

This paper has been accepted for publication in *Autism*.

Predicting intervention use in autistic children: demographic and autism-specific characteristics

Kim M. Jonkman¹, Elisa Back² and Sander Begeer¹

¹ Department of Clinical, Neuro and Developmental Psychology, Vrije Universiteit Amsterdam, and Amsterdam Public Health Research Institute.

² Department of Psychology, Kingston University London

Abstract

Autism is a heterogeneous disorder with symptoms that present in different ways. There is a large variety of interventions for autistic individuals. Little is known about who chooses which specific interventions. We aimed to explore intervention prevalence and predict intervention use, based on demographic and autism-specific characteristics. This study used data on autistic children (N=1464, aged 1-17 years) from the Netherlands Autism Register. Most children (88%) had received therapies, about half had received medication. Intervention use was mostly related to additional factors (lower IQ, special education and co-occurring diagnoses). Children with a lower IQ received less therapies, children attending special education or with a co-occurring diagnosis received more therapies. Children in special education or with a co-occurring diagnosis were more likely to receive several types of therapy and medication. Older age, higher IQ and being female were related to more guideline (autism-specific) or mainstream (targeting co-occurring problems) therapy use. Lower parental education was related to more mainstream medication use. More severe sensory issues increased the chance of other medication use. Other autism-specific characteristics (autism severity, social skills, repetitive and restrictive behaviours) were not related to intervention use. More transdiagnostic interventions should be available for children with autism and additional problems.

Keywords: Autism spectrum disorders, treatment use, interventions – pharmacologic, interventions – psychosocial/behavioral, health services

Predicting intervention use in autistic children: demographic and autism-specific characteristics

Autism is a heterogeneous disorder and it is defined by atypical social communication as well as restrictive and repetitive behaviours or interests (APA, 2013; Lord et al., 2020). In addition, the majority of autistic children (70%) have at least one other psychiatric diagnosis (Simonoff et al., 2008). Many different interventions are available for autistic individuals (DeFilippis & Wagner, 2016), some aimed at reducing core autism symptoms while others target co-occurring problems. The diverse nature of autism and its treatment options justify the need to understand which individual characteristics are associated with the use of which intervention. In this study, demographic and autism-specific characteristics will be used to predict intervention use in autistic children.

The estimated total (personal and societal) lifetime costs of supporting a person with autism (without an intellectual disability) is \$1.4 million (Rogge & Janssen, 2019). The majority of these costs are accounted for by services, such as interventions. There is no intervention that can cure autism nor is this a desired outcome according to most people (Kapp et al., 2013). Interventions instead focus on either reducing autism-specific symptoms, alleviating co-occurring problems or improving overall quality of life. Guidelines for autism treatment agree that interventions should start as early in life as possible. Most guidelines advise psycho-education to be used as a crucial step in treatment. Additionally, guidelines state that interventions should also reduce core autism symptoms and stimulate social behaviour or social learning abilities. Furthermore, specific problems should be targeted, and long-term care should be established (See the Dutch Youth Institute (NJI, 2017), the Dutch mental health care quality standards (GGZ Standaarden, 2020), the European Society of Child and Adolescent Psychiatry (ESCAP; Fuentes et al., 2020), the British National Institute for Health and Care Excellence (NICE, 2013) and the Centers for Disease Control and Prevention (CDC, 2019)).

The majority of diagnosed autistic children between 2 and 17 years old receive therapy (we define therapy as non-medication interventions) with estimates ranging from 64% to 96% (Monz et al., 2019; Patten et al., 2013; Xu et al., 2019). On average, young children (2 to 7 years old) have received 4.5 different therapies (ranging from 1 to 11; Patten et al., 2013). Medication use is less common than therapies among autistic children, ranging from 27% to 34% (Mayes et al., 2020; Monz et al., 2019; Xu et al., 2019). Medications generally included drugs for symptoms of ADHD, depression and anxiety

(Eissa et al., 2018; Mayes et al., 2020). Unsurprisingly, people with autism who have co-occurring psychiatric problems were more likely to use medication (Houghton et al., 2017). While the use of therapies decreased with age, both in number (Mire et al., 2015; Xu et al., 2019) and intensity (Monz et al., 2019), medication use increased with age among those up to 24 years old (Houghton et al., 2017; Mire et al., 2015). A change in the manifestation of the child's symptoms might make parents more comfortable giving medication to older children, or because medication is a last resort for parents who have tried a variety of interventions during their child's younger years (Mire et al., 2015). One study found a higher percentage of autistic boys using medication than girls, however in the same study sex was not a significant predictor of medication use (Xu et al., 2019).

Treatment guidelines for autism are based on scientific evidence, general practice, and the theoretical foundation underlying the interventions. Looking at -freely available - guideline directions for four different nations (UK, US, Europe and the Netherlands), three categories can be distinguished that are included in all guidelines (CDC, 2019; Fuentes et al., 2020; GGZ Standaarden, 2020; NICE, 2013; NJI, 2017). First, there is a stable international agreement on what would be considered *guideline interventions* for autism. These interventions are officially recommended, by national government organisations/institutions for mental health, specifically for autism or target core autism symptoms, such as social skills and restrictive and repetitive behaviours and interests. These interventions can be directed at the child, family or community (Lord et al., 2021). In all referenced guidelines these include: psycho-education (for both child and family), social skills training and NDBIs (naturalistic developmental behavioural interventions) for the child, and parent and home trainings for the family. Second, *mainstream interventions* include interventions not specifically for autism, targeting associated symptoms (e.g., challenging behaviours like aggression or hyperactivity) as well as co-occurring problems (e.g. epilepsy or sleep problems). These interventions are included in guidelines for autism to treat co-occurring problems. This category includes medication (Houghton et al., 2017) and, among others, physiotherapy (also referred to as physical therapy), speech therapy and mindfulness-based interventions. Third, *other interventions* are therapies or medications that are not included in the treatment guidelines or are actively discouraged by the guidelines (e.g. because they have shown to be harmful or ineffective). This includes alternative interventions like diets, supplements, homeopathic

medication (often referred to as CAM) and animal therapy (Höfer et al., 2017).

Factors that influence parents' decision-making about interventions change over time, whilst parents gain more expertise about autism (Edwards et al., 2018). Parents base their decisions on a variety of factors including recommendations from other parents, professionals and service providers, pragmatic issues (e.g., the availability or accessibility of the intervention, the costs and time), service characteristics (e.g., whether the staff seems experienced and professional), and their child's individual needs (Edwards et al., 2018; Carlon et al., 2013, 2015; Lord et al., 2021). Furthermore, research suggests that higher parental education levels were associated with a higher number of interventions (Patten et al., 2013), and also more use of alternative interventions, including dietary and vitamin therapy (Höfer et al., 2017). Family income is not related to intervention use when taking parental education level or health insurance into account (Patten et al., 2013; Xu et al., 2019). Insured children are more likely to receive behavioural interventions in the United States (Xu et al., 2019).

Child characteristics also affect intervention use. Children with more severe autistic symptoms received a greater number of therapies regardless of their age (Green et al., 2006) and are more likely to have received an therapy, from any category, compared to children with less severe symptoms (Green et al., 2006). Children who have more sensory processing problems started using interventions earlier (Patten et al., 2013). Understandably, children with special communication and language needs often received speech therapy, whereas social skills training and play therapy were used when parents wanted to improve their child's peer interaction (Carlon et al., 2013). These findings suggest that intervention use in autism is related to the presence and severity of autism-specific symptoms.

The use of alternative interventions is particularly interesting given that these interventions often have no or a dubious empirical foundation for their effectiveness and can sometimes even be harmful. There is some evidence that the use of complementary and alternative medicine (CAM) interventions is more common in autism compared to other disorders (Höfer et al., 2017). Overall, higher parental education level has been associated with more CAM use - in both autism and other populations (Höfer et al., 2017; Patten et al., 2013, Wang et al., 2018). Other predictors include parents' own use of CAM interventions (Doering et al., 2013; Singendonk et al., 2013), female gender (Keene et al., 2019; Singendonk et al., 2013), higher level of education of the parent (Keene et al., 2019; Wang

et al., 2018) and co-occurring medical conditions (Wang et al., 2018).

Autism treatment is expensive and early intervention can be crucial. Most previous studies have been conducted in the US or UK (e.g. Patten et al., 2013; Wang et al., 2018; Xu et al., 2019), this is the first study of its kind focusing on Dutch families. Although many different and divergent predictors of intervention use have been found in a variety of studies, we aim to increase our understanding of intervention use among autistic children by combining demographic and autism-specific characteristics to predict the use of therapy and medication. We aim to study predictors of the number, type and load (total number of hours) of interventions used among autistic children. Predictors are demographic characteristics (age, sex, parental education level, educational setting) which also include diagnostic information (IQ, co-occurring diagnosis) and autism-specific characteristics (autism severity, social skills, repetitive and restrictive behaviours and interests, and sensory issues). Based on the above discussed literature we expect co-occurring diagnosis, higher autism severity and increasing age to be associated with higher number of interventions used. We also expect higher parental education level to predict the use of other therapies and medication. The impact of the other predictors will be explored as there is insufficient evidence from previous literature to formulate a hypothesis.

Methods

Participants

Participants included 1464 children (below the age of 18) and/or their parent(s) who filled in questionnaires from the Netherlands Autism Register. Of these participants 1225 reported on therapy use and 1450 on medication use. All participants received a formal diagnosis of ASD by a qualified clinician unaffiliated to this study according to the DSM-IV or DSM-5 (American Psychiatric Association, 1994; 2013). The diagnosis was reported by the informant and follow-up questions ensured the diagnosis was given by a qualified clinician at a professional location, in addition to questions about the age of first suspicion and diagnosis. A subgroup (N = 632; this number is lower when predictors are added due to missing data) was further analysed because information on intervention use from multiple years was available for these participants (Table 1). There were no significant differences between this group and the complete sample on the variables included in this study. Within the subsample, participants who completed the AQ-28 were younger and participants who completed the SDQ were

slightly older than those who did not complete these measures. There were no other age differences nor differences in sex and parental education level.

Measures

Demographic variables

For all measures, parents reported on their child if they were younger than 16, adolescents aged 16 or 17 reported on themselves. For the category of sex participants could choose from male or female. Parental education level was categorized as high, middle and low (using the highest from the two parents), based on Dutch guidelines (CBS, 2020). The educational setting was categorized as special or mainstream education. Children who reported attending special education in at least one questionnaire were included in the special education category. Some diagnostic information was also included as ‘demographic variables’: participants were asked to choose their (child’s) most recent IQ test-score from seven categories. For 6.6% of the children no recent IQ-test result was available, these participants were asked to estimate their (child’s) IQ. The different answer options were then combined into three categories: 1 = below 85, 2 = 85-115, 3 = above 115. For co-occurring diagnosis children were divided in two groups: those who had no additional diagnoses and those who had at least one additional diagnosis (any diagnosis including psychiatric and physiological diagnoses).

Autism severity

Autism severity was measured by the Autism-Spectrum Quotient (AQ-short, Hoekstra et al., 2011). The AQ-short has 28 items that assess social behavioural difficulties (23 items) and a fascination for numbers/patterns (5 items). The social behaviour factor includes social skills (7 items), routine (4 items), switching (4 items) and imagination (8 items). Each item has a 4-point Likert scale from “definitely agree” to “definitely disagree”. Children could score anywhere between 28 and 112 with a higher score reflecting greater autism severity. The AQ-short has been validated to assess autistic traits in three independent samples from The Netherlands and the UK (both clinical and controls) (Hoekstra et al., 2011). The AQ-short highly correlates with the full-scale AQ and it has shown a good internal consistency with a Cronbach’s alpha between .77 and .86.

Sensory issues

Sensory issues were measured using the Short Sensory Profile (SSP, McIntosh et al., 1999). This questionnaire has 38 items about observable child behaviours including tactile sensitivity (7 items), taste/smell sensitivity (4 items), movement sensitivity (3 items), underresponsive/seeking sensation (7 items), auditory filtering (6 items), low energy/weak (6 items) and visual/auditory sensitivity (5 items). The behaviours are scored based on their frequency on a scale from 1 (always) to 5 (never). This results in a score between 38 and 190 with a higher score representing less sensory abnormalities meaning a low frequency of sensory issues. The SSP is widely used to assess sensory impairments and has shown excellent reliability and validity (McIntosh et al., 1999).

Social skills

The Strengths and Difficulties Questionnaire (SDQ, Goodman, 2001; a brief behavioural screening questionnaire) was used to measure social skills. To reflect social skills, two scales of this questionnaire were combined: peer problems and prosocial behaviour. The peer problems scale has 5 items that focus on how well the child gets on with other children. The prosocial scale has 5 items that focus on being helpful, kind and considerate towards others. The items on the prosocial scale are recoded to ensure that the combined score of the two scales represents problems with social skills (a higher score reflects more problems). The reliability and validity of the self-report and parent-report SDQ were judged to be satisfying, making it an appropriate short measure for psychological problems and skills in clinical assessment or as a research tool (Goodman, 2001).

Repetitive and restrictive behaviours and interests

The Childhood Routines Inventory-Revised (CRI-R, Evans et al., 2017) used to measure the child's repetitive and restrictive behaviours. The questionnaire has 62 items concerning possible restrictive or repetitive behaviours. The items question to what extent the child or adolescent engages in behaviours with the answer options ranging from 1 "Never" to 5 "Always". The CRI-R has two scales: repetitive motor behaviours and compulsions, and rigidity/insistence on sameness. For this study

we use the total score of all 62 items resulting in a score between 62 and 310 with a higher score representing more repetitive and restrictive behaviours. The CRI-R has shown excellent psychometric properties for assessing restricted and repetitive behaviors in children under 18 with neurodevelopmental disorders (Evans et al., 2017).

Intervention use

Type of intervention. Participants could report on 16 types of therapies and 30 types of medication. At entry, participants reported on their intervention use up to that point. After that, intervention use was surveyed yearly. The total number of therapies was based on the number of therapies used at entry and the average yearly use. Interventions were grouped into three categories: (1) guideline therapies (therapies for core characteristics of autism, e.g., social skills training, there is no guideline medication), (2) mainstream therapies or medication (interventions aimed at other associated problems) and (3) other therapies or medication (discouraged, alternative or rare interventions) (see Appendix A and B for a full overview).

Intervention load. Participants reported the duration of each selected therapy with the following options: 0 to 4 months, 4 to 7 months, 7 to 12 months and more than 12 months. They were also asked to report the intensity of the therapy: 0 to 1 hour a week, 1 to 4 hours a week, 4 to 8 hours a week or more than 8 hours a week. For the intervention load the duration of therapies was calculated in weeks by taking the median of the category (e.g. 0-4 months = 2 months) and multiplying this by 4.348 to convert months into weeks. A similar transformation is applied to the therapy intensity by determining the median of the category to get a single value for hours per weeks (e.g. 0-1 hours/week = 0.5 hours/week). Intervention load was then calculated by multiplying the duration by the intensity to obtain the total number of hours of therapy. The number of hours were then added per year and the different years were then added. This total number of hours of therapy was corrected for by the number of years that the participant had participated in the questionnaire as mentioned above.

Procedure

Participants are made aware of the Netherland Autism Register (NAR) by recurrent

professional and lay publications in national and local media. People who want to participate in the NAR questionnaires can register on their website (<https://www.nederlandsautismeregister.nl/english/>). Upon entering the NAR participants receive a link to fill out the baseline questionnaire, followed by yearly invitations. The content of the yearly questionnaires differ and every year the participant can decide whether they want to participate or not (without having prior knowledge of the questionnaire content). For this study data from 2013 to 2019 was used. The study was preregistered at the OSF/Center for open science (<https://osf.io/2uqkg>). The NAR has been reviewed and approved by the ethics committee of the Vrije Universiteit Amsterdam (VCWE 2020-041R1).

Statistical analyses

The following analyses were performed on the subsample (N=632). Multiple linear regression was performed to predict the number of therapies used and intervention load with ten predictors mentioned in the introduction (age, sex, parental education level, IQ, educational setting, co-occurring diagnosis, autism severity, social skills, repetitive and restrictive behaviours and interests, and sensory issues). Binary logistic regressions were used to predict whether participants used guideline (yes/no), mainstream (yes/no) or other therapies (yes/no) and to predict the use of mainstream (yes/no) and other medication (yes/no). For these analyses the demographic characteristics were put in the model first. The four autism-specific predictors were then added to the models separately because when they are combined, the sample size decreases significantly. Post-hoc power analyses were performed for each regression and are reported in Appendix C.

Community involvement statement

The Netherlands Autism Register works closely together with autistic people. We rely on input from the autism community and also provide yearly feedback to all participants regarding the general findings of the questionnaires and personal feedback on how the participant's scored on the subjects included in the latest questionnaire. This study is in line with the Dutch Autism Research Agenda, which was developed by autistic researchers using data from the NAR (Van den Bosch & Weve, 2019), which indicated that support, treatment and medication were key themes requested by autistic people and

parents of autistic children. Autistic individuals work in the NAR team and are also consulted through panels.

Results

Data on therapy use on at least one time point was available for a total of 1225 children. With respect to these children 88.1% reported using some type of therapy, 76.6% of the children had used mainstream therapies, 77.2% had used guideline therapies and 27.7% had used other therapies. Only 0.8% received *only* other therapies. A total of 1450 children reported on medication use of which 51.9% had received medication, 51.4% had used mainstream medication and 4.8% had used other medication, 0.5% received *only* other medication. When entering the NAR, children had received an average of 4.07 therapies ($SD = 2.05$, range 1-12). They had used on average 2.08 guideline therapies, 1.76 mainstream therapies and .24 other therapies amounting to an average total intervention load of 232.51 hours (Table 4). The most commonly reported therapies included physiotherapy, parent training and social skills training (see Figure 1).

For all analyses of the subsample ($N=632$), demographic predictors included age, sex, IQ, educational setting, parental education level and co-occurring diagnosis, and autism-specific predictors included autism severity, social skills, repetitive and restrictive behaviours and interests, and sensory issues. The latter were separately and individually added. The autism-specific predictors were correlated to each other and some correlated with age (Table 5). However, there was no indication of multicollinearity as all variance inflation factors (VIF) for the predictors were below 10. Only statistically significant ($p < .05$) results are reported.

A higher number of overall therapies used was predicted by older age ($B = .14$, $SE = .04$), having a co-occurring diagnosis ($B = .50$, $SE = .25$) and special education ($B = 1.12$, $SE = .29$), while children with a lower IQ used less therapies ($B = -.71$, $SE = .33$) (Table 6). The use of guideline therapies was predicted by older age ($OR = 1.13$). Children with a lower IQ were less likely to have used guidelines therapies ($OR = .41$). Boys were less likely to have used a mainstream therapy ($OR = .28$) while children who attend special education were more likely to have used a mainstream therapy ($OR = 3.49$). Children with a co-occurring diagnosis were more likely to have used other therapies ($OR =$

1.70). None of the autism specific variables were predictive for therapy use (Table 7).

Higher parental education level decreased the chances of having received mainstream medication ($OR = .48$). Children who had a co-occurring diagnosis or attended special education had increased chances of having used mainstream medication ($OR = 2.14$ and $OR = 1.97$ respectively). Children with more sensory issues were more likely to receive other medication ($OR = .98$, note: the SSP is scored reversely; a higher score indicates less sensory issues). None of the other autism specific variables were significant predictors for medication use (Table 8). There were no significant predictors of intervention load (Table 9).

Moreover, all analyses were rerun using only parent-reported data (children younger than 16) to ensure the results are not influenced by the self-reported data. There were no significant differences in the results between the sample including 16 and 17 year olds and the sample excluding them, and the same predictors for intervention use were found. See Appendix C for the post hoc power analyses.

Discussion

This study aimed to explore and predict intervention use in Dutch autistic children by using demographic and autism-specific characteristics. The majority of children (88.1%) received some type of therapy and approximately half of the children had received medication. As expected, older children reported using more therapies overall, and more guideline therapies. Boys were less likely to have used a mainstream therapy. Children with a lower IQ were less likely to use a guideline therapy and used a lower number of therapies overall. Children who attend special education used more therapies and were more likely to have used a mainstream therapy and mainstream medication. Parents of children with a co-occurring diagnosis reported using more therapies, and were more likely to have used other therapies and mainstream medication. Higher parental education level decreased the likelihood of mainstream medication use. More sensory issues were related to greater other medication. Against expectations, other autism-specific characteristics did not predict intervention use.

In our study, age was positively related to the total number of therapies used; older children have received more therapies. Older age also increased the likelihood of having received a guideline therapy. The guideline category includes psycho-education (for parents or child) and early intensive

interventions, both of which are advised to be (an essential) part of any autism treatment (Fuentes et al., 2020; GGZ Standaarden, 2020; NICE, 2013; NJI, 2017). This means that all diagnosed children, regardless of their current age or age of diagnosis, should have received a guideline therapy. These findings suggest that guideline therapies might sometimes be used when the child is older. This could depend on the age of diagnosis which should be taken into account in future research. Early (guideline) therapies are important, it might be an area of improvement for clinical practitioners to ensure that children receive these therapies as early as possible after their diagnosis.

Previous studies did not provide a clear conclusion about the predictive value of IQ on intervention use. We found that children who had a lower IQ, as reported by parents, used less therapies and less often used guideline therapies. Guideline therapies might be less suited for children with a lower IQ. For example, a review showed that most social skills-groups for autistic children required children to have an IQ above 70 (Reichow et al., 2013). Social skills training is one of the most frequently used therapies (Figure 1). It raises some concerns if such a popular and effective therapy is not suitable for a considerable number of autistic children. This shows a clear point of improvement for practice; all (guideline) therapies should be adapted to suit children with moderate to profound learning difficulties. However, it should be acknowledged that this study did not test the children's IQ directly, but instead relied on parents to report their child's IQ.

Boys were less likely to have used a mainstream therapy. The most commonly used mainstream therapies include physiotherapy (physical therapy), speech therapy and play therapy. There are no indications in the literature that boys would use these types of therapies less (or girls more). This difference could be related to variation in expression of autism symptoms or co-occurring problems between boys and girls (e.g. Hiller et al., 2014; Ormond et al., 2018). It could also be that parents expect more communication and language skills from girls and are therefore more likely to choose play or speech therapy for them.

Children who attend special education or reported co-occurring diagnoses use more therapies. Attending special education was related to having used more (mainstream) therapies and medication, which might be better suited for additional problems which children who attend special education are likely to have. As expected, children with co-occurring diagnoses more often used mainstream

medication or other therapies. Having an additional diagnosis most likely complicates the process of finding suitable interventions as the child might present with multiple main symptoms whereas interventions usually focus on one problem at a time. Medication and other therapies could be a last resort for these children (Mire et al., 2015). It is important that more transdiagnostic interventions (interventions focussed on multiple diagnoses or problems) are developed. These would simplify the intervention choice for children with autism and additional problems and thus prevent them from receiving an array of interventions that each only treat part of their symptoms.

While previous studies showed that current medication use increases with age within childhood (Houghton et al., 2017; Mire et al., 2015; Xu et al., 2019), age did not predict medication use in this study. It could be that this trend found in the literature is specific for the autistic population in the United States, where the previous studies were conducted, whereas the current study was conducted in The Netherlands. Perhaps the trend was not found because attending special education and having a co-occurring diagnosis were controlled for, both of which increase the likelihood of using mainstream medication. It should be acknowledged that the current findings only inform us about whether children used medication and not about whether they used more or less of it when they were older.

Higher parental education level was previously found to predict alternative medication use (Höfer et al., 2017; Patten et al., 2013), in our study it predicted lower likelihood of mainstream medication use, but not more other interventions. These findings are problematic, as all children should receive the interventions they need, regardless of their parents' level of education. When medication is prescribed it is important that the parents as well as the child is adequately informed about the short- and long term pro's and con's of the medication. This ensures that the involved clinicians, parents and the child can make a well-considered joint informed decision.

Children with more sensory issues received more other medication. Severe sensory issues can disrupt daily life in home, social and educational settings. Children with more sensory issues might need medication to reduce stress. Parents of these children might be more likely to look beyond mainstream medication to find medication to improve their child's daily functioning. Interestingly, sensory issues was the only autism-specific characteristic that was predictive of intervention use, none of the other autism-specific characteristics were related to either therapy or medication use. Our findings

suggest that intervention use is mostly guided by additional factors (co-occurring diagnoses, special education and lower IQ) and demographic characteristics (age, sex and parental education level). Although autism-specific characteristics are suggested to guide intervention use (Fuentes et al., 2020, GGZ Standaarden, 2020; NJI, 2017), co-occurring problems may also be a legitimate reason to choose specific interventions. However, demographic factors and IQ levels should not refrain autistic children from receiving appropriate care. Interventions might have to be adapted to suit all demographic groups, as they should be available and accessible for children of all ages, sexes and levels of intelligence, and with all levels of parental education.

Limitations

When interpreting the results from this study, various points should be considered. Firstly, the three categories of interventions (guideline, mainstream and other) are very broad and include very diverse therapies. However, these categories are not exhaustive and some types of guidance and support were not included. Secondly, the sample that was used for this study is a convenience sample and as participation is voluntary, self-selection bias could be present. Participants of the Netherlands Autism Register are relatively highly educated. Thirdly, there was a lot of missing data for the autism-specific predictors, reducing the power to detect possible effects of these characteristics. Fourthly, alternative social skills measures could have been used as the SDQ is only a brief behavioural screening questionnaire. These limitations may have contributed to the current findings and affect their generalizability.

Other factors, not included in this study, such as the availability of interventions, recommendations from others and the emergence of new innovative interventions, can also affect intervention use. Therefore, more research is needed to clarify the reasons behind intervention choices. Future research should further investigate how different co-occurring diagnoses (e.g. ADHD or anxiety) or problems (e.g. internalising problems vs. externalising problems) could affect intervention use, and subscales of sensory issues may elucidate the relation between sensory issues and therapy and medication use.

Conclusions

By combining demographic and autism-specific predictors we were able to conclude that

intervention use is mostly related to IQ, special education attendance and the presence of co-occurring diagnoses but also to age, sex and parental education level. Autism-specific child characteristics do not influence intervention use, except for a increased chance of using other medication among children with more sensory issues. This study was the first of its kind focusing on Dutch families and draws attention to possible shortcomings of current autism interventions. Nearly a third of the participants reported using other interventions including alternative interventions which can be harmful (Jonkman et al., 2022). Guideline interventions should be available and accessible for children of all ages, sex and with all levels of intelligence. Transdiagnostic interventions could be beneficial for children with autism and additional problems. Furthermore, parents should be accurately informed about medication to ensure that the use of mainstream medication does not depend on parental level of education. Overall, intervention use seems to be guided more by co-occurring problems rather than by autism-specific characteristics.

Funding

This research was supported by a ZonMW Research grant (The Netherlands) [636340005] and by the Senior Research Advancement Fund/Research Development Allowance, School of Law, Social and Behavioural Sciences, Faculty of Business and Social Sciences, Kingston University, UK.

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Table 1*Demographic information*

Variable	Full sample N=1464	Subgroup N=632
Age at entry in years		
Mean (SD)	11.18 (3.34)	10.78 (3.03)
Range	1.44-17.99	1.44-17.97
Age of diagnosis		
Mean (SD)	5.97 (2.75)	5.79 (2.53)
Range	1.50-17.33	1.67-14.67
Sex of child or adolescent		
Male	77.7%	78.3%
Female	22.3%	21.7%
Parental education ^a		
Low	3.9%	4.7%
Middle	19.8%	25.2%
High	45.6%	60.9%
Unknown	30.7%	9.2%
IQ		
Below 85	22.6%	22.5%
86-115	35.4%	36.9%
Above 115	32.9%	32.6%
Education		
Regular education	30.9%	27.1%
Special education	62.2%	68.8%
Unknown	7.0%	4.1%
Additional diagnosis		
No additional diagnosis	52.0%	49.5%
1 or more additional diagnoses	44.0%	47.8%
Unknown	4.0%	2.7%

Note. ^aCategorisation based on Dutch guidelines (CBS, 2020)

Table 2*Family background characteristics*

Variable	Full sample N=1464	Subgroup N=632
Migration background		
Mother's country of birth		
The Netherlands	94.5%	94.6%
West-Europe	1.0%	0.9%
North-America	0.5%	0.8%
Other	3.9%	3.7%
Unknown	0.1%	None
Father's country of birth		
The Netherlands	92.3%	93.7%
West-Europe	1.4%	1.4%
Africa	0.8%	1.3%
Other	5.4%	3.6%
Unknown	0.1%	None
Number of full and half biological siblings		
Mean (SD)	1.37	1.38
Range	0 – 8	0 – 8
Missing	33.3%	14.56%
Sibling(s) with autism		
Sibling(s) with suspected autism	8.9%	11.6%
Sibling(s) with diagnosed autism	15.6%	22.0%
Missing	51.8%	40.7%

Table 3*Participant's scores on autism-specific measures*

Variable	N available	<i>M</i>	<i>SD</i>	Minimum score	Maximum score
<i>AQ-28</i>	786	80.6	11.2	28	112
<i>SDQ</i>	488	-3.6	3.5	-10	10
<i>CRI-R</i>	285	161.4	37.5	62	310
<i>SSP</i>	266	129.2	26.4	38	190

Note. AQ-28 = Autism-Spectrum Quotient; SDQ = Strengths and Difficulties Questionnaire; CRI-R = Childhood Routines Inventory-Revised; SSP = Short Sensory Profile

Table 4*Therapy use at entry (N=955)*

Variable	<i>M (SD)</i>	Range
Total number of therapies	4.07 (2.05)	1.00-12.00
Guideline therapies	2.08 (1.31)	0.00-6.00
Mainstream therapies	1.76 (1.24)	0.00-7.00
Other therapies	.24 (.46)	0.00-2.00
Intervention load (hours)	232.51 (304.80)	4.35 – 1381.58

Table 5*Correlations among the continuous predictor variables*

Variable	Age	<i>AQ-28</i>	<i>SDQ</i>	<i>CRI-R</i>	<i>SSP</i>
Age	1				
<i>AQ-28</i>	-.202**	1			
<i>SDQ</i>	.014	.317**	1		
<i>CRI-R</i>	.003	.501**	.370**	1	
<i>SSP</i>	.115	-.470**	-.337**	-.742**	1

Note. *AQ-28* = Autism-Spectrum Quotient; *SDQ* = Strengths and Difficulties Questionnaire; *CRI-R* = Childhood Routines Inventory-Revised; *SSP* = Short Sensory Profile

* $p < 0.05$ ** $p < 0.01$

Table 6*Multiple linear regression to predict the number of therapies used*

Predictor	<i>N</i>	<i>B</i>	<i>SEB</i>	<i>t</i>
Demographics	499			
Age		.14**	.04	3.45
Sex		-.37	.29	-1.27
Parental education		-.12	.21	-0.56
IQ below 85		-.71*	.33	-2.17
IQ above 115		-.02	.28	-.07
Co-occurring diagnosis		.50*	.25	1.99
Education		1.12**	.29	3.86
F				4.95**
R ²				.07
Adjusted R ²				.05
AQ-28 ^a	409	.01	.01	1.00
SDQ ^a	282	-.00	.04	-.10
CRI-R ^a	118	.01	.01	1.14
SSP ^a	148	-.01	.01	-1.37

Note. AQ-28 = Autism-Spectrum Quotient; SDQ = Strengths and Difficulties Questionnaire; CRI-R = Childhood Routines Inventory-Revised; SSP = Short Sensory Profile

^a Autism-specific characteristics are added separately and individually to the model

* $p < 0.05$ ** $p < 0.01$

Table 7

Binary logistic regressions to predict use of guideline, mainstream and other therapies

Variable	Guideline					Mainstream				Other			
	<i>N</i>	<i>B</i>	<i>SEB</i>	<i>Wald</i>	<i>OR</i>	<i>B</i>	<i>SE</i>	<i>Wald</i>	<i>OR</i>	<i>B</i>	<i>SE</i>	<i>Wald</i>	<i>OR</i>
Demographics	499												
Age		.12	.06	4.16	1.12*	-.05	.05	.73	.96	-.01	.03	.13	.99
Sex		-.95	.56	2.95	.39	-1.26	.50	6.47	.28*	.21	.23	.81	1.23
Parental education		.02	.30	.00	1.02	.10	.26	.14	1.10	-.01	.16	.01	.99
IQ below 85		-.88	.42	4.38	.41*	.05	.46	.01	1.05	.35	.25	1.91	1.41
IQ above 115		.86	.55	2.44	2.37	.21	.35	.36	1.23	-.28	.23	1.52	.76
Co-occurring diagnosis		-.12	.39	.10	.89	.02	.32	.00	1.02	.53	.20	7.25	1.70**
Education		-.11	.55	.04	.90	1.25	.35	13.03	3.49**	-.15	.23	.44	.86
Chi-square				24.06**				23.11**				17.86*	
AQ-28 ^a	409	.04	.02	3.40	1.04	-.01	.02	.91	.99	-.01	.01	1.84	.99
SDQ ^a	282	.06	.07	.68	1.06	.02	.07	.12	1.02	-.05	.04	2.00	.95
CRI-R ^a	118	.00	.01	.11	1.00	.00	.01	.05	1.00	.01	.01	1.49	1.01
SSP ^a	148	.01	.01	.40	1.01	-.02	.02	1.03	.98	-.00	.01	.02	1.00

Note. AQ-28 = Autism-Spectrum Quotient; SDQ = Strengths and Difficulties Questionnaire; CRI-R = Childhood Routines Inventory-Revised; SSP = Short Sensory Profile

^a Autism-specific characteristics are added separately and individually to the model

* $p < 0.05$ ** $p < 0.01$

Table 8

Binary logistic regressions to predict use of mainstream and other medication

Variable	Mainstream					Other				
	<i>N</i>	<i>B</i>	<i>SE</i>	<i>Wald</i>	<i>OR</i>	<i>B</i>	<i>SE</i>	<i>Wald</i>	<i>OR</i>	
Demographics	499									
Age		.01	.03	.11	1.01	-.05	.06	.62	.96	
Sex		-.13	.23	.33	.88	-.16	.41	.15	.70	
Parental education		-.74	.19	15.42	.48**	-.02	.31	.01	.98	
IQ below 85		-.49	.27	3.28	.61	.29	.45	.41	1.33	
IQ above 115		-.16	.23	.48	.85	-.63	.46	1.87	.53	
Co-occurring diagnosis		.76	.21	13.53	2.14**	-.49	.39	1.60	.61	
Education		.68	.23	8.72	1.97**	-.01	.45	.00	.99	
Chi-square				50.01**				5.42		
AQ-28 ^a	409	.01	.01	2.01	1.02	.03	.02	2.00	1.03	
SDQ ^a	282	-.04	.04	.97	.96	.01	.06	.02	1.01	
CRI-R ^a	118	-.00	.01	.16	1.00	.01	.01	.82	1.01	
SSP ^a	148	-.02	.01	3.24	.99	-.02	.01	3.90	.98*	

Note. AQ-28 = Autism-Spectrum Quotient; SDQ = Strengths and Difficulties Questionnaire; CRI-R = Childhood Routines Inventory-Revised; SSP = Short Sensory Profile

^a Autism-specific characteristics are added separately and individually to the model

* $p < 0.05$ ** $p < 0.01$

Table 9*Multiple linear regression to predict intervention load*

Predictor	<i>N</i>	<i>B</i>	<i>SEB</i>	<i>t</i>
Demographics	159			
Age		4.27	7.09	.60
Sex		-39.15	53.09	-.74
Parental education		-8.64	41.74	-.21
IQ below 85		90.22	64.90	1.39
IQ above 115		-25.49	52.20	-.49
Co-occurring diagnosis		93.06	48.58	1.92
Education		18.21	54.94	.33
F				1.84
R ²				.08
Adjusted R ²				.04
AQ28 ^a	131	2.56	2.14	1.20
SDQ ^a	141	-.74	7.85	-.09
CRI-R ^a	63	1.51	1.03	1.46
SSP ^a	84	-2.93	1.51	-1.93

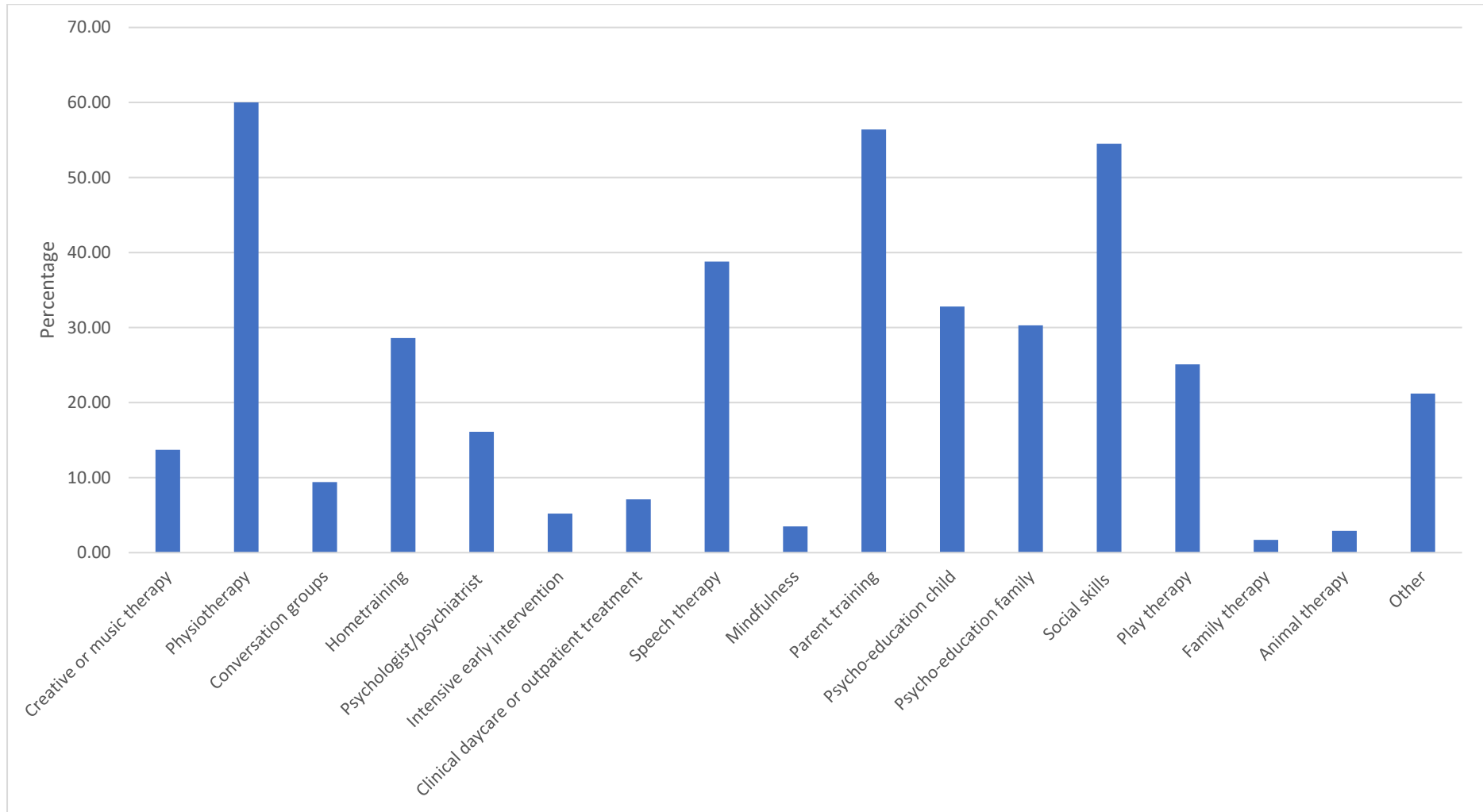
Note. AQ-28 = Autism-Spectrum Quotient; SDQ = Strengths and Difficulties Questionnaire; CRI-R = Childhood Routines Inventory-Revised; SSP = Short Sensory Profile

^a Autism-specific characteristics are added separately and individually to the model

* $p < 0.05$ ** $p < 0.01$

Figure 1

Percentage of children using each type of therapy when entering the NAR (N=955)



Appendix A: Therapies included in the NAR questionnaire

Answer option	Category
Parent training or guidance	Guideline
Psycho-education for the person with autism	
Psycho-education for the parents, siblings or environment	
Early intensive interventions (e.g., early intensive behaviour interventions, applied behaviour analysis, pivotal response treatment, discrete trial teaching, psychiatric intensive treatment)	
Social skills training and resilience treatment (e.g., theory of mind training, aggression regulation)	
Hometraining or other coaching/guiding treatments in the home situation (e.g., intensive orthopedagogical family treatment, practical pedagogical family treatment, video interaction guidance, parent-child interaction therapy, Floortime)	
Creative therapy or music therapy	Mainstream
Physiotherapy or other motor therapies (e.g., occupational therapy, psychomotor therapy, sensory integration therapy)	
Conversation groups	
Individual conversations with a psychologist or psychiatrist (e.g., psychotherapy, CBT, EMDR)	
Clinical daycare or outpatient day clinics	
Speech therapy	
Mindfulness	
Play therapy	
Family therapy (e.g., multi system therapy, functional family therapy)	
Other treatment	Other
Therapy with animals	

Appendix B: Medications included in the NAR questionnaire

Answer options	Type of medication	Category
Abilify/aripiprazol(e)	Atypical antipsychotic	Mainstream
Risperdal/risperidon(e)		
Seroquel/quetiapine		
Zyprexa/olanzapine		
Dipiperon/pipamperon(e)	Typical antipsychotic	
Haloperidol/Haldol		
Orap/pimozide		
Concerta/metylfenidaat (methylphenidate)	Psycho-stimulant	
Medikinet/equasym/methylfenidaat (methylphenidate)		
Ritalin/methylfenidaat (methylphenidate)		
Cipramil/citalopram	Selective serotonin reuptake inhibitor	
Fevarin/fluvoxamine		
Lexapro/cipralex/escitalopram		
Prozac/fluoxetine		
Seroxat/paroxetine		
Venlafaxine		
Zoloft/sertraline		
Wellbutrin (bupropion)	Antidepressant	
Avanza/axit/mirtaz/mirtazon/remeron/zispin/mirtazapine	Atypical antidepressant	
Amitriptyline	Tricyclic antidepressant	
Dixarit/clonidine	Adrenergic α_2 receptor agonists	
Ativan/orfidal/lorazepam	Benzodiazepine agonist	
Seresta/oxazepam		
Valium/diazepam		
Strattera/atomoxetine	Selective norepinephrine transporter	
Restoril/normison/temazepam	Benzodiazepine agonist	
Dexamfetamine (dextroamphetamine)	Amphetamine	
Rivotril/clonazepam	Anti-epileptic	

Propranolol	Beta blocker	
Depakine (valproic acid)	Anticonvulsants	
Other... (<i>people could fill this in</i>)		Other
Don't know/unknown		None

Appendix C: Power analyses

Post hoc power analyses were conducted using GPower (Faul et al., 2009) for linear multiple regression (this was used to predict the number of therapies as seen in Table 6). The model with the 7 demographic predictors, a sample size of 499 and $\alpha = 0.05$ had a statistical power of $1-\beta = 1.00$ for detecting a medium ($f^2 = 0.15$) effect. The statistical power to detect a medium effect when the autism-specific predictors are added to the model is:

AQ-28 (8 predictors, sample size 409 and $\alpha = 0.05$): $1-\beta = 1.00$

SDQ (8 predictors, sample size 282 and $\alpha = 0.05$): $1-\beta = 1.00$

CRI-R (8 predictors, sample size 118 and $\alpha = 0.05$): $1-\beta = 0.84$

SSP (8 predictors, sample size 148 and $\alpha = 0.05$): $1-\beta = 0.93$

Post hoc power analyses were conducted for binary logistic regression (these were used to predict the use of guideline, mainstream and other therapies and medication as seen in Table 7 and 8). The model with the demographic predictors has a sample size of 499 and a power of $1-\beta = 0.99$ to predict an odds ratio of 1.5.

The statistical power to detect an odds ratio of 1.5 when the autism-specific predictors are added to the model is:

AQ-28 (sample size 409): $1-\beta = 0.98$

SDQ (sample size 282): $1-\beta = 0.91$

CRI-R (sample size 118): $1-\beta = 0.55$

SSP (sample size 148): $1-\beta = 0.65$

Post hoc power analyses were conducted for linear multiple regression (this was used to predict the intervention load as seen in Table 9). The model with the 7 demographic predictors, a sample size of 159 and $\alpha = 0.05$ had a statistical power of 0.96 for detecting a medium ($f^2 = 0.15$) effect. The statistical power to detect a medium effect when the autism-specific predictors are added to the model is:

AQ-28 (8 predictors, sample size 131 and $\alpha = 0.05$): $1-\beta = 0.89$

SDQ (8 predictors, sample size 141 and $\alpha = 0.05$): $1-\beta = 0.94$

CRI-R (8 predictors, sample size 63 and $\alpha = 0.05$): $1-\beta = 0.49$

SSP (8 predictors, sample size 84 and $\alpha = 0.05$): $1-\beta = 0.66$