

# A 6-year follow-up of children assessed for suspected autism spectrum disorder: parents' experiences of society's support

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**Background:** Early support and interventions are suggested to be important for children with autism spectrum disorder (ASD) and other developmental problems and their families. Parents are described to have a burdensome life situation where the child's problems have a great impact on the family's well-being.

**Aim:** To obtain increased knowledge of parents' experiences of support and interventions 6 years after their child was assessed for ASD.

**Methods and procedures:** A semi-structured questionnaire was sent to all parents (n=101) whose preschool children (<4 years of age) had been assessed for ASD about 6 years prior in Gothenburg, Sweden. The open-ended questions were analyzed thematically using a hermeneutic phenomenological approach.

**Outcomes and results:** Parents of 56 children answered 30 questions about their experiences concerning support from society after the neuropsychiatric assessment. From the eight open-ended questions, three themes were identified: parental responsibility, resources and competence among actors in society, and inequality. The parents experienced that they had to take responsibility for meeting the needs of and securing support for their child. They found that the support given was unequal, uncoordinated, and with great variations between both geographical areas and professionals. Parents' own resources were described as impacting the possibility to secure adequate interventions, resulting in unequal treatment of families depending on socioeconomic status. Several parents also expressed experiencing a lack of individualization of services and interventions. All children had received some kind of action from society, but not to the degree they had wished for when the children got their ASD diagnosis.

**Conclusion and implications:** The essence of parents' comments was the experience of authorities and societal actors trying to push the responsibility onto someone else. The study indicates a need for continuous longitudinal support for children identified with neurodevelopmental problems before the age of 3 years. This requires collaboration and coordination between different societal bodies.

**Keywords:** ASD, children, parents, support, interventions, coordination

## Introduction

Caring for children with different developmental disorders can be demanding for families, and parents often have very early concerns about their child's development.<sup>1,2</sup> Having a child with developmental problems, especially autism spectrum disorder (ASD), defined as severe problems with communication and social interaction as well as restricted and repetitive behavior,<sup>3</sup> has been shown to have a significant impact

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on the family's well-being.<sup>4-6</sup> Parental stress and fatigue are commonly related to concerns of raising the child, especially when the child has very challenging behavior. Previous research has also shown financial strain, time pressure, and a lower overall well-being to be common.<sup>7</sup> Many parents have reported a burdensome situation also in the challenges faced when trying to get help and support from the community. Previous research has reported frustration among parents struggling to find adequate help regarding education for the child, therapists, or other forms of support.<sup>8,9</sup> Overall, many parents have reported a lack of help from professionals after the diagnostic process and that they are expected to take a disproportionate responsibility in addition to their parenthood.<sup>4,10</sup>

The term Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations (ESSENCE) describes symptoms across disorders. ESSENCE underlines the importance of clinical examinations in early years, even when the child does not meet criteria for a complete diagnosis such as ASD, and that neuropsychiatric disorders rarely occur alone but are symptoms of different types of problems.<sup>11</sup> Many professionals have urged worried parents to wait for an assessment until the child gets older and see if the problem disappears with age, but recent studies have shown that early signs of developmental problems often become clearer over time and persist into adulthood.<sup>12,13</sup> Instead, a watchful waiting approach has been suggested in order to provide different types of interventions depending on the child's current problem and the family's current needs, which may vary over time. In the last few years, there has been an increasing focus on the importance of early interventions for these children.<sup>14,15</sup> The main findings of two recent studies were that while early interventions matter for long-term symptom reduction,<sup>16</sup> the type of intervention is not critical for outcome of adaptive or global functioning.<sup>17</sup>

While early interventions are important, research has shown that interventions for children with ASD and their parents can also increase the level of stress in parents,<sup>18</sup> which may in turn reduce the effectiveness of the interventions given.<sup>19</sup> Thus, children with ASD and other developmental problems in the field of ESSENCE need continuous support, monitoring, and adjustments in their everyday life for a positive development.<sup>20</sup>

Like, for example, the USA, the Swedish health care system is regulated by the Health and Medical Services Act.<sup>21</sup> The aim of the health care system is to achieve good health and equal care for the entire population. The health care should be accessible, built on respect for the patient's

autonomy and integrity, and facilitate positive contacts between the patient and the health care staff. It should also provide continuity and good coordination in an appropriate way. In 2015, the Swedish government in collaboration with local governments signed agreements on further strengthening existing good and equal care, the so-called patient-centered care.

The social rights in many western countries (eg, USA, UK, Australia, and Sweden) are regulated by public security systems. The Swedish Social Insurance Agency is a Swedish government authority providing economic compensation to individuals in various situations. Parents of children with disabilities can apply for care allowance, which can be received if the children need more care than children of the same age without disabilities. This is often given to parents of children with ASD, intellectual disabilities, or attention-deficit/hyperactivity disorder (ADHD). The amount paid varies depending on the level of disability and is individually assessed.

The Law regulating Support and Service to Persons with Certain Functional Disabilities (LSS) in Sweden<sup>22</sup> is an entitlement law and entails supplementary support for individuals with significant and long-term functional disabilities. The law applies to: 1) persons with intellectual disabilities and people with ASD or conditions similar to ASD, 2) persons with significant and permanent intellectual functional disabilities following brain damage as an adult, and 3) persons who as a result of other serious and permanent functional disabilities, which are clearly not the result of normal ageing, have considerable difficulties in everyday life and a great need of support or services. According to LSS, different kinds of assistance can be provided: 1) advice and other personal support, 2) personal assistance, 3) companion service, 4) contact person (the function of a contact person is to be a contact outside the applicant's own family who can, for example, help to break the child's isolation and make an independent life easier), 5) relief service (in the Municipal District, there is a group of persons who go to the homes of families with children and relieve the parents in the care of a functionally impaired child [Eskilstuna Municipal Authority]), 6) short-term stays away from home, 7) short-term care for school children >12 years of age, 8) living in family homes or housing with special services for children and young people, 9) housing with special services for adults or other specially adapted housing for adults, and 10) daily activities.

In Sweden, all preschool children with ASD are given interventions in habilitation centers. In some

municipalities, habilitation centers are in addition performing the ASD assessments, but not the centers included in this study. The children are instead diagnosed at the Child Neuropsychiatric Clinic (CNC) and then referred to the habilitation center. Children with speech and language problems are assessed and given language interventions by speech and language pathologists, mostly at Pediatric Speech and Language Pathology (PSLP) clinics. Children with ASD plus language impairment (LI), registered at the habilitation center, usually have their language intervention there. As a comparison, children with LI in the UK often receive language interventions within the school system.<sup>23</sup>

In 2014, the medical guidelines for children with ASD in Gothenburg, Sweden, where the present study was performed, were changed. Before 2014, all school-aged children were included in the habilitation centers, in accordance to regulations in the Health and Medical Services Act.<sup>21</sup> From 2014, school-aged children with ASD, but with no intellectual disability, are referred to the Child and Adolescent Psychiatry (CAP) clinics. CAP clinics provide support for children/adolescents <18 years of age (and their families) who have psychiatric problems or neuropsychiatric impairments. CAP clinics also provide neuropsychiatric assessments or examinations of other psychiatric disorders.

Special educational interventions are required for children with ASD and other developmental problems.<sup>20,24,25</sup> For the child's development, it is, therefore, of great importance that teachers have knowledge of neuropsychiatric disorders and of appropriate educational efforts. According to the Swedish education act,<sup>26</sup> all children should have an education based on their needs. The principal is responsible for the planning and the decisions related to the child's support in preschool or compulsory school, but the parents should be involved in the procedure. Individual educational help and strategies most commonly are provided in regular preschool groups or school classes, but there are also some special schools for children with different disorders. A child with intellectual disabilities has the right to study on the basis of a special curriculum that is adapted to his/her intellectual conditions, regardless of whether the child attends a special school or a regular school.<sup>26</sup>

The approach and terminology within the school system regarding students in need of special support over the years have been discussed and changed. In the 1980s, the word inclusion was more frequently introduced in many Anglo-Saxon countries. Previously, the word integration had come to represent an approach where children in need

of special support were supposed to adapt to the school system. Inclusion would instead shift focus to how the school could be designed to accommodate all students with the goal of providing every student with an optimal school situation. This, however, resulted in different interpretations, leading to the inclusion concept being given different meanings. Some researchers argue that community in the classroom should be in focus, while other researchers stress that all students should have a good school situation as individuals, meaning that the community in the classroom should be secondary.<sup>27</sup> In Swedish schools, the focus over the last years has been on community in the classroom, and the number of special classes has, therefore, significantly decreased.

An individual's ability to function in everyday life depends both on personal conditions and environmental factors, which means that the degree of disability largely depends on to what extent the environment is adapted to the individual's needs. The purpose of International Classification of Functioning, Disability and Health<sup>28</sup> is to provide a common language and a description of health and health-related states in everyday life. Interventions should be individually planned and designed to reflect the heterogeneity in children's and families' needs.<sup>29</sup> According to the Convention on the Rights of the Child, meeting every child's individual needs shall be a primary consideration.<sup>30</sup> Every child has the right to grow up in a positive family environment, and the state parties have a responsibility to provide the parents with necessary support.

With some exceptions,<sup>2,4,31</sup> the research focusing on parents' experiences of the process associated with receiving an ASD diagnosis is still limited. Existing studies directed at parental perception of receiving diagnoses tend to focus on the disclosure of the diagnosis rather than the process preceding and following the disclosure.<sup>31</sup> A Swedish report focusing on parents of children with different kinds of disabilities and their experiences of support shows that the majority are not satisfied with the support as a whole and that they had to struggle to receive the right support.<sup>32</sup>

Against the background stated above, this study was designed to gain further understanding of the parents' experiences and opinions regarding support from society on the basis of legal rights, and the support which is offered after their child had screened positive and been assessed for ASD in early preschool years. The aim was to provide a rich description of how parents' experience this support 6 years after the initial assessment. The following research question was posed: How do parents experience support

and interventions 6 years after their child was assessed for suspected ASD?

## Methods

### Design, procedure, and empirical material

This is a qualitative study that aims to gain a deeper understanding of parents' experiences of getting support from society after having had their child go through an assessment process and be diagnosed with ASD or other ESSENCE problems in early preschool years. Qualitative research is characterized by an aim to understand a specific phenomenon from the perspective of those experiencing it<sup>33</sup> and hence lends itself well to the study's research question. The study follows an inductive approach, where the empirical material provides the starting point for an analysis that moves from the specific to the general and where the empirical material provides the basis from which the analytical concepts are derived.<sup>34</sup> The empirical material, consisting of eight open-ended questionnaire questions (q 6, 11, 16, 18, 21, 25, 28, and 30), was analyzed thematically. The questionnaire (found in Table 1) also included 22 multiple-choice questions on contacts with and support offered to families by various social institutions. Both multiple-choice questions and open-ended questions were formulated based on the overall research aim – to shed light on parents' experiences of support. When formulating the questions, consideration was given to include all actors that commonly take part in an intervention chain. This was done in order to cover all the areas that in this specific context should be included in the “support” concept. Thematic analysis entails searching for common patterns or themes in a text material, where a theme represents “an abstract entity that brings meaning and identity to a recurrent experience and its variant manifestations” (p. 362).<sup>35</sup> In thematic analysis, the importance of a theme does not have to be based on quantifiable measures. Instead, a theme is primarily defined through its ability to capture something important in relation to the overall research question.<sup>36</sup> In the current article, the themes have been derived using both number of occurrences and relevance to the main research question as selection criteria. The thematic analysis process contains a number of steps summarized as follows by Braun and Clarke: “getting familiarized with data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing a report” (p. 87).<sup>36</sup> In the present study, these steps have been carried out adopting the hermeneutic notion that the whole must be understood in relation to the detailed parts and vice versa. Following this notion, the empirical material

**Table 1** Parental questionnaire

Question	N (%)
1. My child is a	
1. Girl	13 (23)
2. Boy	43 (77)
2. Has your child been referred to Habilitation and Health (Child and Adolescent Habilitation Services)?	
1. Yes	51 (91)
2. No	5 (9)
3. Don't know	0
3. Has your child not been referred to Habilitation and Health Services in spite of you wanting it?	
1. Yes	1 (2)
2. No	5 (9)
3. Don't know	1 (2)
4. Has your child been referred to Habilitation and Health Services in spite of you not wanting it?	
1. Yes	3 (5)
2. No	39 (70)
3. Don't know	1 (2)
5. From your perspective as a parent; do you feel that you and your child have been given support sufficient to your needs from the Habilitation and Health Services?	
1. Yes, definitely	20 (36)
2. Yes, to some extent	18 (32)
3. No	13 (23)
6. If you have been in contact with Habilitation and Health Services, please describe briefly what kind of support you have received.	
7. Has your child been referred to the PSLP (Pediatric Speech and Language Pathology) Clinic?	
1. Yes	16 (29)
2. No	35 (62)
3. Don't know	5 (9)
8. Has your child not been referred to the PSLP (Pediatric Speech and Language Pathology) in spite of you wanting it?	
1. Yes	9 (16)
2. No	25 (45)
3. Don't know	1 (2)
9. Has your child been referred to the PSLP (Pediatric Speech and Language Pathology) in spite of you not wanting it?	
1. Yes	0
2. No	20 (36)
3. Don't know	3 (5)
10. If you have been in contact with the PSLP (Pediatric Speech and Language Pathology); do you feel that you and your child have been given support sufficient to your needs from PSLP (Pediatric Speech and Language Pathology)?	
1. Yes, definitely	5 (9)
2. Yes, to some extent	8 (14)
3. No	2 (4)
11. If you have been in contact with the PSLP, please describe briefly what kind of support you have received.	
12. Has your child been referred to Child and Adolescent Psychiatry Services (CAP)?	
1. Yes	12 (21)
2. No	41 (73)
3. Don't know	1 (2)

(Continued)

**Table 1** (Continued)

Question	N (%)
13. Has your child not been referred Child and Adolescent Psychiatry Services in spite of you wanting it?	
1. Yes	1 (2)
2. No	32 (57)
3. Don't know	2 (4)
14. Has your children been referred to Child and Adolescent Psychiatry Services in spite of you not wanting it?	
1. Yes	3 (5)
2. No	13 (23)
3. Don't know	3 (5)
15. If you have been in contact with Child and Adolescent Psychiatry Services; do you feel that you and your child have been given support sufficient to your needs from Child and Adolescent Psychiatry Services?	
1. Yes, definitely	3 (5)
2. Yes, to some extent	4 (7)
3. No	4 (7)
16. If you have been in contact with Child and Adolescent Psychiatry Services, please describe briefly what kind of support you have received.	
17. Has your child been offered interventions according to the The Swedish Act concerning Support and Service for Persons with Certain Functional Impairments (LSS)?	
1. Yes	29 (52)
2. Yes, but it hasn't been relevant to us	11 (20)
3. No, but we have wanted interventions from LSS	11 (20)
18. If you have received interventions according to the The Swedish Act concerning Support and Service for Persons with Certain Functional Impairments (LSS), describe in a few words what kind of help you have received, eg, support family, relief service, personal assistance etc.	
19. Did your child go to preschool or child-minder after the assessment?	
1. Yes, to preschool	55 (98)
2. Yes, to child-minder	0
3. No, neither preschool nor child-minder	1 (2)
20. Did you then receive any extra interventions for your child for example changed work procedures based on the child's needs, extra staff, smaller group, communication support (= images, signs) etc.?	
1. Yes	43 (77)
2. No	10 (18)
3. Don't know	1 (2)
21. If you received any extra interventions in preschool, please describe what kind of interventions.	
22. What is your child's school placement?	
1. Regular comprehensive school	35 (62)
2. Regular comprehensive school class but following the compulsory school for learning disabilities curriculum	3 (5)
3. In a compulsory school for learning disabilities class	11 (20)
4. Other (Special class within the regular comprehensive school)	4 (7)
5. Does not go to school, does not work	1 (2)
23. Does your child go to recreation center/child-minder?	
1. Yes, recreation center	43 (77)
2. Yes, child-minder	0
3. No neither recreation center nor child-minder	12 (21)

(Continued)

**Table 1** (Continued)

Question	N (%)
24. Has school and/or the recreation center made any specific adjustments based on your child's needs, for example changed their work procedures based on the child's needs, extra staff, smaller group, communication support (= images, signs) etc.?	
1. Yes	39 (70)
2. No	13 (23)
3. Don't know	2 (4)
25. If you received any extra interventions in school and/or at the recreation center, please describe what kind of interventions.	
26. Have you applied for childcare allowance from the Swedish Social Insurance Agency?	
1. Yes	49 (87)
2. No	3 (5)
3. Have not received information about childcare allowance	3 (5)
27. If you have applied, were you granted childcare allowance?	
1. Yes 100%	12 (21)
2. Yes 75%	12 (21)
3. Yes 50%	15 (27)
4. Yes 25%	7 (12)
5. We have recently applied but have not yet obtained an answer	0
6. No, our application was denied by Swedish Social Insurance Agency	0
28. Have you applied for any other support from society based on your child's needs? If so, please describe the type of support.	
29. If you have applied for other types of support, have you been granted what you applied for?	
1. Yes	7 (12)
2. Partly	0
3. No	10 (18)
30. Is there any other information you want to convey to us regarding support to your child following assessment at the Child Neuropsychiatric Clinic (CNC)?	

**Notes:** Only questions 1, 2, 7 and 19 are answered by all 56 parents. The response rate varies in the other questions. Percent rate is calculated in relation to all 56 questionnaires.

enters into the hermeneutic circle, where interpretation is done by consistently moving back and forth between parts/details and the whole.<sup>37</sup>

In the initial stage of analysis, the three article authors individually read the questionnaire's open-ended answers and comments to arrive at a sense of the whole and identify "meaning units", that is, words or statements that relate to the same central meaning.<sup>38</sup> This stage was followed by a joint discussion where the researchers presented, compared, and discussed their individual findings to one another in order to ensure credibility and reach agreement. In the next stage, the identified "meaning units" were related to each other and to the text as a whole to identify themes. Employing the same approach as in the initial analysis stage, this was first done individually and then followed by a joint discussion in which



all three researchers took part. Once the themes have been formulated, quotes were chosen from the empirical material to illustrate the individual themes in our analysis. The quotes were numbered to distinguish individual responders while retaining anonymity.

The quality of a study with this methodological approach can be measured in terms of its trustworthiness, defined in relation to the procedures used to achieve the study's findings.<sup>38</sup> The measures taken to ensure trustworthiness in this study have aimed to accomplish a high level of transparency. By thoroughly accounting for the various steps of the research process and including illustrative quotes from the empirical material in the analysis, we strive to enable readers to form their own opinion on the credibility of our findings. Throughout the analysis stage of the study, the researchers have also engaged in continuous discussions related to the sorting and interpretation of data, such as how well the identified themes represent and make use of the empirical material as a whole and how the selected themes relate to one another. While the article focuses on the parents' experiences as expressed through the open-ended questions, the multiple-choice questions have also been summarized in a table. This is in line with the aim of qualitative methods to enhance research transparency.

## Participants

Participants in this study comprised the parents of children who participated in the Autism Detection and Intervention in Early life (AUDIE) project,<sup>39,40</sup> where all children in Gothenburg detected with suspected ASD through ASD screening at the age of 30 months in Child Health Care were assessed at the CNC. One of the main goals of the AUDIE project was to provide early interventions. This group of children who were diagnosed with ASD were offered 2 years of interventions. While all children were offered interventions based on applied behavior analysis (ABA) entailing at least 25 hours per week, some children had modified interventions due to the lack of cooperation between preschool, parents, and habilitation services.<sup>17</sup> The children who were diagnosed with other ESSENCE problems such as LI or ADHD (with no ASD) were referred and offered individually planned interventions from the PSLP clinics or the CAP clinics. The questionnaire in the present study was sent to parents of all 101 children who accepted participation in the last part of the AUDIE project 6 years after the initial assessment. The study was approved by the Ethics Review Board at the Sahlgrenska Academy, Gothenburg. All informants provided written informed consent.

## Ethics

The study was approved by the Regional Ethics Committee in Gothenburg, Sweden. Written informed consent was obtained from at least one of the parents in each case.

## Findings

Out of 101 eligible parents, 56 (55%) answered the questionnaire (parents of 13 girls, 43 boys) (Table 1). Thirty-four of the parents answered the last question (q 30), which provided the most expounded comments in the questionnaire. For 33 of the children, both parents were born in Sweden; for 7 of the children, one of the parents was born in Sweden; and for 16 children, both of the parents were born in another country. Fourteen of the participating families had more than one child with ASD. The age of the 56 children at the time of the diagnostic process was 27–49 months (mean age 37 months). Forty children had ASD, six children had ASD plus ADHD or LI, three had LI, two had ADHD, and five children did not receive any diagnosis, but showed ESSENCE problems such as developmental delay. The children were diagnosed about 6 years before the current questionnaire was answered by the parents. Forty children had a developmental quotient (DQ) <70, and 16 children a DQ >70. The response rate varied reflecting the various levels of contact with the different societal actors mentioned in the questionnaire. Sixteen of the questionnaires were answered by both of the child's parents, 23 by mothers, and 7 by fathers. In 10 of the questionnaires, the question of who responded was left unanswered.

It is clear from the multiple-choice part of the questionnaire that the majority of the children had been referred to the habilitation center, but there was a notable variation in their experience of the received support. ABA was commonly mentioned as the main intervention. Most of the parents answered that the children had not been in contact with the PSLP clinics or the CAP clinics. The majority said that they had been offered support in their everyday life through LSS with relief service being the most commonly reported support, and none of the parents said that they had been refused care allowance from the Swedish Social Insurance Agency. Most parents also said that there had been special adjustments in the child's preschool and school setting, but there were large variations regarding type and quantity of interventions described (Table 1).

From all available information provided by the questionnaire's open-ended questions and comments, a number of themes were identified. We identified three main themes: 1) parental responsibility, 2) resources and competence among actors in society, and 3) inequality.

## Parental responsibility

The first theme we identified we refer to as parental responsibility. It highlights the parents' feeling of being left on their own to fight for their child's right to support while at the same time trying to cope with the challenges in the family situation. Within this theme, we identified two subthemes: 1) early diagnosis is good, but there is a lack of help after the diagnostic process, and 2) there is a great responsibility placed on parents and relatives for meeting the child's need of support.

### Early diagnosis is good, but there is a lack of help after the diagnostic process

Overall, the parents were satisfied with the diagnostic process, expressing that they were provided with information about the child's needs, and of the importance of early intervention for the child's positive development. Parents however reported having to wait for interventions to start and feeling that the process after diagnosis did not proceed.

After diagnosis of a child it becomes very clear what weaknesses the child has and what help the child is in need of. You also get information about the importance of early interventions. Unfortunately there are no resources anywhere to meet this need. [10]

After the assessment at CNC all the responsibility was dropped. We have wanted but been denied a new assessment. Everyone wants to push the responsibility onto someone else. [21]

The support following assessment is non-existent. No resources or interventions are provided by the municipality, school, county council without lobbying, nagging and insistence. [23]

Yes, but an incredible amount of work from us parents. He got his own individual support but not trained so that person quit all the time due to not suitable. Staff turnover high. Would have needed a smaller children's group – not possible according to principal and area manager. [10]

### A great responsibility is placed on parents and relatives to meet the child's need of support

The parents expressed that they had to fight hard for their child's rights to support and interventions. Experiences entailed having to chase support, navigating among the various societal actors, and taking a disproportionate responsibility. Parents described that this affected the family to such a degree that they worried about not being able to cope with their situation.

X is 7 years old and in need of adult support absolutely every waking minute, from a parent or from the grandmother. The family is having a very tough time and it is extreme now that the school is acting the way they do. [8]

It is incredibly tough to be fighting against the school about the child's right to support [...] The family is going under [...] It is a struggle just to get everyday life to work and then you have to fight this battle. [27]

Parents are no authority in the autism/school debate and we wish that some more influential profile could help. [9]

When one challenge with X disappears, a new one comes along. [7]

I myself take a leave of absence from work for two hours so that I can pick up and drop off my child at school. [11]

The support provided from professionals was often found to be limited, unclear, and lacking in continuity. The parents felt that professionals placed too much responsibility on parents to have knowledge about intervention methods that they did not know how to handle. They expressed a feeling of being left on their own.

I expect a concrete, structured and comprehensive program but NOPE. Instead we are drowning in TIPS AND IDEAS, we are to try various methods ourselves without supervision and design the exercises on our own. It is completely unreasonable that a parent should have to be trained as a special education teacher, psychologist or speech and language therapist. My education is within marketing. That should be sufficient to handle the family's economy. Other types of knowledge should come from those who are trained as speech and language therapists, psychologists and special education teachers. [26]

In connection with the child starting school, many parents described having to fight hard for their child's rights to obtain support.

Been a constant struggle for support and adaptations after starting school. Attends regular comprehensive school. Received some adaptations but been a huge struggle for us parents. At school X has an individual support person 1 hour/day in class except for Fridays in spite of both the teacher and the special education teacher stating that X needs constant adult support. Not had any adaptations at the recreation center and HATES the recreation center but can't be home alone [...]. [27]

Numerous weeks, months and years of coordination meetings, written compilations of X's needs and a constant battle for the extra individual support that in preschool has

come after 7 months of school refusal. Very long preparatory training period and the right staff (special education teacher) supervised by others was a success during one single period. [9]

## Resources and competence among actors in society

The second theme that we identified was resources and competence among actors in society. This theme captures parental disappointment particularly with habilitation services and the school system. Within this theme, we identified four subthemes: 1) support offered in the home setting is perceived to be of poor quality, 2) resources and competence at the habilitation center are not enough, 3) frustration with the preschool/school situation, and 4) interventions need to be more individualized.

### Support offered in the home setting is perceived to be of poor quality

Many families were offered relief service in the home, but were disappointed when they felt that the staff did not have the right skills to take care of their child.

Relief service at home. This does not work as there are many different relief service employees who don't understand the child's needs. Becomes a strain and a disappointment. [6]

Been offered relief service that didn't work. Our efforts to get started with the relief service are disproportionately much bigger than the help we have been able to get from the relief service. 7 months of preparatory training/getting to know the relief service person to realize that you can't leave him with the relief service person. (Also, it is young people who quit just when your child has got to know them.) [9]

Got help with cleaning and shopping once a week but the quality was so bad that it was terminated. X had a couple of hours with a relief service person, which could be used only after a year – could not be alone with a stranger. [32]

### Resources and competence at the habilitation center are not enough

The parents expressed major disappointment in not receiving the support from the habilitation center that they had expected. Some parents also found the referral from the assessment clinic to the habilitation center to fail.

The referral between CNC and habilitation services did not work. Habilitation services are overloaded and in the midst of a generational renewal, ie, there is neither staff nor

competence to provide the support and interventions that CNC has shown in the assessment. [4]

X was initially left completely without help from habilitation services and 2–3 years ago she was dismissed from there as she X did not belong to the right “customer group”. I always expected the Swedish Social Insurance Agency to be the big, heavy battle. Never thought that habilitation services would be my headache! Now we refuse to even think about habilitation services anymore, it only takes energy from us and there has never been any help or resources there. [3]

Many parents perceived the habilitation centers' competence regarding neuropsychiatric disorders to be poor. They also thought that other disorders were prioritized and that children with autism were secondary.

You are referred to habilitation services where there is neither competence nor resources. [10]

At this time we have no support/contact with habilitation services. At the last talk around 2011 they stressed that “you are so good that you can manage on your own”. It feels like their interest lies in children with physical disabilities or Down syndrome. [22]

With the exception of the diapers and protective bed covering offered by habilitation services our collaboration overall has been negative. X had access to a speech and language therapist before habilitation services took over but hasn't had that since. [1]

Some parents even considered themselves to have higher knowledge of neuropsychiatric disorders than the professionals.

The support from habilitation services is beneath all contempt as NPD-specific competence is lacking in both psychologists and special education teachers. Often the parents have better knowledge of NPD than the habilitation staff. [23]

Parents perceived a lack of flexibility regarding interventions. Financial and organizational restrictions were also put forward as factors limiting the help to the children.

Habilitation services all of a sudden figured out after 5 years, that X did not belong to habilitation services anymore since X was not intellectually disabled now?!! X has never been intellectually disabled but always only had autism. [15]

Initially we got to attend intensive training that merely followed a document 1–12 points. The work thus was not adapted to the child's level. X got fed up because he had already passed the first points. Habilitation services are bad



at adapting their training to the individual. Like to follow a doc from A–Z. [15]

Relatively well-functioning intensive learning, after that virtually no support. Habilitation services are a very large, inefficient, slow and impersonal organization. [20]

We perceive habilitation services as simple-minded and underfunded. [1]

### Frustration with the preschool/school situation

Many parents felt frustrated about the situation in preschool and with the school system. They believed that the “inclusion” did not benefit the child but was perceived to have other primary purposes. Moreover, a concern was raised that the knowledge of children with different disabilities is lacking among politicians and decision makers in the school system.

Inclusion has become a mantra for managers within childcare services and efficiently masks cost cuts affecting these children. Who can assess whether adjustments that are carried out are sufficient for the child to thrive and develop? This has to be done by someone with competence! Schools Inspectorate staff has no knowledge in this field and argues that the preschools/schools have done what they can merely by setting up a plan of action for the child. Whether what is in the plan of action has any effect or is even implemented apparently does not matter. [10]

Some parents said that with the current organization of the Swedish school system, an adverse effect arises instead of being included in the social environment.

More knowledge in school is needed to be able to support these children. “Inclusion”, at what price? [...] It amounts to exclusion in class instead! [27]

Inclusion is a joke in Swedish school! A cruel joke [...]. [26]

One parent described the positive change in the child when the school provided more help.

I don't think we have received much help after the diagnosis. The school has been beneath all contempt, which resulted in school refusal, been feeling mentally unwell with anxiety and self-harming etc. Did not even get help then by habilitation services. The school has finally opened its eyes and X has got a new assistant. Goes to school with a smile now. [14]

### Interventions need to be more individualized

Experiences of lack of individualization emerged among many of the parents. They found this to be a problem both in the habilitation services and in school.

Habilitation services we don't award any marks whatsoever. They need to become more individualized and need to be able to read each child according to her/his needs. [15]

As more and more children get the diagnosis within this spectrum the interventions need to be tailored in a whole other way than what is done today!! It is great that for example parental courses etc. are arranged – but these too should be divided into parents of children with high functioning and parents of children with non-high functioning autism. Today the interventions are inadequate for very many!! [16]

Difficult to find the right school form. X is between two school worlds, can't manage regular school, can't yet read (10 years) and can count to 10. [18]

Several parents expressed frustration in relation to the gap between research in the field of autism and what has been implemented in society. Some parents described this as a contrast to the knowledge presented by the professionals about the importance of early interventions.

It is completely crazy that Gothenburg are world-class in research – assessment within the field, but then it is totally inadequate! [16]

## Inequality

The third theme we identified was inequality. This theme reflects parents' expressed experiences of inequality with regard to access to and quality of health care and support. Within this theme, we identified three subthemes: 1) you have to live in the right geographical area, 2) parents' own resources have an impact on family support, and 3) there is a need for coordination and guidance.

### You have to live in the right geographical area

The parents had experienced variations between different geographical areas regarding the quality and amount of support given in preschool and school, even if you live in the same city.

Circumstances vary widely in the boroughs of Gothenburg regarding the view of and resources for these children. In Northern Hisingen there isn't even a resource group for these children, whereas in Western Hisingen there is even a special preschool for children with autism. [10]

There are enormous differences in support between boroughs and between municipalities. We parents of children with autism do share a lot of information and experiences and as social media etc. increases the flow. Then

you become even more aware of the considerable national differences in the support to these children!! Would never have been accepted within the somatic care!! [16]

Parents further described experiencing uncertainty as regards the continuity and duration of support, stating that the law in this respect was not enforced.

Municipal interventions in preschools/schools are a pure lottery depending on which municipality and borough you live in. Any support in school upon school placement across borough borders can suddenly disappear from one day to the next depending on the borough's/the school's budget. The legal certainty when it comes to decisions according to The Swedish Social Services Act, LSS (Act concerning Support and Service for Persons with Certain Functional Impairments). The Swedish Education Act etc. legislation within this field is zero! [23]

When moving to another community, better support was offered.

In Gothenburg often fight to get support. While the support was good it was tough always having to ask for help. Moved now to another municipality, where support is offered. [24]

### Parents' own resources have an impact on family support

Some parents described themselves as having great knowledge of autism and they believed that this had benefited them in their contact with authorities.

As parents we have a high level of autism competence and have been good at verbalizing our needs and wishes. We have always had good relations with the principals and teachers. This has made it easier for us. [19]

They also thought that families' resources might affect the care given to children with disabilities, hence resulting in unequal treatment.

We have many views on the subject and we are fortunate in that we are two driven people with a good economy who have had an X with mild problems compared to many others. We have been able to fight, read up, pay for education, private speech and language assessment and support etc. But that's a rare luxury. [16]

Some parents stressed the importance of having a good knowledge of your rights, as you could not depend on authorities to provide you with information or to grant you

access to the support that you are eligible for. This added responsibility was described as very burdensome especially since they were already struggling to get their daily life with the child to work.

You get a really good package with diagnosis and how things are looking at the CNC but then you are completely dependent on ending up with the right caseworker. It is arbitrary, particularly within the municipality. You have to fight your way forward and then it is very important to be aware of your rights and coping all the way. It is not easy. [32]

Where is the support for parents who can't and/or don't manage to read the Education Act, have the time to make material for exercises etc.? [4]

### There is a need for coordination and guidance

The parents asked for better coordination in society of the support to these children and their families. This request referred to information on where adequate help could be obtained, as well as to increased coordination between different parties. Greater coordination was put forward as the most important step towards better support to the children and their families.

Missing a "guide" for parents regarding where NPD competence can be found within the school/preschool system. [4]

The biggest need would be increased coordination, a pilot/coordinator that assisted in the jungle. [17]

The support is not coordinated. The school and habilitation services are not collaborating even if they have had joint meetings. Those meetings don't lead to anything. SPSM (The National Agency for Special Needs Education and Schools) should assist schools. [26]

Some parents described good examples from preschool/school. These were often based on engagement and competence of individuals in the school system, but also collaboration between different actors.

The principal kept X following our request, the staff received extra support in autism competence, additional support to the children's group to free up regular staff for X. Extra space as X needed seclusion. Intensive learning in collaboration with habilitation services. [19]

Division XX preschool was special, with about 15 children and 4 adults with particular skills. 4 children had diagnoses and the staff was amazingly knowledgeable and competent, especially regarding autism. [15]

We had an amazing trained individual support person who did intensive program training several times a week.

She is the one who has helped our son to be the amazing guy he is today. We are eternally grateful!!! [29]

Now in the fourth grade he has finally had a guy as support during some lessons. Before it has not been deemed necessary. But now, more demands, more pressure, and now you notice that the gap between him and his peers is increasing even if he is a clever and sweet boy. [29]

## Discussion

Coping with the child's problems has been shown to affect the well-being of families with children with ASD.<sup>4-6</sup> Therefore, it was important to ask the parents themselves about their experiences after their child had been diagnosed. The participants of this study were recruited from the AUDIE project where the aim was early detection of children with communication and interaction problems to provide early interventions.<sup>39,40</sup> To our knowledge, the material from the AUDIE project is unique in that it is based on a representative group of children in a big city, screened for language and ASD. With this in focus, we wanted to evaluate the parents' experiences of the support given from society 6 years after diagnosis. Carlsson et al<sup>4</sup> used in-depth interviews for analyzing a smaller number of parents' (parents of 11 children) experiences more closely to the diagnosis. Our study, by contrast, focused on all kinds of interventions from society over a longer time period after the initial diagnosis. The participants in both studies were from the same population, but in the present study, we had a larger number of participants, where all parents of children from the AUDIE project were invited, and using a different method of data collection (questionnaires). The Carlsson et al's study identified the following themes: 1) seeking knowledge, 2) trusting and challenging experts, and 3) empowered but alone. For the participants in our study, the initial assessment was performed in early preschool years. All children underwent a follow-up assessment after 2 years. In some cases, the follow-up confirmed the first diagnosis and global functioning, and in other cases, the severity and/or diagnosis had changed.<sup>40</sup> At the time of the present study, the children had left preschool and were now part of the compulsory school system. Comparing the results of the Carlsson et al's study with the present study, the essence of the two studies is very similar. However, from the multiple-choice questions, we noted a variation regarding how the parents found the amount and quality of interventions from society. The majority of the comments were more negative, and the negative comments were also more expounded, which is reflected in our selection of quotes. We found it important to

analyze and further discuss the issues that parents identified as negative in order to find implications for societal improvement in handling children with ASD.

The first identified theme in our study, parental responsibility, highlights a feeling of being left on your own to fight for the child's rights while at the same time trying to cope with the challenges in the family situation. This is in line with previous research<sup>4,6,7</sup> that has identified parental stress as a very common problem when having a child with developmental problems such as ASD. Parents in our study were trying to work things out themselves by, for example, taking a leave of absence from work to facilitate for the child (for example, to enable picking the child up and dropping the child off at school). Such measures have negative financial implications for the family. Several parents also described the amount of meetings and discussions they had had to attend, to fight for their child's right to get accurate help from school, habilitation, etc. Many parents also highlighted the problem of knowing where to turn in terms of authorities and bodies. In Sweden, different authorities are responsible for different disabilities, such as ASD, ADHD, ID, or LI. Furthermore, the division of responsibility can differ between different areas, further adding to the difficulty for parents in knowing where to direct their questions. This is in line with the review of Karst and Van Hecke,<sup>7</sup> which highlights the relationship between the practical demands put on parents and parental stress.

The children included in our study were screened for language and ASD at 2.5 years of age. In a previous study from this population,<sup>2</sup> most of the parents had had very early concerns for their child's development. However, there were a few parents who had not been worried. This emphasizes the importance of providing a well-functioning organization for identification and assessment as well as for interventions and family support. Our findings demonstrate a need for the community to improve this organization to reduce the responsibility placed on parents, as we know from research that early intervention is important and that family stress can decrease the impact of interventions given to a child.<sup>19</sup> Thus, providing parents with individual support in the form of consultation from professionals who have good knowledge of developmental problems and what could be an appropriate approach for the child is a very important task.

The second theme that was identified, resources and competence among actors in society, indicates a disappointment especially towards the habilitation center and the school system as the child grows older. One can speculate that the parents had had high expectations of receiving good-quality

support from the professionals, but found resources and knowledge to lack significantly in relation to what they had hoped for. We believe that there has to be a transparency in the system, meaning that the parents should be adequately informed from the beginning of what they can expect from society. In addition, it is very important to listen to parents and to include them in the planning and evaluation of interventions and education, on both the organizational and individual level.

Some parents in our study expressed a frustration related to the word “inclusion” being used and implemented in the Swedish school system. They perceived the outcome of the inclusion strategy to be the opposite of what was indicated, as their child became increasingly excluded within the class when he/she was unable to adjust to the environment in the classroom situation. They felt that the child “just sat there isolated” without social interaction with his/her peers. It is important to view the situation through the lens of the child. Rather than employing one template for everyone, the school system must reflect the heterogeneity of children’s needs and be organized to adjust to each individual child.

Since children with ASD and other ESSENCE problems are as different from one another as neurotypical individuals, professionals need to increase their knowledge of neurodevelopmental symptoms and disorders. Every child/patient should achieve good care and support based on the individual needs, according to the Swedish education act<sup>26</sup> and the Health and Medical Services Act.<sup>21</sup> This points to the need for further and continuous education for professionals. Many parents in our study expressed that they could not leave their child in the hands of relief service in their home, since the staff had a lack of competence to take care of the child with ASD. In addition, they described a lack of continuity, when the staff often consisted of young people waiting for other job options. As children with ASD often display very problematic behavior,<sup>7</sup> it is of great importance that employees taking care of the child on their own have the appropriate knowledge and experience. Appropriate training is vital both for the sake of the child and for the employee to be able to handle the many difficult situations that may arise. Our own clinical experiences also suggest that there is a need for greater cooperation between the health care system and the school system, where we find it far too separated today both in terms of perception and the cause of the child’s problems. Parents are included in planning for interventions at one level. However, according to the experiences from parents in our study, we need to improve the routines for participation to achieve the individualization for meeting

every child’s individual needs in the way that is prescribed by the WHO<sup>28</sup> and UNICEF.<sup>30</sup>

The third theme identified from the parents’ comments is inequality, which describes an experience of inequality from different health care levels and areas. This theme highlights the parents’ experience of a lack of cohesive organization in society. The present study is performed in the second-largest city of Sweden, which is divided into 10 districts. The parents describe a difference in support, depending on in which district you belong to, even if you live in the same city. One family in the study had moved to another city, where they experienced the support to be more easily accessible. One can more easily understand if different cities have different resources depending on number of inhabitants, etc, but in the same city, we should expect a common organization and equality in terms of support. Considering that the support can never be the same for each individual depending on the heterogeneity in the children and families, different solutions and types of support must be made available. However, the guidance should be equal and available regardless of where you live or what the problem is. The parents’ experiences must be said to differ from what is expressed in the Health and Medical Services Act,<sup>21</sup> where the importance of equality and availability for patient-centered care is underlined. The law of the Swedish school system<sup>26</sup> is also very clear regarding the rights to an education based on the child’s/student’s individual needs and abilities. This should be planned in collaboration with the parents and the principal of the school.

Parents who described themselves as having a great deal of knowledge on ASD concluded this to be beneficial in their interaction with society regarding support for their child. Research has suggested that parents’ knowledge is important for the child’s improvement in daily life.<sup>41</sup> However, it should not have an impact on equal care and support from authorities to the families. This should be considered an area for change, where the responsibility should be put on the authorities, not on the parents. We need to consider the fact that parents have different resources, in terms of both education and economic factors.

Parents could also have limited resources due to own disabilities. Finally, having a child with disabilities is often a great burden for the parents, not only due to the child’s behavior or raising the child but also due to the psychological impact of having a child with developmental problems. We believe that there has to be a common and well-structured organization, extensive collaboration between authorities, and equal but individually planned care and support



for the child and his/her family. In the 4-year time period between the study by Carlsson et al<sup>4</sup> and the present study (with participants from the same population), the parents' experiences of society's support seem to have remained the same or become somewhat more negative. The parents' situation seem to have become even more strenuous as the child has reached school age and the demands on the child have increased at the same time as the societal support has decreased. Results from studies in other countries show similar results<sup>8,10</sup> where parents often describe having to struggle not least within the school system. This indicates that improving the long-term planning and implementation of support has to be made a priority.

### Limitations

This study is based on a questionnaire, which could be seen as a limitation in terms of amount of information from the parents. One might argue that high attrition would limit the opportunity to identify the essence of parental long-term experiences of raising a child with ASD. In addition, if we had used in-depth interviews or focus group methodology, we might have received more detailed and developed comments. However, we identified the same essence as Carlsson et al<sup>4</sup> when using our questionnaire. Hence, our results replicated previous findings but with a less time-consuming method.

### Implications

In spite of the aim of early detection to provide early intervention, parents experience also 6 years after identification that society fails in their responsibility to provide these interventions and support. The parents in our study asked for coordination, guidance, and better knowledge of children with neurodevelopmental problems in professionals. These parental views should be accounted for and provide the baseline for further planning of interventions and family support regarding children with ASD and other ESSENCE problems. Therefore, it is important to work for a common organization, where medical care, schools, and other agencies work together to better meet the needs of children and families. Based on what is known today, there are no such general, shared guidelines, and this is an area that needs further empirical studies. However, at the CNC in Gothenburg, changes in the assessment routines have been made following the results from the Carlsson et al's study, which showed similar results as the present study.<sup>4</sup> During the assessment process, the parents are now offered a contact person, that is, a professional from the assessment team, who they can call if they have any questions related to the assessment as a whole.

After the diagnosis (as a part of the assessment process), the parents are offered a parent training course, which includes five lectures. The course provides information about ASD and presents an opportunity for parents to share experiences with other parents in the same situation. As a parallel to this, the teachers from the child's preschool are offered a lecture at the CNC about ASD and two additional meetings with the special education teacher from the assessment team at the CNC. The aim is to ensure that all adults in the child's daily life have a basic knowledge of ASD. A scientific follow-up is under way.

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The authors report no conflicts of interest in this work. The authors alone are responsible for the content and writing of the paper.

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