more than one co-occurring condition (50, 57-61). The

most frequent psychiatric conditions are anxiety, depression, ADHD, tic disorders, oppositional defiant disorder and obsessive compulsive disorder (50). Symptoms of depression, which include lack of energy and withdrawal from daily activities, are of interest in this study.

The frequencies of co-occurring depression in individuals with ASD vary widely, with estimates between 12-70% (50). Diagnosing depression in individuals with ASD can be challenging due to overlapping symptoms, idiosyncratic expressions of the symptoms and problems in communicating or expressing emotions (62, 63). Depression is most often diagnosed in adolescent and young adults rather than in childhood (50, 63). Furthermore, depression is reported to be more common in individuals with normal intellectual ability than those with intellectual disability. However, this could reflect the fact that symptoms are more difficult to identify in individuals with intellectual disability (50, 64). Little is known about factors associated with depression in individuals with ASD. However, depression in parents, not related to parental stress, proposes a genetic influence on depression in offspring. Most likely, these are individuals more prone to responding with depression when exposed to negative life events (63, 65). Depression is strongly associated with poorer functioning in everyday living and can lead to serious withdrawal that affects not only the individual with ASD, but also the family (60, 62, 63, 66).

### 1.7 ASD and social functioning

Social deficits are among the defining symptoms of ASD, however the deficits differ in severity concerning the different aspects of social functioning, i.e. social communication, social awareness, social cognition and social motivation (67-69). Findings indicate that a

higher level of social interest and motivation is associated with increased and spontaneous social interaction (70).

The Social Motivation Theory (SMT) hypothesizes that an intrinsic deficit in social motivation leads to impaired social- cognitive development in individuals with ASD. Impaired social motivation comprehends deficits in social orientation - seeking, liking and maintaining social interactions (71, 72). However, the evidence for the SMT is mixed and two other explanations are also supported by findings. One suggests that the deficit in processing stimuli as rewarding impacts both social and non-social stimuli, and another that individuals with ASD have exaggerated reward processing of non-social stimuli (71). This complex research field, containing bi-directional relations between social motivation, environmental shaping and biological development, needs to be continued to establish the causes of the core social deficits observed in individuals with ASD.

### 1.8 Executive functions and deficits in individuals with ASD

The theory of executive functions was one of the three theories raised in the 80s that hypothesise ASD as a cognitive deficit (73, 74). The theories have not been able to explain unique factors that capture the heterogeneity of the ASD. However, the contributions from cognitive psychology have advanced our understanding, and will most probably continue to do so, in their collaboration with the other disciplines involved in ASD research (73). Executive functions are defined as metacognitive processes necessary to disengage from the immediate context to maintain effective goal-directed behaviours, which comprise abilities in shifting, initiating, inhibiting, impulse control, working memory, planning, organising and the monitoring of responses or behaviour (74, 75). Executive functions impact both social and non-social functioning in individuals and are essential for coping in life (74, 76-79).

Executive dysfunctions are common in individuals with ASD (74, 77, 80). Because individuals with ASD often display the deficits in daily life, but can perform well in laboratory settings, assessment in the everyday setting is recommended (81). The executive functions of initiating, planning and organizing, assessed in everyday living, are the focus of this study.

### 1.8.1 *Initiating, planning and organizing deficits in individuals with ASD*

Initiating deficits comprise impaired abilities to initiate activities or tasks and to generate ideas, responses or problem-solving strategies. Initiation deficits in everyday living for individuals with ASD are associated with overall adaptive behaviour problems and poor quality of life, especially related to social functioning (76, 78, 79). Initiating deficits are found to increase from childhood to adolescents, indicating that the gap between functioning in the students with ASD and expectations from others expands (77).

Planning deficits are found to be one of the most significant executive deficits in ASD (74, 82). Planning and organizing comprises abilities such as gaining an overview, setting goals, estimating the time factor and accomplishing tasks, and are linked to poorer outcomes for quality of life, especially in school functioning (79). Planning and organizing are linked to social deficits and adaptive behaviour problems (76, 78, 79, 83). Furthermore, in a study of students in the general child and adolescent population, planning, but not set-shifting and inhibition, was found to negatively impact motivation and to be associated with depression (84).

### 1.9 Prognosis

Prognosis for individuals with ASD is poor, and even those with cognitive abilities within the normal range do not reach their full potential in adulthood (50, 85, 86). A good or very good outcome is reported in only 17% and poor or very poor in 60% of an adult sample. Severity in reciprocal social interaction is found to be a strong predictor for a poor outcome (86). However, increased provision of evidence-based practice from an early age, in addition to parent training and social skills programmes, could improve the outcomes for future generations (86-89).

### 1.10 Parents of students with ASD

Families with children with ASD are characterized by heterogeneity in perceived burden and hardiness (90). However, higher levels of stress and psychopathology, less participation in work life and more frequent use of long-term sick leave are documented in parents of children with ASD compared to children with other chronic medical conditions and disabilities (90-93). In particular mothers, who often are regarded as the primary caregiver, report high rates of mental health problems (94, 95). Factors associated with depression in fathers are high rates of depression in the mother and having an another child with a disability (96). The child's behaviour, especially defiance, non-compliance and being demanding, but also behaviour patterns such as insecurity, anxiousness or over sensitivity, are found to be strongly associated with parental stress (97, 98). Furthermore, to increase the likelihood of the child attending different arenas, parents often adapt their behaviour, and plan their structured activities and communication to a higher extent than expected regarding the child's intellectual ability (97). The discrepancy between the parents' expectations and the responsiveness in the child is described as a major stressor (98). Furthermore, parenting a

child with ASD in transitions is often reported as being challenging and associated with uncertainty (99). Behavioural problems in the child and parental stress seem to exacerbate each other, and long-term stress is found to be a risk factor for poorer psychopathology (95, 98).

### 1.11 Inclusion of students with ASD in primary and secondary school

Students with ASD are entitled to access an inclusive, high quality and free primary and secondary education on an equal basis with other students according to Article 24 of the UN Convention on the Rights of Persons with Disabilities (100). The Convention is also ratified by Norway. According to the Norwegian Directorate for Education and Training, eight percent of students with an administrative decision of special education attend groups or schools organized for students with disabilities, while 92% of such students attend inclusive schools. However, 60% mainly have their lessons in special groups or alone (101). There is an ongoing debate, both internationally and in Norway, between those who promote education for students with disabilities organized in special groups or schools, and those who favour inclusive school and classes.

Teachers who had previous positive experiences with inclusion of students with disabilities were generally more positive about the enrolment of students with ASD (102). However, students with ASD with more severe symptoms and co-occurring emotional and behavioural problems are reported as being challenging for the teachers' inclusive attitude and practice (102, 103). Many students with ASD do not have their needs adequately met in school, and among the reasons that justify exclusions from classes, school trips and other activities are the students' challenging behaviour or unavailable school personnel (104, 105). Greater access to peer role models, to relationships with peers, and to the general curriculum

available in inclusive schools is not only a right, but regarded as beneficial for students with ASD (70, 106, 107). However, to ensure these benefits it is crucial that possible barriers related to the core symptoms of ASD and co-occurring conditions are understood and met on a daily basis with the best practice available (108). The current status is that the legislation and the formal regulations are not implemented in educational practice (104).

### *1.11.1 Teacher competence in ASD*

The Norwegian Government has stated that teachers' competence is a key adaptation of the educational environment, necessary for the inclusion of students with disabilities (109). This statement is supported by teachers, who report that understanding the characteristics of students with ASD and having access to best practice training is necessary to support the students' academic, social and personal development (27, 102, 104, 108, 110, 111). Furthermore, collaborative teams of schools supported by external professionals are regarded as crucial for success (27, 111). However, several obstacles have been identified by teachers (102, 110, 111). One is the tension between different layers in school which comprises a lack of understanding from the school administration of the social and learning difficulties characterizing students with ASD and interpersonal disagreement between general teachers, special teachers and educational assistants. These tensions could impede the development of a culture that accepts and welcomes diversity among the students (102, 111). The prioritization of resources by the administration for teachers to enhance their competence and adapt the education was another reported obstacle (110, 111). Additionally, the lack of adequate support and guidance from external services could negatively impact the teachers' abilities to adapt the education and further leave the teachers unsupported in their challenges concerning teaching students with ASD (102, 111, 112).

### 1.11.2 *School-home collaboration*

Close collaboration between parents and teachers is important for the students' academic, social and personal development and, furthermore, to ensure school attendance. However, school-home collaboration can suffer from tension and poor communication (27, 111, 113-115). Students with ASD often have difficulties expressing their needs, interpreting occurrences, and passing on information between the two arenas. Thus, frequent contact between parents and teachers is necessary to avoid misinterpretations and support the student (102). Open and honest communication and a flexible and positive attitude from the teachers are related to the parents' satisfaction with school - home collaboration (102, 111, 113, 115). However, when parents experience incidences that lower their trust in school, they may, for example, attend meetings more prepared to fight for their child's rights, and this can change the climate from one of collaboration to one of conflict (113). Although parents and teachers report that good communication is essential, they often perceive the communication differently. While the parents perceive the collaboration as not being sufficiently frequent and informative, the teachers report being satisfied with the collaboration (102).

## 2. AIMS

The overall objective of this study was to advance the understanding regarding SRB in students with ASD without intellectual disability who attend inclusive primary and secondary public schools. The specific study aims were:

1. To assess SRB in students with ASD without intellectual disability attending $4^{th}$ – $10^{th}$ grade in inclusive schools and to explore socio-demographic variables in the family (Paper I).

2. To explore the association between SRB and individual characteristics in children with ASD (Paper II).
3. To explore the agreement between parents and teachers regarding school–home collaboration, teachers' competence in ASD, and rates of emotional and behavioural problems in the students with ASD overall, and separately in the students with and without SRB (Paper III).

## 3. METHODS

### 3.1 Design

The study was descriptive and the questions of interest were explored in naturalistic settings with assessment procedures and questionnaires commonly used in clinical practice. A cross-sectional design was used to assess the frequency of SRB in a population of students with ASD (Paper I), and the association between SRB and other variables of interest (Paper I, II and II).

### 3.2 Sample

The recruited sample consisted of 216 students aged 9–16 years; i.e. 88 ASD and 138 TD students. The participants attended 72 different primary and secondary public schools of different sizes and geographical spread, from both rural and urban areas. Seventy eight students with ASD were included in the study (response rate: 88.6 %); two of the students withdrew from the study, five were excluded because they did not meet the inclusion criteria of an IQ score above 70, and three did not complete the questionnaires.

The age of 9 - 16 years was chosen because, in Norway, the majority of children diagnosed with ASD without intellectual disability are approximately nine years old at the

time of diagnosis and compulsory school ends at the age of 16 years (55). Students with an IQ score below 70 were excluded from the study because they often attend more specialised school settings.

ASD and additional diagnoses were assessed by specialists in child and adolescent psychiatric and paediatric outpatient clinics. Comprehensive diagnostic procedures involving interviews, clinical observations and cognitive ability tests were used. Diagnoses were set according to ICD-10 criteria (13). Twenty-seven (34.6%) of the 78 students with ASD had an additional psychiatric diagnosis, mainly hyperkinetic disorder/ADHD (n = 13), tic disorder (n = 5) and obsessive compulsive disorder (n = 3).

The TD students had similar gender and age, were attending the same classes as the students with ASD and did not have any known somatic or psychiatric disorders. The sample in Paper I included 68 students with ASD (response rate 87.2 %) and 127 TD students (response rate 92 %) assessed by teachers. Parents assessed SRB in 62 students with ASD (response rate 79.5 %).

The sample in Paper II was a subsample of 62 students with ASD from the initial sample of 78 (response rate 79.5%), with CBCL, SRS parent and BRIEF data available from parents.

In Paper III, there were 35 students with ASD (response rate 44.9%) from the initial sample, from whom CBCL, TRF and parent reports regarding collaboration and teachers competence were available. Teacher reports regarding collaboration with parents and own competence were available in 29 students with ASD (response rate 37.2%). The numbers of participants in the initial sample and in the subsamples are presented in Figure 1 and characteristics of the samples are presented in Table 1.

Figure 1. Initial sample and subsamles

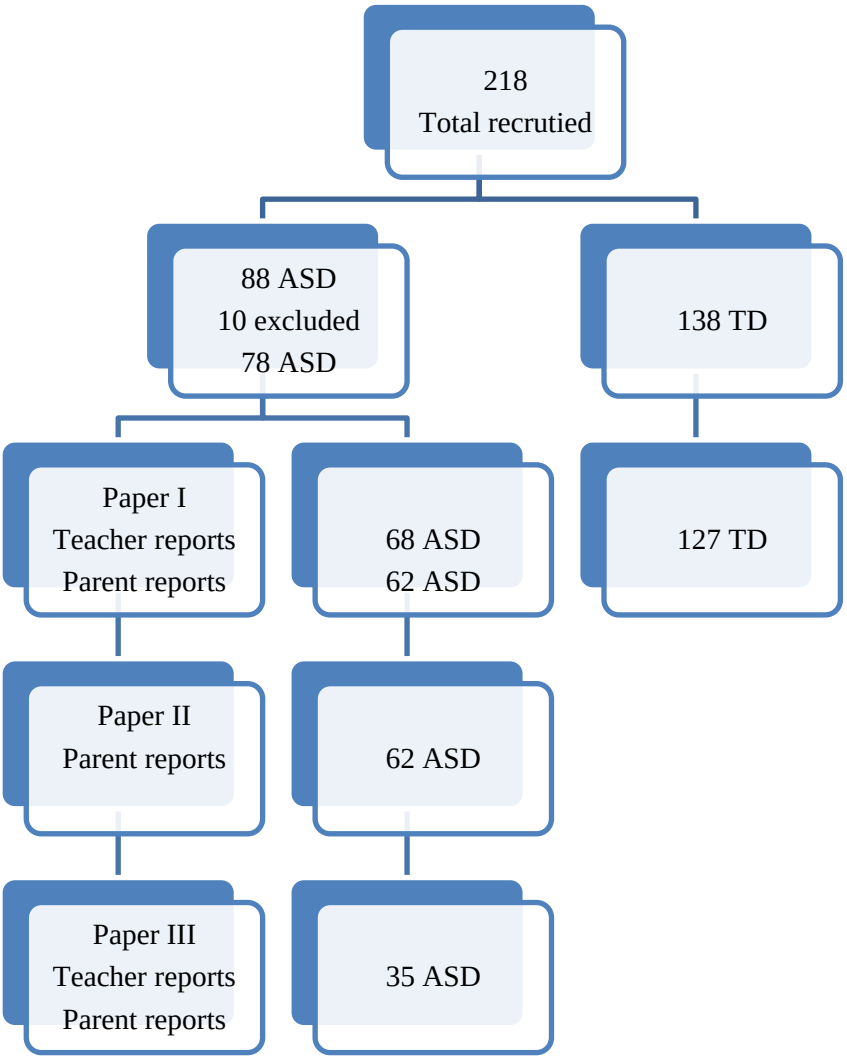

Table 1. Characteristics of the initial sample and subsamples. Values are reported as n (%) unless otherwise stated.

| | Paper I | | Paper II | Paper III |
|---|---|---|---|---|
| Variables | ASD | TD | ASD | ASD |
| | n = 78 | n = 138 | n = 62 | n = 35 |
| Gender | | | | |
| Male | 67 (85.9) | 120 (87) | 53 (85.5) | 30 (85.7) |
| Female | 11 (14.1) | 18 (13) | 9 (14.5) | 5 (14.3) |
| Age Mean (SD) | 12.3 (1.98) | 12.0 (1.99) | 12.3 (2.0) | 12.1 (2.1) |
| Schools | | | | |
| Primary school | 36 (46.2) | 75 (54.3) | 28 (45.2) | 17 (48.6) |
| Secondary school | 42 (53.8) | 63 (45.7) | 34 (54.8) | 18 (51.4) |
| IQ Mean (SD) | 100.8 (18.1)a | - | 100.8 (18.1)a | 98.9 (16.7)b |
| Childhood autism | 12 (15.4) | - | 8 (12.9) | 4 (11.4) |
| Atypical autism | 4 (5.1) | - | 2 (3.2) | 1 (2.9) |
| Asperger Syndrome | 53 (68) | - | 45 (72.6) | 24 (68.6) |
| PDD NOS | 9 (11.5) | - | 7 (11.3) | 6 (17.1) |
| Additional diagnosis | 27 (34.6) | - | 23 (37.1) | 14 (40) |
| SRB (parent reports) | 33 (53.2)c | - | 33 (53.2) | 17 (46.8) |
| SRB (teacher reports) | 29 (42.6)d | 9 (7.1) | - | 17 (46.8) |

a: n= 51 students; b: n= 29 students; c: n=62 students; d: n=68 students.

### 3.3 Procedures

Information regarding the study was sent to all the inclusive primary and secondary public schools in the south-east region of Norway (116). The principals were asked to forward the

information and a consent form to all parents of students with ASD attending fourth – tenth grades, and to the parents of two TD students with the same gender and in the same class. Later, the information was followed up with phone calls to approximately 40% of the schools. Furthermore, child and adolescent psychiatric and paediatric outpatient clinics in the region were contacted through written material and asked to forward information about the study and a consent form to parents of children and adolescents with ASD aged 9 – 16 years. Additionally, the study was advertised on the Norwegian Autism Society's website. The recruitment of TD students was later altered from participation based on parents' consent to anonymous participation because of the low response rate. The schools were asked to inform all the parents and randomly draw two TD students from the students' list in the same class and of the same gender as the recruited student with ASD.

After the parents of the students with ASD had provided written consent, information about the study and a questionnaire were sent to the child and adolescent psychiatric and paediatric outpatient clinics that had diagnosed the students with ASD. The clinics were asked to confirm the ASD and additional diagnoses, to give information about the elements of the diagnostic process and to confirm that the students' intellectual ability was within or above the normal range. The parents of the students with ASD and the teachers were given instructions of how and when to assess attendance and SRB during the assessment period of 20 consecutive schooldays. Attendance and SRB was assessed on the same days for the student with ASD and the matched TD students. The parents of the students with ASD were asked to fill out the CBCL; the BRIEF; the SRS; two questionnaires regarding experiences receiving services and collaboration with the social and health care system, the hospitals and the schools; and a socio demographic questionnaire.

The teachers were asked to fill out the TRF, the BRIEF and a questionnaire regarding the school and collaboration with other professionals and parents.

## 3.4 Measures

### *3.4.1 SRB assessment*

A questionnaire was developed for this study based on Kearney's (12) description of SRB. The parents and the teachers of the students with ASD and the teachers of the TD students in the comparison group were asked to fill out the questionnaire on a daily basis, by marking a 'x' in one of the following six categories: 0) attendance, 1) pleas for not attending school, 2) misbehaviour in the morning to avoid school, 3) tardiness followed by attendance, 4) pleas to not attend classes during the day, 5) did not attend classes, or 6) did not attend school. Furthermore, if they marked an 'x' in one of the categories, except for option 0, they were asked to write the child's motivation in the comment field in the questionnaire.

To determine whether the student showed SRB or not, each 'x' was scored as one and was summarised into two categories: SRB 'yes' or 'no'. The 'yes' category consisted of 1- 20 days of verbal or physical refusal and partial or complete unauthorised absenteeism. The definition of unauthorized absenteeism was based on the categories: 3, 5 or 6, and without written excuse for the absenteeism in the comment field in the questionnaire. Verbal and physical refusals were associated with categories 1, 2 and 4. Furthermore, if the teachers and parents had recorded comments for excusable absenteeism in the comment field, such as for gastric flu, leave of absence or oversleeping, this was defined and counted as authorized absenteeism. The category 0 served as a control variable to ensure that the questionnaire had been answered and was not summarised. If more than one category was marked in the same day, only one was counted. If one of those 'x' were noted in the categories 3, 5 or 6, it was summarised as partial/complete unauthorised absenteeism.

### *3.4.2 Family socio-demographic assessment*

Socio-demographic variables in the families of the students with ASD were assessed by using a socioeconomic questionnaire (117). One of the parents answered the 27 questions regarding

mother's and father's education, work experience, their relationship, siblings, living, health conditions, and the family's financial status by circling the alternative that suited the best. Mothers' educational level, parents' marital status, health conditions of other family members, and location and ownership of residence were chosen as the factors of interest because these factors are generally used and regarded as important socio-economic variables associated with mental and psychosocial impairment in children and adolescents (118, 119).

### *3.4.3 Assessment of school factors*

Demographic data

The Norwegian educational information system (116) was used to collect data regarding the number of students at the relevant grade and the total number of students in the participating schools.

Parent ratings

The parents of the students with ASD answered a questionnaire developed for the study with 30 questions, regarding experience and satisfaction with social and health services, their child's school experiences, and satisfaction with parent teacher collaboration and teachers' competence in ASD. One parent answered the questions by circling the most suitable alternative on a five-point scale: most satisfied, satisfied, neither satisfied nor dissatisfied, dissatisfied, very dissatisfied and not relevant, with the values from 5 (most satisfied) – 1 (very dissatisfied).

Teacher ratings

A questionnaire was developed for the teachers of the students with ASD in this study. The questionnaire included 14 questions regarding satisfaction with own and other teachers'

competence in ASD, the possibilities to achieve a higher level of competence, and satisfaction with collaboration with other professionals and with the parents and routines for assessing and reporting absenteeism among the students in the school. The questions regarding satisfaction with competencies in ASD and collaboration were answered on a five-point scale: most satisfied, satisfied, neither satisfied nor dissatisfied, dissatisfied, very dissatisfied and not relevant, with the values from 5 (most satisfied) – 1 (very dissatisfied). The other questions were answered by circling the most suitable alternative.

### 3.4.4 *Assessment of executive functions*

The BRIEF assesses executive function in daily living in children and adolescents aged 5-18 years (120, 121). The parent and teacher inventory was used in this study, and parents and teachers marked 1) never a problem, 2) sometimes a problem or 3) often a problem for each of the 86 items describing the child's behaviours for the past six months. The BRIEF comprises eight sub-scales, i.e. Inhibit, Shift, Emotional Control, Initiate, Working Memory, Plan/Organize, Organization of Materials and Monitor. These sub-scales form two broader indexes: the Behavioural Regulation Index (BRI) and the Metacognition Index (MI) and a total score, the Global Executive Composite (GEC). The BRI includes the sub-scales: Emotional control, Inhibit and Shift, and the MI the sub-scales: Initiate, Working memory, Plan/Organize, Organization of Material and Monitor. Gender- and age-standardized *T*-scores are provided for each scale. Scores above 50 indicate a borderline level of concern and the clinical cut-off is 65. The BRIEF is commonly utilized in research and in outpatient child and adolescent psychiatric and paediatric outpatient clinics. It takes approximately 10 – 15 minutes to administer and 15 – 20 minutes to score the form.

3.4.5 *Assessment of social functions*

The Social Responsiveness Scale (SRS) is a 65-item questionnaire that assesses the severity of social impairment and ASD symptoms in children and adolescents aged 4-18 years (122). The questions focus on the child's behaviours during the past six months and can be completed in 15–20 minutes by a parent or teacher who is familiar with the individual's current behaviours and developmental history. A parent completed the questionnaire by circling, either 0) not true, 1) sometimes true, 2) often true, or 3) almost always true. The SRS comprises five treatment subscales, i.e. Social Awareness, Social Cognition, Social Communication, Social Motivation and Autistic Mannerisms, and a Total Score. The raw-scores were transformed in to *T*-scores. *T*-scores of 76 or above indicate severe interference in daily social interactions and are strongly associated with ASD. Furthermore, *T-scores* in the range of 60-75 indicate deficiencies in reciprocal social behaviours that interfere with everyday social interactions in a mild to moderate way. Several studies have shown that SRS is useful in screening for ASD symptoms (122-124).

3.4.6 *Assessment of emotional and behavioural problems*

The Achenbach System of Empirically Based Assessment (ASEBA) is an integrated system of multi-informant (parent, teacher, child/youth) assessment, containing manuals with forms and profiles with well-documented psychometric properties for assessing competencies, adaptive functioning, and emotional and behavioural problems in children (125). In this study, we used the parent and teacher forms: CBCL and the TRF for children and adolescents aged 6 – 18 years. A parent and a teacher who knew the child or adolescent well rated the youth's emotional and behavioural problems in the last six or two months, respectively. The forms comprise 112 items that are rated on a three-point scale: 0) Not True, 1) Somewhat or Sometimes True, and 2) Very True or Often True. The items are transferred into eight

syndrome scales and six DSM-oriented scales. The broadband scales Internalizing, Externalizing and Total Problems are constructed from the syndrome scales. We utilized the eight syndrome scales, i.e. Anxiety/Depressed, Withdrawn/Depressed, Somatic Complaints, Social Problems, Thought Problems, Attention Problems, Rule-Breaking Behaviours, and Aggressive Behaviours in the study. The parallel forms CBCL and TRF facilitate a systematic comparison of the different perspectives within 97 items assessing emotional and behavioural problems. Cross-informant agreement between CBCL and TRF (Pearson`s *r*s) was found to be significant at $p < 0.05$ for all the problem scales, with a mean $r = 0.28$ for the eight subscales (125). Gender- and age-standardized *T*-scores are provided for each scale. Scores within or above borderline (65-70 for the syndrome scales and 60-64 in the broadband scales) represent reasons of concern for the youth. The CBCL and the TRF are often utilized in clinical practice and research, including studies assessing comorbid emotional and behavioural problems in children with ASD (125-133).

### 3.5 Ethical considerations

Participation in the study was based on consent that could be withdrawn at any time without any consequences, following which unpublished data would be edited. The parents were instructed to consider their child's attitude to the participation before signing their consent. The participants were allowed to see the data regarding themselves and were informed of the time it would take to participate in the study. Prepaid envelopes were enclosed with the information, consent and questionnaires sent to the parents, schools and clinics. Furthermore, the parents were asked if they would allow their child to be asked to attend an interview based on two questionnaires. The interviews should be performed by a familiar person to the child at home or at school. However, none of the parents gave their consent to this. If the assessments

revealed health related problems in the TD students, the parents were allowed counselling. However, none such information was revealed.

The participants could contact the PhD candidate by phone and mail with questions regarding the studies.

All participants will receive a written summary of the results from the study. The study protocol was approved on 11/04/2011, by the Norwegian National Committee for Research Ethics, and was carried out in accordance with the Declaration of Helsinki.

### 3.6 Statistical approach

Continuous variables were presented as the mean ± standard deviation (SD), and categorical variables were presented as the number of observations (percentages) in all studies. Variables with answers: 'most satisfied', 'satisfied', 'neither satisfied nor dissatisfied', 'dissatisfied' or 'very dissatisfied' were presented as continuous variables ranging from 5-1 (Paper III).

Statistical comparisons between groups were assessed by the chi-square tests for crosstabs, the independent samples t-test or by the paired sample test as appropriate. Bonferroni correction was conducted due to multiple comparisons within the SRS, the BRIEF and the CBCL and the significance levels for the t-tests within these variables were adjusted according to the number of subscales (SRS 0.05/5 = 0.01, BRIEF 0.05/8 = 0.006 and CBCL 0.05/8 = 0.006) (Paper II).

Cohen's *d* was calculated in order to analyse the effect size for SRB on the variables assessed with the SRS, the BRIEF and the CBCL. Cohen's *d* defines 'small' (0.2), 'medium' (0.5) and 'large' (0.8) effect sizes, and it could be larger than one (134) (Paper II).

The Pearson`s bivariate correlation coefficient *r* was used to analyse the correlation between the parents' and teachers' rates of emotional and behavioural problems in students with ASD, and separately in students with ASD and SRB and in students with ASD without SRB (Paper III).

Logistic regression analysis was used to analyse the associations between SRB in students with ASD and the socio-demographic variables, and the CBCL and the BRIEF variables with large effect sizes (Paper I and II). Stepwise logistic multiple regression analyses, using both a forward and backward approach, were performed. The criterion for including a variable in the model for both forward and backward stepwise regression was set to $p$ <.20 (Paper I) and $p$ < .10 (Paper II).

Multivariate analysis of variance (MANOVA) was performed to assess the independent contributions of the SRS, BRIEF and CBCL to SRB (Paper II).

In the power calculations, we used different scenarios of the population parameter of Cohen's d effect size, expressed as follows:

$$\delta = \frac{\mu_1 - \mu_2}{\sigma}$$

where δ is the population parameter of Cohen's d, $\mu_1$ and $\mu_2$ are the mean of the respective populations, and $\sigma = \sigma 1 = \sigma 2$ is the homogenous population standard deviation. The estimation of the statistical power for an independent- samples t-test with two groups of 29 and 33 subjects, respectively, was conducted using different scenarios of the population parameter of Cohen's d (Paper II).

The assumptions of linearity, independence of errors and normality of residuals were assessed with appropriate tests and descriptive statistics. Multicollinearity was assessed by estimating correlations between the predictors in the regression models (Paper II).

A linear mixed model analysis that adjusted for primary versus secondary school as a confounding variable was performed to assess parent and teacher ratings (Paper III). The statistical method took the dependence between parent and teacher assessment of the same student into account. However, the linear mixed model analysis was very similar to those reported from more basic statistical approaches, e.g. by using t-tests on scores and change scores. The degree of confounding by primary versus secondary school seemed low. Therefore, we choose to report unadjusted results from basic statistical tests.

Analyses were performed using SPSS version 21.0 (IBM SPSS Statistics, IBM Corporation) and estimations of statistical power were performed using Stata/SE version 14.1 (Stata Corp, College Station, TX). Statistical significance was defined as $p < .05$ if no other ways stated.

## 4. SUMMARY OF PAPERS

### 4.1 Paper I: School Refusal Behaviour: Are Children and Adolescents with Autism Spectrum Disorder at a Higher Risk?

*Aim:* To assess the frequency of SRB in students with ASD aged 9–16 years without intellectual disability (IQ > 70) compared to TD students. Furthermore, to explore the duration and expression of SRB and possible socio-demographic variables associated with the condition in children with ASD.

*Methods:* The sample included 78 students with ASD without intellectual disability and 138 TD students aged 9 – 16 years attending inclusive public schools. Parents and teachers

assessed attendance, refusal to attend school or classes, and absenteeism in a period of 20 consecutive schooldays. Additionally, parents answered a socio-demographic questionnaire.

*Results:* Based on teacher ratings, the frequency and duration of SRB were significantly higher in the students with ASD than in the TD students, 42.6% and 7.1%, respectively. Parent ratings showed a frequency of SRB in the students with ASD of 53.2%. The frequency and duration of SRB were not significantly different between the students with ASD in primary and secondary schools. However, 84.6% of the students with ASD in primary school and 35 % of the students with ASD in secondary school expressed their SRB as a refusal to attend school or classes. Furthermore, illness in other family members was associated with SRB in the students with ASD.

*Conclusion:* The study revealed a major risk for displaying SRB in students with ASD and IQ >70 compared to TD students, aged 9 – 16 years and that illness in other family members was associated with the condition. Students with ASD in primary school expressed SRB mainly as refusal, thus our findings underline the importance of a broad understanding of the condition to be able to identify early expressions of SRB. Further research is necessary to understand SRB in students with ASD.

### 4.2 Paper II: Individual characteristics of students with autism spectrum disorders and school refusal behaviour.

*Aim:* To explore social and executive functioning and emotional and behavioural problems associated with SRB in students with ASD without intellectual disability aged 9 – 16 years in inclusive schools.

*Methods:* The 62 students with ASD without intellectual disability aged 9-16 years attending inclusive schools were a subsample from a previous study assessing the rates of SRB in students with ASD. Thirty three (53.2%) of the 62 students displayed SRB. Parents completed the SRS the BRIEF and the CBCL.

*Results:* Students with ASD and SRB displayed higher total problem scores than those without SRB in the SRS, CBCL and BRIEF. The MANOVA was statistically significant for CBCL and BRIEF but not for SRS. Furthermore significant differences between students with and without SRB were revealed in the subscales: Social Motivation (SRS), Initiate and Plan/Organize (BRIEF) and Anxiety/Depressed, Withdrawn/Depressed, Somatic Complaints and Thought Problems (CBCL). The Initiate and the Withdrawn/Depressed remained significant after performing the logistic multiple regression analyses.

*Conclusion:* Compared to the students without SRB, the students with SRB were significantly less socially motivated, displayed more deficits in initiating tasks or activities, in generating ideas, responses or problem-solving strategies, and displayed more withdrawn and depressive symptoms. As this study is the first of its kind, there is a need for replication studies that address the methodological and research design limitations.

### 4.3 Paper III: Students with Autism Spectrum Disorders and School Refusal Behaviour: do the parents and teachers agree?

*Aim:* To explore the agreement between parents and teachers regarding: school–home collaboration, teachers' competence in ASD and their assessments of emotional and behavioural problems in a sample of students with ASD, with or without SRB, in primary and secondary inclusive schools.

*Methods:* The sample included dyads of 35 parents and teachers of students with ASD and IQ >70 and is a subsample from a previous study assessing the rates of SRB in students with ASD. Seventeen (48.6%) of the 35 students displayed SRB. The parents and the teachers answered questionnaires regarding teachers' competence in ASD, school – home collaboration and the CBCL and the TRF assessing emotional and behavioural problems in the students.

*Results:* The results showed a larger mean difference between the parents of the students with SRB and the teachers regarding the level of satisfaction with school–home collaboration compared to parents of students without SRB and teachers, respectively 0.7 and 0.5 points. A similar result was revealed regarding satisfaction with the teachers' competence in ASD, respectively a mean difference of 0.5 and 0.1 points. The modifying effect of SRB on satisfaction with school – home collaboration and perceptions of the teachers' competence in ASD was not significant. Furthermore, analysing the mean difference between the CBCL and the TRF scores showed that SRB had a statistically significant modifying effect ($p$ <0.05) on the subscales Withdrawn/Depressed, Thought Problems and Aggressive Behaviours.

*Conclusion:* The parents of the students with ASD and SRB tend to rate satisfaction with collaboration and the teachers' competence lower than the teachers do. Furthermore, SRB in the students negatively modified the agreement between the parents and the teachers, especially concerning symptoms of depression in the students. However, more studies are necessary to understand this field and the increased challenges in school – home collaboration when SRB is present.

# 5. DISCUSSION

## 5.1 Main findings

### *5.1.1 High rates of SRB and poor health in families with ASD are associated with SRB in the students*

Rates of SRB was significantly higher in students with ASD (42.6 %) compared to TD students (7.1 %), aged 9 – 16 years and going to inclusive public schools, based on teacher assessments. The difference in rates of SRB between students with ASD and TD students was revealed both in primary and secondary school. This is in line with studies of SRB in the general child and adolescent population showing that SRB occurs in all ages. Furthermore, levels of psychopathology, adaptive functioning and peer victimization in students with ASD did not increase during the transition to secondary school, but they persisted through elementary school (6, 8, 135). However, SRB is commonly reported to be more frequent in adolescents, and transition to secondary school is considered to be challenging for the students with ASD (6, 8, 106, 135). Comparing rates of SRB across studies is difficult because of different samples and definitions of the condition. The definition used in the study, which included refusal or absenteeism from the first occurrence, may have contributed to the high rates. However, the rates of SRB in our study, both in the students with ASD and the TD students, corresponds with previous reports of SRB in students with ASD and in the general child and adolescent population (4-6, 14).

Duration and expression of SRB needs to be assessed when considering the severity of SRB. Nearly 60% of the students with ASD displayed SRB on four or more days in the 20-day period; in comparison, none of the TD students displayed SRB for more than three days. Thus, SRB in the students with ASD was more severe than in the TD students. Expression of SRB in students with ASD was explored based on the parents' assessments because, in

contrast to the teachers, they were able to collect data at home. Eighty-five percent of the students with ASD in primary school displayed SRB as verbal or physical refusal to attend school or classes, while 35% of the students with ASD in secondary school shared the same expression. Verbal or physical refusal might be considered as milder forms of SRB than partial and complete absenteeism. Nevertheless, refusal should be taken seriously because it causes distress in the student and the family, and may represent early signs of later SRB expressed as partial or complete absenteeism (136). Sixty-five percent of the students with ASD in secondary school expressed SRB as partial and complete absenteeism. This is in line with Kurita (14) who reports that the severity of SRB increased in older students with ASD, and corresponds with findings of SRB in the general child and adolescent population (12). However, longitudinally studies are necessary to explore whether verbal and physical refusal in primary school increases the likelihood of SRB expressed as partial and complete absenteeism in adolescent students with ASD.

Illness in other family members was found to be associated with SRB in the students with ASD in our study. This finding is not supported by Kurita's study (14); however, it is commonly reported to be associated with SRB in the general child and adolescent population (6, 17, 30, 31). Other family variables commonly explored in studies of children with mental and psychosocial problems, e.g. low educational level in mothers, divorced parents, and living in urban areas, were not associated with SRB in the students in our study. Parenting children with ASD, especially those without intellectual disability, is associated with high levels of anxiety and depression, and without sufficient help, parents may experience increased levels of stress, use of sick leave and decreased work participation (90, 93, 137). Further studies are necessary to address whether SRB in students with ASD triggers illness in other family members, or alternatively, whether illness in the family furthers SRB in the students.

### 5.1.2 *High rates of social, executive and emotional problems in students with SRB*

The students with ASD and SRB showed higher overall rates of social deficits compared to the students with ASD without SRB. Low social motivation to engage in social settings was significantly associated with SRB in the students with ASD. Furthermore, the students with and without SRB did not differ concerning social communication skills and ability to recognize relevant social cues. Restricted social engagement in the school setting and poor relationship with peers has commonly been reported both in students with ASD and in students with SRB in the general child and adolescent population (4, 6, 70, 138). It can be speculated that lower social motivation in the students with ASD and SRB represents temperamental and personality traits or social withdrawal due to negative social experiences (71). Further studies are necessary to explore the relationship between social motivation and SRB in students with ASD.

The students with ASD and SRB showed overall more executive deficits than the students without SRB. This is in line with a study in a clinical population with prolonged anxiety-based SRB (139). Differences between the students with ASD and SRB and those without SRB were present in several of the BRIEF subscales, suggesting that neuro-cognitive components are associated with SRB. However, the ability to inhibit or monitor behaviours, to organize material or the working memory capacity did not differ between the students with and without SRB. The executive functions that showed the strongest association with SRB were initiating activities, generating new ideas and engaging in problem solving, and furthermore planning and organizing tasks and activities. Except for working memory deficits, these findings are similar to findings from quality of life studies and in studies of adaptive behavioural problems, especially in poor school functioning and social problems in students with ASD (76-79, 83). We can speculate that deficits in initiating, planning and organizing cause problems for the students in school related to beginning academic work,

engaging in social activities and asking for help. Furthermore, these deficits could result in poorer academically achievements and friendship than necessary, because the teachers and peers could interpret the deficits as lack of interest and thus not provide for sufficient education and support. At home these deficits could cause problems, e.g. in the morning routines, resulting in late arrival to school, which in turn was reported in the SRB questionnaire as reasons for the students' SRB. The association between executive functioning and SRB in students with ASD has not been reported previously, thus further studies are necessary on the topic.

The students with ASD and SRB were rated with overall higher internalizing problems scores than the students without SRB in our study. For four of the eight CBCL subscales - anxiety, depression, somatic complaints and thought problems - the students with SRB showed significantly more problems than those without SRB. Anxiety, depression and somatic complaints are frequently reported in students with SRB in the general child and adolescent population (4, 5, 16, 24). Furthermore, low expectations of coping with stressful situations, negative automatic thoughts and limited emotional support from teachers are reported amongst students with SRB (25, 33, 140). Similarly, we found in our study that some of the reasons the students with ASD and SRB had for not attending school were negative thoughts on relationship with teachers and peers, and towards different school subjects and school outings. Furthermore, symptoms of depression were strongly associated with SRB in the students with ASD. We can speculate that the teachers were not able to identify the students' needs for emotional and social support, and adapted education. However, other factors, at and outside the school, could also underlie the symptoms of depression.

### *5.1.3 Discrepancy in perceptions between parents and teachers*

Almost 30% of the parents did not share the teachers' opinion on school-home collaboration. The discrepancy in the parent-teacher dyads was larger among parents of the students with ASD and SRB compared to parents of students with ASD and without SRB, indicating that more problems increase the discrepancy. These findings are in line with previous studies that report tension and challenging communication in school – home collaboration in students with ASD and in students with SRB in the general child and adolescent population (33, 102, 113, 115, 141). Furthermore, although more than 70% of parent-teacher dyads shared the same concerns regarding students with ASD, only 23% shared the concerns in meetings (114).

The parents of the students with ASD and SRB rated the competence on ASD among the teachers less satisfactorily than the teachers and the parents to the students without SRB. A reduced understanding of the students' needs and insufficient adaptation of the school environment from the teachers has been related to dissatisfaction with collaboration, as reported by parents of students with ASD both with and without SRB (111, 113, 115, 142). Similar factors have been reported by parents of students with SRB in the general child and adolescent population (33). However, other school factors, e.g. willingness to acquire necessary competence, lack of resources and a negative attitude towards the inclusion of students with ASD from the school administration, cannot be ruled out as factors that impact the dissatisfaction reported by the parents. SRB present in the students did not significantly modify the results, thus our findings need to be interpreted with caution.

Overall, parents and teachers rated the students' emotional and behavioural problems as somewhat similar in our study. However, SRB present in the students reduced the agreement on several of the emotional and behavioural symptoms. The discrepancy in ratings of symptoms of depression is of particular interest because these symptoms were found to be

strongly associated with SRB in students with ASD (142). Several factors may impact the discrepancy between the rating from the parents of the students with SRB and the teachers. First, we can speculate that the parents capture changes in students' mood more easily than the teachers do. Schooldays are characterized by many transitions, such as between different subjects, teachers, rooms and the shift between classes and recess, which could impact the teachers' opportunity to discover symptoms of depression. Meanwhile, at home there are more similar routines throughout the week, fewer shifts and fewer people that could make it easier to discover mood changes in the students. However, more important is probably how well the adult person knows the student. Obviously, parents know their children or adolescents better than the teachers, thus parents may be more able to discover symptoms of depression. Teachers of students with SRB in our study reported that they knew the students less well than teachers of the students without SRB. This may be caused by the fact that the students with SRB were mainly attending secondary school in contrast to the students without SRB. Commonly, teachers in secondary school spend less time with the students than those in primary school due to presence of more subject teachers. Furthermore, when the students display SRB they are not attending school or classes as frequently as the other students and that could impact the teachers' possibility to get to know them.

A third possible explanation for the increased discrepancy between parents and teacher may be related to the teachers' competence in ASD. To be able to identify symptoms of depression, knowledge about the core symptoms of ASD and the students' individual characteristics is crucial. Because students with ASD may express emotional symptoms in idiosyncratic ways, parents may be better able to interpret these expressions than the teachers due to their experiences throughout the child's lifespan (66).

Due to the discrepancy between parents' and teachers' perceptions of collaboration, competence and emotional symptoms, it is not surprising that it could lead to tension and put

the collaboration to test (113, 115). Thus, parent – teacher communication needs to be facilitated to ensure that all concerns are put on the agenda and discussed frequently in an open and mutual way (102, 114). One may argue that SRB present in the students with ASD could hamper good collaboration and communication between parents and teachers, which is regarded as crucial for treatment of SRB (27).

## 5.2 Strengths and limitations

### *5.2.1 Design*

The cross – sectional study design utilized is neither appropriate to discover causal relationships nor the directions of the relationships between SRB and the factors explored. However, this design is commonly used and considered to be appropriate for exploring associations between the topic studied across different groups and ages in a fixed period. A 20 day assessment period was considered as both manageable for the parents and the teachers, and sufficient to answer the aim of the study. Appropriate time for assessment was decided as the periods with the most regular timetable. Research in SRB in students with ASD is in an early stage, thus we consider an open research approach to explore the topic as appropriate. However, the design is not considered to be scientifically rigorous.

### *5.2.2 Sample*

The sample was not clinically referred and probably not biased regarding comorbid problems. However, the sample could be biased with respect to the presence of SRB because the topic was announced in the information about the study. Thus, parents of students with attendance problems may have been more motivated to participate.

Assessing the frequency of SRB in a comparison group of TD students is considered as a strength, because similar studies utilizing a broad definition of SRB have not been previously performed (Paper I). Even though the TD students were of a similar gender and age and attended the same class as the students with ASD, it is not certain that they match completely due to the lack of socio-demographic information. The sample of students with ASD with and without SRB were comparable, thus suitable for discovering characteristics associated with SRB.

The age range of 9-16 years was chosen as, in Norway, the majority of the children diagnosed with ASD and IQ> 70 are approximately nine years at the time of diagnosis and compulsory school ends at the age of 16 years (55). Students with an IQ score below 70 were excluded from the study because they often tend to attend more specialised school settings. The sample size could statistically detect associations with medium and strong effect sizes (Paper II), however it was probably not sufficiently large to detect true associations (Paper III). Furthermore, due to the small sample size, a comparison between genders was not performed. These factors represent limitations regarding the generalisation of the findings to the ASD population overall and to the general child and adolescent population.

### *5.2.3 Assessments*

The assessments of this study were answered both by parents and teachers who contributed with information of the students from the different environments assessed, and thus this is considered as a strength (125, 143, 144) (Paper I and III). Parents commonly rate emotional and behavioural problems more highly than teachers, and mothers rate more highly than fathers (125, 145, 146). The majority of the parent-rated questionnaires in the study were answered by mothers, which could have biased the findings (Paper II and III). Parents and teachers assessed emotional and behavioural problems within the same period of time, which

is considered important to avoid temporal assessment bias. Due to lack of self-reports and laboratory assessments, it should be kept in mind that the findings represent the parents' and the teachers' perceptions of the characteristics of the students studied, and the validity of the information assessed depends on the quality of informant reports. Both the BRIEF, the SRS and the ASEBA questionnaires contains self – report versions, and the use of these would have made the study more complete (120, 122, 125). However, executive functions assessed in everyday life settings could have higher ecological validity than neurocognitive testing in the laboratory since some executive deficits might not be observable there, or the students with ASD might perform better in a structured task-related setting than in real life (81). The BRIEF, the SRS and the ASEBA questionnaires are commonly used in the ASD population, although developed to assess problems in the general child and adolescent population.

The questionnaire for assessing SRB was developed for this study due to the lack of an existing formal questionnaire suitable for the study purpose (Attachment I). The visual expression of the questionnaire was designed to be easy to navigate for the raters and the categories were well defined (1, 147). However, the use of a not formally tested questionnaire represents a limitation regarding the reliability of the instrument both within and across different raters. Absenteeism that was not confirmed by the parents or the teachers as legitimate was counted as SRB. Furthermore, students were regarded as students with SRB from the first occurrence of the behaviour. These decisions could have included students who might not have a problem of concern. A further limitation was that the parent and teacher ratings of SRB in the student with ASD were not completely comparable due to environmental and temporal bias (Paper I).

The questionnaires collecting information from parents and teacher regarding supervision, collaboration and competence were developed with regards to easy navigating and well defined categories, however, this may represent a limitation (147, 148).

### 5.3 Implications for clinical practice

The high frequency of SRB in students with ASD revealed in this study underlines the importance of awareness of this phenomenon amongst clinicians, teachers and parents. SRB expressed mainly as refusal was most frequent among students in primary school and could be considered as early signs of SRB. Early identification and intervention are regarded as beneficial to successfully treating SRB. Thus, refusal to attend classes or school should be addressed in the school – home collaboration and possible factors should be identified and steps taken to ease the stressful situation.

Factors associated with SRB were found both in the individuals, the families and in the schools, thus supporting the importance of a broad assessment ahead of intervention (19). Individual characteristics in the students were limited to motivation to engage in social relationship, deficits in initiating, planning and organizing tasks and activities, in generating new ideas, in solving problems and displaying symptoms of depression. Both social and emotional problems are commonly reported among students with SRB in the general child and adolescent population, thus it is recommended to assess them ahead of treatment. We suggest that these recommendations are also valid for the assessment of students with ASD and SRB. However, executive functioning should be assessed in students with ASD because they often display executive deficits, and the information revealed could be valuable for the adaptation of education, daily routines and social skills training. The complexity of SRB present in students with ASD calls for interdisciplinary professionals with expertise in ASD to be involved in the assessment and treatment phases.

A higher frequency of illness was revealed in the families of students with ASD and SRB compared to those without SRB. Parenting a child with ASD and especially those with

intellectual abilities within the normal range is found to be challenging and causes distress in the families. We may assume that parenting a child with ASD and SRB could increase the distress, similar to parents of students with SRB in the general child and adolescent population (27, 33). To overcome the negative consequences of stress and depression, social support, perceived self-efficacy, positive reappraisal and confrontational coping style, and access to social and health services are documented as being important (27, 90, 96, 149, 150).

Awareness of tension in the school – home collaboration should be present among principals and teachers of students with ASD, especially when the students display SRB. Thus, at the beginning of schooling, open and honest communication and collaboration with the parents should be provided for by the professionals in school. Parents of students with ASD should be encouraged, by the principals and the teachers, to address their observations and concerns' regarding their children's well - being in school. The lack of concordance between parent and teacher rates of emotional problems is known in research. To prevent parents and teachers entering trenches and blaming the other for not making observations similar to themselves, it is crucial that this knowledge is communicated and the different perspectives are explored equally in the school – home collaboration. Furthermore, less than half of the teachers were satisfied with their competence in ASD. Students with ASD should, according to their rights, be provided with a learning environment that is equal to that of students in general. Thus, the principals should arrange for the use of best practice and ensure possibilities for the teachers to increase their skills in educating and adapting the learning environment for these students. Competence in ASD and in identifying additional problems in the students among the teachers could positively impact the school – home collaboration when students display SRB.

Overall, SRB in students with ASD is a frequent, complex condition increasing the likelihood for tension and dropout. The school authorities and principals are mandated to

provide the teachers and the whole school environment with the competence to fulfil these students' rights to be included in their schools. The educational, health and social services need to have expertise in ASD and SRB, and furthermore should establish committed interdisciplinary collaboration. The complexity of the condition calls for the principals to involve these services early and put together a group of professionals and parents responsible for assessments and interventions. Furthermore, empowering the parents is valuable and should be prioritized (27). Steps should be taken to establish regular access to parenting programmes from the hospitals and health and social services in the municipalities. At present, the accessibility to such programmes, and to support and supervision is limited and provided randomly.

### 5.4 Further research

Most studies of SRB have reported prevalence rates based on national registers of non-attendance and large surveys of students in the general child and adolescent population. Thus, larger studies focusing on non-attendance and SRB among students with neurodevelopmental disorders are necessary.

Clinicians underline the importance of early intervention when students display SRB, thus studies assessing signs of SRB in early stages would be appreciated, together with longitudinal studies mapping the trajectories of the condition.

Descriptive studies collecting information from multiple informants, including the students themselves, are necessary to enhance the understanding of this complex condition. Furthermore, studies of interdisciplinary cooperation between professionals in educational and health services revealing knowledge of best practice in assessing and treating SRB in community settings are of great importance.

At the present time, treatment studies are necessary to describe best practice for students with ASD and SRB.

Last but not least, researchers in this field should take the responsibility to use definitions that are more congruent with each other to increase the possibility of comparing different studies and communicating clearly with professionals that provide services for students, parents and teachers in the communities.

## 5.5 Conclusion

The overall aim for this study was to advance the understanding of SRB in students with ASD without intellectual disability going to inclusive primary and secondary public schools. The high rate of SRB revealed in our study indicates that students with ASD are not given equal opportunities in inclusive schools. Providing education that is not able to meet the students' needs is serious, not only for the students and the families but for the whole society: ethically, legally and financially.

The high rates of SRB, social and executive deficits and symptoms of depression in the students with ASD, illness in other family members, and different perceptions between parents and teachers underline the importance of awareness from professionals in educational and health services, principals, teachers and parents. Refusal to attend school or classes was present in students from 4$^{th}$ grade. In order to establish better conditions for the students at an early stage, refusal to attend school should be taken seriously and addressed in the school – home collaboration.

Several of the findings in this study are in line with findings in the general child and adolescent population, indicating that general recommendations can be utilized for students with ASD and SRB. However, the assessments should also include domains more specific to

difficulties in students with ASD, and in addition, the treatment should account for the ASD core symptoms. However, several questions are still to be explored and it is important to bear in mind that each student is unique, and thus assessment and treatment procedures should be individually adapted.

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# Paper I

# Paper II

# Paper III