Parents’ experiences from participating in an infant sibling study of autism spectrum disorder

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ABSTRACT

Background: Prospective longitudinal studies of infant siblings of children with autism spectrum disorder (ASD) play an important role in advancing our knowledge about early developmental pathways in ASD. Despite this clear benefit, currently little is known about potential risks or disadvantages for participating families. As a first step in addressing this issue, we asked parents about their experiences from participating in an infant sibling study.

Method: Eighty-eight families responded to a questionnaire examining parents’ experiences from participating in an infant sibling study. The questions assessed parents’ satisfaction with the study, the child’s perceived satisfaction, and the parents’ motivation for participating. The study included parents of two groups, (1) infants with an older sibling diagnosed with ASD (HR, high risk, n = 43) and (2) infants with no familial history of ASD (LR, low risk, n = 21).

Results: The results indicated that parents are generally positive about study participation and few disadvantages were reported. This pattern was mirrored when splitting parents’ responses into the two groups. There was no indication for group differences between parents of infants at high risk and low risk for ASD.

Conclusion: Our findings present a first step into understanding parents’ experiences from participating in an infant sibling study. Most parents were satisfied with participation in the study and only few disadvantages were reported. Our results have implications for ethical discussions about benefits and risks regarding infant sibling studies in various fields.

1. Introduction

Neurodevelopmental conditions are a group of diagnoses characterized by early emerging developmental alterations, including cognitive, motor control, language, learning, as well as social functions (American Psychiatric Association, 2013). Studying the developmental trajectories of these functions and identifying early signs of neurodevelopmental conditions is critical to our understanding of these conditions. It is presumed that increased knowledge about developmental pathways associated with neurodevelopmental disorders will facilitate early identification and timely treatment (Elsabbagh & Johnson, 2010).

Autism Spectrum Disorder (ASD) is a complex and common neurodevelopmental condition of heterogeneous origin (Bölte, 2013).
Girdler, & Marschik, 2019; Vorstman et al., 2017). Prevalence estimates of ASD in children are indicated to be around 1.7% (Baio et al., 2018). In families with one child already diagnosed with ASD, the probability of having another child on the spectrum is substantially increased. Specifically, the recurrence rate in infant siblings of children with ASD is reported to be around 10–20% (Ozonoff et al., 2011; Sandin et al., 2014). Therefore, research has turned to prospective longitudinal studies of infant siblings in search for early precursors of ASD (Bölte et al., 2013). Findings from infant sibling studies have generated new knowledge about early development of various behaviors in ASD, ranging from social orientation and interaction (Bedford et al., 2014; Elsabbagh et al., 2012; Gliga, Bedford, Charman, Johnson, & BASIS Team, 2015; Thorup et al., 2016), to communication and language (Blasi et al., 2015; Hudry et al., 2014; Landa, Gross, Stuart, & Bauman, 2012; Sheinkopf, Iverson, Rinaldi, & Lester, 2012), as well as motor functioning (Einspieler et al., 2014; Flanagan, Landa, Bhat, & Bauman, 2012; Leonard, Elsabbagh, Hill, & BASIS Team, 2014). Collectively, these results show clear progress of our knowledge about early developmental pathways in ASD through studying infant siblings of children diagnosed with ASD. Recent data even suggest that this new knowledge can be applied to improve early detection of infants later developing autism, although replication is needed (Bosl, Tager-Flusberg, & Nelson, 2018; Hazlett et al., 2017). In light of these promising findings, ethically challenging aspects of infant sibling research may easily be neglected (Chen, Miller, & Rosenstein, 2003; Fletcher-Watson et al., 2017; Walsh, Elsabbagh, Bolton, & Singh, 2011; Yudell et al., 2013; Zwaigenbaum et al., 2007).

There are a number of characteristics making infant sibling studies of ASD different from other studies on infants. Firstly, the heterogeneous nature of ASD makes research aimed at finding early markers complex (Walsh et al., 2011). Studies are often designed to measure development across a broad range of behaviors. Thus, study protocols tend to be extensive and demanding, including a multitude of experimental tasks with the child, and clinical measures and questionnaires for the parents to complete. Some assessments, such as brain imaging or blood sampling, are or may be experienced as invasive. Therefore, the burden for families participating in an infant sibling study is rather high, involving substantial commitment over time. The fact that parents of high-risk infants also have an older child with ASD can create substantial challenges for enrolling in an infant sibling study with a demanding protocol. Another factor to reflect on is that families with children on the spectrum might be contacted by research facilities more frequently than neurotypical families. Extensive participation in research may affect the perceived burden of participating in studies over time.

Secondly, participating in a sibling study may increase concerns for some families, due to the focus on the (potentially atypical) development of the young child. While this question has never been studied, it is well established that heightened parental concerns about their children’s developmental status during infancy is associated with higher probability of actually receiving an ASD diagnosis at a later age (Hess & Landa, 2012; Ozonoff et al., 2009). Presumably, in all infant sibling studies, parents are informed about the increased probability of ASD in siblings at enrollment. Throughout the study, many questionnaire items and various other measures cover aspects of atypical development, including but not restricted to ASD symptoms, symptoms of related conditions, family psychiatric history, and prenatal and genetic risk factors. On the other hand, families may be worried anyhow, and participation might be perceived as positive, owing to continuous receipt of professional attention and potentially timely support and referral to service in case of a clinically relevant development.

Thirdly, focusing on siblings potentially increases the risk of stigmatization of these children and their families. Most of the infant siblings will not develop autism, and from that perspective giving them, explicitly or implicitly, an “at-risk” label could affect peoples’ attitudes towards the children, or the parents’ impression of others’ attitudes towards their child. When surveying parents on the causes of their children’s autism, the recurrence rate of the condition in families has been overestimated by many (Mercer, Creighton, Holden, & Lewis, 2006). Although sibling studies may contribute to disseminating knowledge about accurate recurrence rates, it is still a risk that focusing on the sibling at-risk and the familial aggregation of ASD could increase parents’ distress, as well as feelings of guilt and self-blame. Although facing potential stigmatization, parents of children with ASD expressed strong support for early ASD research in a large international study and indicated that early diagnosis was of primary interest (Fletcher-Watson et al., 2017). Relatedly, applying a “high-risk” label to children, may increase their experience of stigma, shame and anxiety, which has been observed in young people facing other familial disorders (Anglin, Greenspoon, Lighty, Corcoran, & Yang, 2014; Yang et al., 2015, 2019).

Against this background, it is surprising that, to our knowledge, there has been no study investigating parents’ experiences from participating in an infant sibling study of ASD. Studying early signs of ASD is strongly supported and large international research collaborations on infants at risk are continuously developed further (Bölte et al., 2013; Fletcher-Watson et al., 2017), reflecting a rather non-controversial view of infant sibling studies. However, infant sibling studies may raise certain concerns for participating families, making infant sibling studies different from other types of infant studies. If parents identified negative aspects and potential risks of participating in an infant sibling study, these results would be of importance for future ethical discussions. Generally, a favorable benefit-risk ratio is attained if potential risks of being involved in a study are minimized and justified in relation to the scientific knowledge gained (Chen et al., 2003). As a first step to illuminating this important but unexplored area, we surveyed parents about their experiences from participating in a prospective longitudinal study of infant siblings of children with ASD.

2. Methods

2.1. Participants

The survey was part of the EASE study (Early Autism Sweden; www.earlyautism.se), following infant siblings from age 5 months to age 72 months. Questionnaire data was obtained after the 18-month visit (n = 69 families, response rate: 67.0%) or after the 36-
month visit (n = 19 families, response rate: 70.4%). No family provided data at both time points and the data sets for the different time points were distinct populations with no overlap. The study included parents of two groups, (1) infants with an older sibling diagnosed with ASD (high risk group (HR), n = 43, 48.9%), and (2) infant siblings in the comparison group with no familial history of ASD in first and second degree relatives (low risk group (LR), n = 23, 26.1%). An additional 22 families filled out the questionnaire without indication of risk status (25.0%). Further, socioeconomic status of the families was estimated by using parental income and education. There was no evidence found in support of a group difference regarding this measure (HR M = 7.08, LR M = 7.60, p > .25; based on the larger EASE sample). Families were recruited through the project’s web site, advertisements, clinical units, and from a database of families within the larger Stockholm region (Sweden) who had previously indicated interest in participating in research studies. Parents in our study received a gift voucher worth 500 Swedish kronor (approximately €50) for their participation after each visit to the lab. In addition, if behavioral or neural atypicalities were observed, parents received feedback and were referred for further evaluation. All parents provided written informed consent, and the study was approved by the Regional Ethical Board in Stockholm. The study was conducted in accordance with the standards specified in the 1964 Declaration of Helsinki.

2.2. Procedure

Within the EASE study, children and their families undergo multiple measures and assessments including eye tracking, motion tracking, parent-child-interaction, electroencephalography (EEG), and magnetic resonance imaging (MRI). The EASE protocol includes six visits to the lab (at 5, 10, 14, 18, 24, and 36 months). At each visit, families typically spend around four to five hours in the lab. In addition to each visit, families filled out several online questionnaires. At the 36-month visit a full diagnostic assessment is conducted by a group of experienced psychologists. The current questionnaire assessing parents’ experiences from participating in our study was introduced after completion of the 18-month visit. The questionnaire was distributed in paper form, completed by the parents at home and sent back to the lab. Families were informed that the questionnaire was voluntary and anonymous, given the longitudinal character of the study. Additionally, after the 18-month visit, families would not meet the same research personnel again. Families, who already completed the 18-month visit without the current questionnaire, received the questionnaire after completion of the 36-month visit.

2.3. Questionnaire

The survey consisted of items reflecting parents’ satisfaction with study participation, the perceived child experience, study recommendation, and information received about the study. Parents were asked to rate their agreement with each of these statements, ranging from completely agree to partially agree, or don’t agree. In addition, parents had the opportunity to comment further on each of the statements in an open text box. In addition, parents were asked to leave comments on suggestions, recommendations and general comments on study participations (Table 1).

To analyze the open comments, relevant themes were determined based on putative topics of interest for infant sibling studies, our specific study design and questionnaire items. In addition, the first author read through the comments and revised the themes in light of the actual responses (e.g. removing themes that were not relevant). The final coding scheme consisted of six categories: (1) positive perception of study participation and research in this area, (2) feedback about the child’s development, (3) positively perceived child experience, (4) negatively perceived child experience, (5) burdensome questionnaires, (6) burdensome experimental measures. In case of uncertainties, the responses were discussed with the other authors. In addition, a second, independent rater blind to the research question, double-coded the two most frequent categories to validate the conclusions (i.e., category 1 and 2). An interrater reliability analysis, using Cohen’s kappa, showed a very good strength of agreement between the two raters (Cohen’s kappa = .80, 95% kappa confidence interval = .73–.87).

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Table 1

Questionnaire items.
3. Results

3.1. Parents’ satisfaction

Eighty-two parents (93.2%) completely agreed with the evaluation that their overall experience was positive, whereas 6.8% \((n = 6)\) partially agreed with the statement. No parent expressed dissatisfaction with study participation (Fig. 1a). When comparing the answers between parents’ answers for infants in the HR and the LR group (where the risk status was known), we found no indication for a group difference (completely agree: HR, \(n = 40\) (93.0%); LR, \(n = 21\) (91.3%); partially agree: HR, \(n = 3\) (7.0%); LR, \(n = 2\) (8.7%); \(\chi^2(1, n = 66) = 0.06, p > 0.25\)). In addition, when comparing parents’ ratings between the 18-month and the 36-months time point, there was no indication for a difference (completely agree: 18 m, \(n = 66\) (95.7%); 36 m, \(n = 16\) (84.2%); partially agree: 18 m, \(n = 3\) (4.3%); 36 m, \(n = 3\) (15.8%); \(\chi^2(1, n = 88) = 3.07, p > 0.08\)).

3.2. Parents’ perceived child experience

Sixty-five parents (73.9%) stated that they perceived participating in the study as a positive experience for their child. A quarter of parents (26.1%, \(n = 23\)) expressed that they perceived their child’s participation as partially positive. No parent indicated that participating in the study was perceived as negative for their child (Fig. 1b). There was no evidence for a group difference between parents’ answers for HR and LR infants (completely agree: HR, \(n = 31\) (72.1%); LR, \(n = 19\) (82.6%); partially agree: HR, \(n = 12\) (27.9%); LR, \(n = 4\) (17.4%); \(\chi^2(1, n = 66) = 0.90, p > 0.25\)). Further, we found no indication for a difference in parents’ ratings with respect to the time point of data collection (completely agree: 18 m, \(n = 52\) (75.4%); 36 m, \(n = 13\) (68.4%); partially agree: 18 m, \(n = 17\) (24.6%); 36 m, \(n = 6\) (31.6%); \(\chi^2(1, n = 88) = 0.37, p > 0.25\)).

3.3. Parents’ recommendation

Eighty-three parents (94.3%) recommended other families to participate in the study, whereas 5.7% \((n = 5)\) partially recommended study participation. Again, no parent expressed that they would not recommend participating in the study (Fig. 1c). We found no indication for a group difference between parents’ answers in the HR and the LR group (completely agree: HR, \(n = 42\) (97.7%); LR, \(n = 21\) (91.3%); partially agree: HR, \(n = 1\) (2.3%); LR, \(n = 2\) (8.7%); \(\chi^2(1, n = 66) = 1.40, p = 0.24\)). In addition, we found no indication for a difference in parents’ ratings between the 18-month and the 36-months time point (completely agree: 18 m, \(n = 66\) (95.7%); 36 m, \(n = 17\) (89.5%); partially agree: 18 m, \(n = 3\) (4.3%); 36 m, \(n = 2\) (10.5%); \(\chi^2(1, n = 88) = 1.06, p > 0.25\)).

3.4. Information received

Seventy-seven parents (87.5%) completely agreed that they were well informed about the study’s aim and content, while eleven parents (12.5%) partially agreed with the statement. No parent reported that they were insufficiently informed about the study (Fig. 1d). In addition, no indication for a group difference between parents’ answers in the HR and the LR group was found (completely agree: HR, \(n = 40\) (93.0%); LR, \(n = 20\) (87.0%); partially agree: HR, \(n = 3\) (7.0%); LR, \(n = 3\) (13.0%); \(\chi^2(1, n = 66) = 0.67, p > 0.25\)). Further, there was no indication for a difference regarding time point of data collection (completely agree: 18 m, \(n = 58\) (84.1%); 36 m, \(n = 19\) (100.0%); partially agree: 18 m, \(n = 11\) (15.9%); 36 m, \(n = 0\) (0.0%); \(\chi^2(1, n = 88) = 3.46, p > 0.06\)).

3.5. Open comments

Almost all parents \((n = 83, 94%)\) chose to leave open comments. A majority of parents stated that it was interesting to follow their child’s development and that research in this area was important and meaningful \((n = 49, i.e., 59\%)\). Some parents stated that getting early feedback concerning their child’s development was much appreciated \((n = 17, i.e., 21\%)\). For example, one parent commented that it was valuable to learn if there was need for further evaluation of the child’s development. Another parent noted that their child’s early diagnosis due to study participation was a great benefit to them. Regarding the testing sessions, one quarter spontaneously expressed that their child enjoyed the tasks and being the center of attention \((n = 24, i.e., 29\%)\), while around one fifth of the

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**Fig. 1.** Parents’ ratings of a) study satisfaction, b) perceived child experience, c) study recommendation, and d) information received.
parents described some of the assessments as boring and tiresome for the child (n = 19, i.e., 23%). For example, one parent noted that not all the tests were fun for the child, but that all researchers were sensitive to the child’s needs and cancelled assessments if they did not work out. Similarly, another parent commented that the visits were a bit long, but that everyone was nice and that they understood when the child was too tired to continue participation. Regarding the large amount of questionnaires used in the study, some parents stated that this was a burdensome aspect of the study (n = 14, i.e., 17%); in contrast, very few mentioned experimental procedures included in the study protocol, such as magnet resonance imaging, as burdensome (n = 3, i.e., 4%).

4. Discussion and implications

Studying infants at risk may give rise to important new knowledge about neurodevelopmental conditions such as ASD. However, as we have noted, very little is known about potential disadvantages associated with participating in an infant sibling study, for the infants as well as their parents. Against this background, the data presented in the current report are important and timely. Specifically, parents in our study reported high satisfaction with the study overall, perceived that their child’s experiences were mainly positive, recommended other families to participate in the study, and stated that they were well informed about the study’s aim and content (Fig. 1). Comparing families in the HR and the LR group mirrored the overall results with no indication of systematic differences regarding risk status of the infant. Similarly, we found no indication of systematic differences in parents’ ratings related to the time point of data collection (i.e., after completion of the 18-month visit or after the 36-month visit).

Infant sibling studies of ASD are often intensive and time-consuming and include a multitude of experimental tasks. Our study included a wide range of assessments ranging from eye tracking, to motion-tracking, parent-child-interaction, EEG and MRI. However, parents very rarely commented negatively on the assessments. One expected finding, however, was that the large number of questionnaires administered was perceived as a burden by a subgroup of parents. This suggests that future studies should acknowledge and thoroughly consider and minimize paperwork burden for participants. It is important to emphasize that the complaints were about the workload as such, not about the content of the questionnaires and although time-consuming, the number of questionnaires / items is not a very serious risk factor per se. Families in our study provided informed consent and were informed about privacy, confidentiality, burden associated with participation and their freedom to withdraw from the study participation at any point. Thus, some complaints regarding the number of questionnaires to complete may be ethically justifiable in terms of a balance of experienced burden and possible scientific and clinical gains.

The perceived child satisfaction was reported to be somewhat lower than the parents’ satisfaction with the study. Some parents stated that a few of the experimental tasks were boring for the child, that it was hard to keep the child sitting still, and that the testing days were long and rather intensive. At the same time, parents found that the procedures were sensitive to the child’s needs and adapted if necessary. Understanding infants’ experiences and being sensitive to their needs is important from an ethical point of view, as infants are not able to give informed consent, which is a central principle in research with human subjects (Chen et al., 2003; Levine, 1989; Thompson, 1990). In research with infants, the concept of consent by proxy is often used. Parents are believed to protect their child’s welfare and best interests. However, giving parents the authority to give consent by proxy entails ambiguities. Giving consent is based on one’s own beliefs and goals and might not correspond directly to the child’s beliefs (Bartholome, 1995). As children grow older, they should be involved in the decision-making process and provided the opportunity to consent or decline participation themselves and any doubts about the child’s compliance to participate should lead to exclusion (Bartholome, 1995; Modi et al., 2014). In infant siblings, however, the time of enrollment is often at a very young age and parents give consent by proxy. In light of this, researchers should be sensitive to families’ experiences and concerns, provide families with information about the study’s background and aim, and safeguard the infants’ wellbeing. Thus, understanding families’ experiences is an important aspect when discussing ethical considerations regarding infant sibling studies.

The open comments may give some additional insight into parents’ experiences and illuminate contributing factors to the overall high satisfaction with study participation. However, it should be noted that every parent and every infant is unique and their concerns may vary largely. While some parents stated that they gained reassurance of the child’s development thanks to study participation, others expressed the request for more feedback. Some parents saw the study as a way to keep track on their child’s development and a first step into the professional health care system if development was atypical. Yet, it has to be acknowledged that a research setting is not equal to a clinical setting and potential diagnoses cannot be given based on experimental tasks. Within this context, it is also important to note that different countries may have different ethical guidelines regarding feedback to parents and referring infants to clinical units (Bölte et al., 2013), an important aspect that is not addressed here. In this study, and in line with the ethical application covering the study, we inform the families if we observe or detect significant developmental or medical issues not already known to the families. Further, in such cases, we provide support and advice, including advice on which health services can provide further assistance and help (e.g. further evaluation and intervention). It is of course possible that these aspects of our study could influence parents’ general attitudes to and experiences from the study.

Another, more quantitative way to shed light on parents’ experiences of participating in an infant sibling study may be found in the attrition rate. A high attrition rate would indicate that many families were not motivated to continue participation, which could be due to negative experiences. It is likely that some of the 18 month data reported above might come from families that later dropped out, but given the anonymity of the questionnaire the exact number is unknown. At the 36 months assessment, there were only 6.09% of the families that had decided not to continue in the overall EASE project in which this study is embedded. Thus, attrition is low and unlikely to threaten the conclusions of this study and can be interpreted as an indication of satisfaction with participation.

In order to highlight the risks and the benefits of infant sibling studies, it is of primary importance to include the views of parents.
actually participating in research. However, not only understanding participating parents’ experiences, but also perspectives of the larger autism community are relevant when discussing ethical issues on this topic. Fletcher-Watson et al. (2017) collected questionnaire data in a large international study from different stakeholder groups, such as practitioners working with ASD in healthcare and education, adults with ASD, and parents of children with ASD. The authors found a large overall support for early ASD research across all groups. Interestingly, parents of children with ASD, in particular, stressed the need of research efforts on facilitating early diagnosis. Observing early atypical behavior in a research setting should therefore lead to referring a child to receive intervention. In fact, most infant sibling studies include referrals for further evaluation or services. However, as a first step, infant sibling studies increase our understanding of developmental pathways that lead to neurodevelopmental disorders. In a second step, efforts are directed towards combining this new knowledge with advances in early detection and intervention. This process may then help to bridge the gap between lab and clinic and achieve the unifying goal of early support for children and families with ASD. Thus, extensive research protocols commonly used in infant sibling studies and the inherent burden of study participation may be justified by the scientific importance of the research and potential for direct benefits to families (in the form of clinical feedback / referrals).

A limitation of our study is that although the results are based on a questionnaire given to all participating families, the findings only reflect the experiences of the roughly 70% that responded to the questionnaire. In addition, when comparing families based on risk status, we had to exclude 25% families as information on risk status was missing. Another limiting aspect is that parents who choose to participate in an infant sibling study may differ from those who choose not to participate, possibly resulting in a bias already before study enrollment. On the other hand, many of the potential risks associated with the sibling study (worry, stigmatization, stress) should be particularly high for the families who participate; hence, understanding their experiences is an important starting point. Another important limitation is that all our statements were framed positively, which might have primed parents to give a positive response. Next, our results reflect the experiences of parents involved in a particular study, and replications in other samples / studies are needed to establish the external validity of the findings. Therein, infant sibling studies may vary regarding other factors not included in our analyses, such as compensation, length, burden and services provided for participating families. In addition, questionnaires were filled in shortly after the family’s visit to the lab. We, therefore, have no information about long-term effects of participating in our study. Roughly 80% (n = 69) of the families participating in this study were surveyed after the 18-months visit, whereas the remaining 20% (n = 19) completed the questionnaire after the 36-months visit. Arguably, the results of this study mainly reflect the experiences of parents of young toddlers, which have not yet undergone a thorough clinical assessment. However, we found no indication of group differences related to time point of data collection, suggesting that the experience of participating in our study did not change over time. Nevertheless, future studies should address parents’ experiences longitudinally and especially when the children reach critical ages for clinical assessments and with a follow up in school age. Finally, it needs to be acknowledged that the findings are based on one relatively short questionnaire that does not cover all aspects of parents’ and infants’ experiences.

When discussing ethical aspects of research, assessing the benefit-risk ratio is important (Chen et al., 2003). While the scientific knowledge gained from infant sibling studies is a clear benefit, potential risks are more difficult to assess. Our study presents a first step into understanding parents’ experiences and highlights this important area. Risks were not directly queried and the general positive phrasing of the questions might have interfered with parents’ tendency to report specific disadvantages of study participation. However, the open-ended questions provided an opportunity to comment on disadvantages and burdens related to participating in the study. Some parents stated negative aspects, such as the large amount of questionnaires and the long and intensive assessment visits. Despite these negative aspects, the overall satisfaction was high and parents recommended others to participate in the study. This finding may reflect that even from a parents’ perspective, some disadvantages can be justified by the importance of early research in ASD and families’ benefits in the form of feedback on the child’s development and the possibility of clinical referrals.

Taken together, our results are pointing towards a favorable benefit-risk-ratio, as benefits are high and appear to outweigh the burdens and disadvantages reported by parents. In addition, there were no indications of diverging experiences for families with regards to risk status. However, future studies are needed to validate this conclusion; for example, by illuminating qualitative aspects of participating in an infant sibling study, during study participation, as well as post hoc administered in-depth interviews including risk status and clinical outcome. Taken together, understanding families’ experiences is important for future ethical discussions concerning infant sibling studies not only of ASD, but also in other fields.

Ethical approval

All procedures in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Consent

Informed consent was obtained from all individual participants included in the study.

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Declaration of Competing Interest

The authors have no conflict of interest to declare. Sven Bölte discloses that he has in the last 5 years acted as an author, consultant or lecturer for Shire, Medice, Roche, Eli Lilly, Prima Psychiatry, GLGroup, System Analytic, Ability Partner, Kompetento, Expo Medica, and Prophase. He receives royalties for textbooks and diagnostic tools from Huber/Hogrefe, Kohlhammer and UTB.

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