



Experiences of Autistic Individuals, Caregivers and Healthcare Providers with ABA-Derived Therapies: a Sequential Exploratory Mixed Methods Study

Kim M. Jonkman¹ · Charlotte den Hartog¹ · Bart Sloot^{1,2} · Sander Begeer¹ · Elisa Back³ · Anke M. Scheeren¹

Accepted: 23 June 2025
© The Author(s) 2025

Abstract

Applied Behavior Analysis (ABA) is a widely recommended intervention for autistic children, but it has recently been criticized because of its potential negative effects on mental health. This study aims to map experiences with ABA and related techniques in the Netherlands by investigating different types of ABA interventions, experiences and satisfaction levels, and explores variations across techniques and stakeholders. An exploratory sequential mixed methods design was employed, beginning with qualitative focus groups ($n=22$) followed by a quantitative online survey ($n=219$). Participants included autistic adults, parents/legal representatives, and healthcare professionals. Focus groups revealed six main themes: diverse interpretations of ABA, variations in its application, positive experiences, concerns about overburdening and psychological impacts, criticisms of the healthcare system, and quality control issues. Survey results indicated that satisfaction with ABA interventions varied, with autistic adults being less satisfied than parents and healthcare professionals. Positive outcomes included improved communication and independence, while negative experiences involved trauma and concerns about ethical application. Better quality interventions were associated with higher satisfaction levels. The study reveals diverse experiences and interpretations of ABA. Participants raised significant concerns that merit attention alongside the noted benefits of ABA. Improving training and ensuring ethical practices are crucial to maximize ABA's potential to positively impact the lives of autistic individuals. Future efforts should focus on enhancing regulation, standardization, and incorporating autistic perspectives to optimize outcomes.

Keywords Applied behavior analysis · ABA · Autism · Intervention · Mixed methods

Introduction

Experiences of autistic individuals, caregivers and healthcare providers with ABA-derived therapies: a sequential exploratory mixed methods study.

People with a diagnosis on the autism spectrum (from hereon: autism) show differences in the domains of social interaction, communication, stimulus processing and limited and/or repetitive behaviors or interests compared to people without autism (Lord et al., 2020). There are various interventions available that can support autistic individuals (Fuentes et al., 2021; Medavarapu et al., 2019). Applied Behavior Analysis (ABA) is one of the most recommended interventions for autistic children in the United States (Anderson, 2023; Graber et al., 2023). ABA in the United States is considered ‘treatment as usual’, whereas in Europe ABA-based interventions are not as widespread (Keenan et al., 2015). Criticism has recently been leveled at ABA, including concerns about compliance, neurotypical norms, and mental health impacts (Anderson, 2023; Graber et al., 2023; Kupferstein, 2018; Mathur et al., 2024).

✉ Kim M. Jonkman
k.m.jonkman@vu.nl

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

² Academy Het Dorp, Arnhem, The Netherlands

³ Department of Psychology, Kingston University, London, UK

ABA covers a range of techniques and approaches that are grounded in the principles of behaviorism and behavior modification, such as reinforcement and punishment (Cooper et al., 2020; Matson, 2021). Since its development in the first half of the 20th century ABA has evolved and several types of ABA interventions have been developed, including Discrete Trial Training (DTT), Pivotal Response Training (PRT), Natural Environment Training (NET), Verbal Behavior Intervention (VB), Functional Communication Training (FCT) (Cooper et al., 2020; Gitimoghaddam et al., 2022). A key aspect of ABA involves conducting functional behavior assessments (FBAs) to identify the causes of challenging behaviors and using strategies like replacement behavior training to address them (Cooper et al., 2020; Matson, 2021). However, because of the wide range in interventions, there is a degree of variability and confusion in the definition of ABA (Gitimoghaddam et al., 2022). The basic principles of ABA (such as operant conditioning) are widespread and applied in many everyday contexts (e.g. parents or teachers use these principles in education or child rearing). In this paper, we use the term ABA intervention as an umbrella term for treatments referred to as ABA or its derivatives (e.g., DTT, PRT, FCT) in the Netherlands.

ABA principles can be applied to build skills or reduce behaviors that hinder a child's development, with the aim of increasing the quality of life for the individual (Cooper et al., 2020). Behavioral therapy for children with autism often focuses on improving communication skills, strengthening social skills and reducing behaviors that hinder the individual's development (e.g. self-injurious behavior) (Gitimoghaddam et al., 2022). The exact behaviors that are set as goals within the intervention differ per child and are determined in consultation with all those involved following the ABA guidelines (Cooper et al., 2020). This should ensure an approach that is tailored to the child's unique needs. Proponents of ABA usually point to research demonstrating the short-term effectiveness of ABA in terms of improved communication skills and reduced problematic behavior such as aggression (Gitimoghaddam et al., 2022; Peters-Scheffer et al., 2011; Reichow et al., 2018; Virués-Ortega, 2010; Yu et al., 2020). Early interventions in particular can provide significant and long-lasting benefits in these areas (Eldevik et al., 2009).

However, critics of ABA claim that the intervention attempts to 'cure' or 'correct' the autistic personality or identity and that the behavioral norms to judge effectiveness of ABA are often neurotypical (Graber et al., 2023; Kirkham, 2017; Leaf et al., 2022; Sandoval-Norton et al., 2019). According to the critics, people with autism are forced (through ABA) to adapt to society and the habits of neurotypical people. A key issue in this debate is who determines the definition of 'normal' (desired) behavior (Graber et al., 2023). Advocates of the neurodiversity movement state that interventions

should not focus on changing the person with autism but on improving their quality of life (Kapp et al., 2013; Lerner et al., 2023; Pellicano et al., 2022). This is in line with the trend that researchers and clinicians increasingly emphasize the impact of environmental factors on the functioning and well-being of autistic individuals (Mathur et al., 2024). This is called the social model of autism. Based on the social model of autism, interventions should therefore not (only) focus on the person with autism, but also on adapting the environment (Mathur et al., 2024).

In addition to the substantive criticism, there are also studies that question the supposed effectiveness of ABA. Review studies report large individual differences and possibly exaggerated effects of ABA (Peters-Scheffer et al., 2011; Reichow et al., 2018). High care needs remained after completion of the intervention (Reichow et al., 2018) and long-term effects are often unknown. Other studies did not find a reduction in unwanted behavior after ABA (Seida et al., 2009). The methodology and design of studies on the effectiveness of ABA have also been questioned (Reichow et al., 2018; Seida et al., 2009; Shea, 2004).

ABA is mainly studied in the United States (Anderson, 2023; Graber et al., 2023). ABA outside of the US and Canada often lacks regulation and recognition. In Europe, this has led to misconceptions about ABA, preference for eclectic approaches over standardized ABA interventions, and limited consumer protection (Keenan et al., 2015, 2023). This situation is worsened by the absence of governmental endorsement and standardized training of practitioners, contributing to variability in service quality and professional standards in Europe (Keenan et al., 2015, 2023). Unlike the United States, where practitioners are required to meet strict certification standards set by the Behavior Analyst Certification Board (Behavior Analyst Certification Board, 2020), most European countries lack a unified regulatory framework for ABA (Keenan et al., 2023). For instance, in some European countries, ABA practitioners may have only limited training or self-reported qualifications (Keenan et al., 2015), leading to inconsistent application of ABA principles. Furthermore, the absence of an official code of conduct specific to ABA practitioners in Europe (Keenan et al., 2023) means there is less oversight to ensure ethical and high-quality practice. Although most European ABA-practitioners have to adhere to general ethical codes for (youth) healthcare professionals. Given these differences, conclusions derived from US-based ABA research might not apply to ABA in Europe.

Although ABA can lead to positive results such as improved communication skills and reduced problematic behavior (Gitimoghaddam et al., 2022; Rosen et al., 2016; Virués-Ortega, 2010), there are also individuals who report negative experiences with ABA such as overemphasis on compliance training and long-term negative mental health impacts such as

posttraumatic stress symptoms (Kupferstein, 2018; Mathur et al., 2024). It is essential to understand both the positive outcomes and potential risks of ABA for people with autism, as well as the diverse opinions and experiences of those directly involved in ABA. The primary aim of this research is therefore to map the experiences with ABA of autistic adults, parents/legal representatives of children/autistic adults and healthcare professionals involved in ABA. This will provide a better understanding of ABA and subsequent implications. We aim to study:

- Which ABA and derivative techniques are offered.
- How individuals with autism, their parents, and ABA therapists describe their experiences with ABA and derivative techniques.
- Whether experiences differ between individuals, groups and between different ABA techniques.

Methods

Study Design

We used an exploratory sequential mixed methods design (Creswell et al., 2017; Shiyanbola et al., 2021), including qualitative research methods (focus groups), followed by quantitative methods (online survey). The qualitative data collection (the focus groups) formed the basis for the quantitative data collection (the survey), thus using a building approach.

Ethical Considerations

The study was approved by the Standing Committee on Science and Ethics of the Vrije Universiteit Amsterdam (Focus groups: VCWE-2023-132R1; Survey: VCWE-2023-187).

Community Involvement Statement

The Netherlands Autism Register (NAR) is a large online database that collects information from autistic individuals and their caregivers. The NAR works closely together with autistic people. We rely on input from the autistic and autism community. Autistic individuals are part of the NAR research team, including an author of the current study, and regularly give feedback through panels. Additionally, in this particular study an advisory team was involved consisting of five people with complementary perspectives or knowledge: three autistic adults (one with personal experience with ABA and one with autistic children); a legal representative of an adult with autism and an intellectual disability and a practitioner (BCBA) with ABA training

and intervention experience both in the Netherlands and the United States. The role of the advisory team was to advise the research team based on their own experience or expertise. The researchers themselves are not ABA practitioners and have not received ABA themselves.

Qualitative Study: Method

Qualitative Study: Participants and Recruitment

Participants for the focus groups were recruited through the NAR, organizations offering ABA services and advocacy groups for autistic individuals. The NAR was the primary recruitment channel with invitations to registered participants ($n \sim 3500$). Social media platforms were also used to post the survey link, although these posts served as supplementary outreach and the actual visibility of posts is unknown.

To ensure clarity and focus, participants were asked about interventions explicitly named ABA or its derivatives (e.g., PRT, DTT, FCT). A general description of ABA was not provided to avoid overgeneralization, as previous anecdotal feedback suggested that participants might include interventions not intended to be ABA (e.g., general reinforcement strategies used in schools). This approach aimed to ensure that participants reported on interventions explicitly identified as ABA by practitioners.

A total of 87 individuals expressed interest in participating in the focus groups. The final selection and allocation of participants to the focus groups were based on the following criteria: informant role (autistic adult, parent or legal representative, healthcare professional), opinion about ABA (positive, negative, neutral), type of ABA (type of intervention) and availability at the proposed dates and times. Groups were formed to include participants with the same role (e.g., parent) while ensuring a diversity in perspectives (positive, negative, neutral) and types of ABA. Each group included up to 7 participants to allow everyone sufficient opportunity to share their views.

Twenty-five participants were selected and divided across five focus groups (see Table 1 for demographics of parents/legal representatives and healthcare professionals). However, three participants (two parents and one autistic adult) did not attend the focus group. As a result, the final composition of the focus groups was as follows: two focus groups with parents/legal representatives ($n=4$ in both groups), two groups with healthcare professionals ($n=7$ and $n=5$) and one group with autistic adults and ABA experience ($n=2$). The group of autistic adults with ABA experience was smaller because only three eligible participants signed up. Demographic information of the autistic adults

Table 1 Demographic information from the focus group participants per group

	Parents/legal representatives of children/autistic adults ($n=8$)	Health-care professionals ($n=12$)
Biological sex		
Male	1	2
Female	7	10
Otherwise	0	0
Nationality		
Dutch	8	12
Non-Dutch	1 ^a	—
Age	46.38 (8.18)	42.83 (13.83)
Highest level of education		
VMBO/HAVO/VWO	1	1
HBO	4	3
University	3	6
Doctorate/PhD	—	2
Biological sex of child		
Male	7	—
Female	1	—
Current education child		
Special education	4	—
No education	2	—
Other ^b	2	—
Initial opinion on ABA		
Positive	4	7
In-between	1	5
Negative	3	0

Demographic information of the autistic adults ($n=2$) is not included in Table 1, due to missing data for one participant and subsequent privacy concerns for the other

^aOne person reported dual nationality; ^bgoes to day care or has finished school

is not included in Table 1, because of missing data of one participant and subsequent privacy concerns for the other. Informed consent was obtained from all participants.

Qualitative Study: Materials

A (semi)structured focus group protocol was created following the literature (Howitt, 2016; Willig, 2021), advice from the advisory team and advice from external research experts with experience in qualitative research.

The following questions were addressed in the focus groups:

- How would you describe ABA?
- What was it like for you to experience ABA?
- What are some benefits/positive things you have experienced during/through ABA?
- What are some disadvantages/negative things you have experienced during/through ABA?

- What do you think ABA should look like in the future?
- What is an outcome of this research that you would be satisfied with?

The focus groups lasted about 2 h per group. These were conducted in November 2023.

Qualitative Study: Data Analysis and Interpretation

Participants' opinions about ABA (positive, neutral, negative) collected prior to the focus groups were not included in the formal analysis, as the focus group discussions provided a more nuanced understanding of participant perceptions. The focus group recordings were transcribed using AmberScript. These automatic transcriptions were then checked, corrected and anonymized by a student assistant. Transcripts were then checked by one of the researchers (KJ).

Thematic analysis was used to analyze the focus group data. CH and BS independently created codes based on the first two focus groups. The coding frames were compared and, in consultation with KJ, one coding frame was created and used by KJ and CH to independently code the first focus group. Inter-coder reliability was 67,1% following the procedure by Campbell et al. (2013). Due to the exploratory nature of the research, the length of text and the large number of codes this reliability is understandably lower than usual (O'Connor et al., 2020; Roberts et al., 2019).

Qualitative Study: Results

The thematic analysis revealed 6 main themes and 16 sub-themes (see Appendix B for an overview of the themes and codes associated with the themes).

Theme 1: The Theory and Definition of ABA

The subtheme '*The Theory of ABA*' revealed varying interpretations of ABA. Most participants believed ABA is scientifically based, using reinforcers aligned with a child's interests. While healthcare professionals frequently discussed behavior analysis, parents were less familiar with it. Similarly, the subtheme '*The Current Definition of ABA*' highlighted confusion among parents about whether elements like punishment and behavior analysis are part of ABA, with some feeling these were absent from the interventions they received.

Healthcare professional: "So and what I notice in discussions that exist about, what is ABA? (...) there is very often an incorrect image of what ABA is and that it is indeed reduced to punishment and reward instead of looking: hey, how can this person function as well as possible, optimally as possible within society?"

Parent: “The core of ABA is behavioral analysis, for example, an ABC, they call it at ABA. But that is indeed very often, simply not— not implemented.”

A subtheme was ‘**Normality**’, where participants debated which behaviors should change and which are part of the autistic individual. Several participants questioned what behavior is (un)desirable and who determines this? While participants agreed that behaviors like hand flapping should be allowed, some parents and autistic adults noted that ABA teaches children to unlearn such behaviors. Healthcare professionals said they always carefully consider whether behavior needs adjustment.

Healthcare professional: “Why do I want this behavior to be different? Does that really have social relevance for this child? Yes or no? And if we arrive at: yes, we do want to change that, because it has certain social relevance, then you consider: what is the best way to do that?”

Theme 2: The Use of ABA

Many parents and healthcare professionals noted that ABA is often misapplied, as seen in the subtheme ‘**Improper Application of ABA**’. Participants agreed that ABA should be tailored to each child’s needs, with adapted reinforcers and punishment should not be part of properly administered ABA. They emphasized the importance of a warm, loving environment. Many professionals strived for this, but some professionals and parents described the intervention as cold and unloving.

Parent: “I believe very much in my parenting towards my children in completely, well, as far as that is possible, unconditional love, love and approval never has a condition and I started to feel more and more that because of the approach, the behavioral approach of our youngest, that it became conditional, that too often there were conditions attached to how we treated him and that- I found that unpleasant.”

Other instances of improper ABA application according to participants included the use of punishments, or violations of the BACB code of conduct.

Adult with autism: “And I remember very well that during the first few times of that ABA, that teddy bear was actually pulled out of my hands by the ABA practitioner and that I would never get it back, until I did that assignment or things they wanted to teach me until I— until I did that properly.”

Healthcare professional: “When it comes to applying ABA principles, we all know that this must be done in a very ethical and responsible manner and at the same time I also see around me that that is not always the case.”

Another discussion point was whether learned behavior is truly internalized, or merely performed for a reward.

Parent: “She reacted well to rewards. But to me, it felt a bit like she was just performing tricks to get a marble, becoming almost robotic in doing whatever was expected to get the marble.”

The subtheme ‘**Good Healthcare is Collaboration**’ highlighted the importance of cooperation between parents, professionals, and agencies, with ABA applied across all areas of the child’s life, for example both at home and at school.

Healthcare professional: “The parents have ideas, the schools have ideas, the therapists have ideas. The child probably also has ideas, they should all sit together and then ensure that a program is developed that everyone can support.”

Participants agreed that ABA is not effective for every child. The subtheme ‘**Customization**’ highlighted the need to tailor ABA to each child’s unique needs, with its success depending on child factors (e.g. IQ, age) and correct application. Some parents felt ABA works best for children with lower intelligence or who are non-speaking.

Parent: “What is needed? (...) What makes him happy? What is functional? Because what do you want to teach him and what don’t you want to teach him?”

Theme 3: Positive Experiences

Several parents found ABA supportive, improving their parenting confidence and their child’s behavior and emotions as shown in the subtheme ‘**ABA is Helpful**’. One parent credited ABA with allowing their child to continue living at home.

Parent: “Now he is a child who is very manageable and who also enjoys life and radiates and lives day by day.”

The subtheme ‘**General Daily Living Skills**’ showed that ABA contributed to children’s development and independence. Some parents reported that ABA helped their child learn to talk and master everyday tasks like dressing and brushing teeth.

Parent: “Our son has a severe intellectual disability and (...) (he) was also completely non-speaking, nowadays he speaks, and he speaks functionally, and I am convinced that without ABA he would never have started speaking.”

Theme 4: Concerns About ABA

The subtheme ‘**Overburdening of the Child**’ revealed concerns from some healthcare professionals and parents about the intensity (frequency and duration) of ABA, while others saw it as essential for effectiveness. Some worried ABA could overload the child or lead to misunderstandings about their abilities.

Parent: “Children with autism already have a slow, slower development speed in general, with exceptions, in

my opinion ABA is simply not necessary, or at least not in that way, because these children will get there anyway, it just takes a little longer."

ABA's impact on the well-being of the child was also a concern as shown in the subtheme '**Psychosocial Problems**'. A parent and adult with autism indicated that ABA had led to psychological problems such as (social) fears, problems with trusting adults and mood problems.

Adult with autism: "It has only caused me trauma. In the end I didn't learn anything from it. Everything I know now and what I- and how I can behave now is mainly because of the therapies I followed afterwards."

The subtheme '**Criticism of ABA**' highlighted further concerns, especially for non-speaking children who may struggle to express when boundaries are crossed, leading some participants to call for ABA's abolition.

Parent: "I have children who can talk, so they are not non-verbal. My fear is what is going on in the heads of those children who are non-verbal? And they can't tell."

Theme 5: Healthcare

The subtheme '**Dissatisfied with the Healthcare System**' revealed criticism of Dutch healthcare for its lack of autism knowledge, budget cuts, and failure to listen to parents and autistic individuals. Some parents struggled to find appropriate care, with ABA often being a last resort ('**ABA as the Only Option**').

Parent: "Then we really started looking for what would help, because everything we had used before didn't help and then we ended up with ABA."

The potential abolition of ABA raised concerns among some parents and professionals.

Healthcare professional: "Where should these children go if we can no longer offer them ABA?"

The subtheme '**Criticism of Schools**' showed that special education was blamed for expecting autistic children to adapt rather than tailoring education. Parents noted reluctance from teachers, and some children did not go to school due to inadequate support.

Theme 6: Quality Control

The subtheme '**training**' showed that the majority of parents and professionals stressed the importance of proper training for ABA practitioners. They criticized the lack of adequate training and mentioned that certificates and diplomas were too easy to obtain. Many parents found it hard to verify which practitioner had the correct training and which requirements this training should meet. There was a call for a register and protected title for ABA practitioners to ensure quality, citing the U.S. as an example.

Healthcare professional: "Professionals who say: yes, I have ABA-principles, I can apply it, I have learned it, or I have seen it somewhere or I have taken a course, and I am just going to do that, without that good background. (...) And then it is up to the parents to decide: yes, which ABA professional is a good one, which one is not, which one has the experience, which one does not have an ethical compass?"

The level of supervision and control of ABA is low, said nearly all focus group participants in the subtheme '**Monitoring and Control**'. Participants expressed a need for a well-functioning control body to monitor quality and enforce general ABA guidelines.

Healthcare professional: "I think we're also missing something there, right, because the- an ethics committee or something that deals with that, something where you can report things and ask for advice."

Quantitative Study: Method

Quantitative Study: Procedure

The content of the questionnaire was based on topics mentioned in the focus groups. Both the advisory team and the focus group participants provided feedback on the questionnaire.

Informed consent was obtained from all participants. This study has been preregistered (<https://osf.io/saf52>).

Quantitative Study: Participants and Recruitment

To recruit participants for the survey, the same organizations were approached as for the focus groups. The questionnaire was distributed to all NAR participants ($n \sim 3500$) and was open for completion between January 15 and February 11, 2024. Participants were included in the analysis if they had experience with an ABA intervention. In total 33 autistic adults, 45 parents, 28 legal representatives and 113 healthcare professionals were included (see Table 2). Healthcare professionals were on average 34.6 ($SD=9.4$) years old and 91.9% was female. They had on average 6.0 years ($SD=5.2$) of experience with ABA interventions. They mainly worked with young children with an average to below average IQ, with 72.6% working with non-speaking children, 48.7% (also) working with speaking children.

Quantitative Study: Materials

The survey included questions about demographic characteristics, details about participants' diagnoses and experiences with ABA (see Appendix A for more details).

Table 2 Demographic information of autistic adults and children with ABA experience as reported by themselves

	Adults 16+ (self- report, <i>n</i> =33)	Children 16- (parent reported, <i>n</i> =45)	Adults 16+ (reported by representa- tives, <i>n</i> =28)
Age	38.5 (11.7)	9.2 (3.4)	27.4 (10.9)
Biological sex			
Male	45.5%	77.8%	78.6%
Female	54.5%	20.0%	21.4%
Other/don't want to say	0%	2.2%	0%
Nationality ^a			
Dutch	87.9%	97.8%	100%
Non-Dutch	12.1%	4.4%	3.6%
IQ			
Above average (> 115)	57.6%	6.7%	14.3%
Average (86–115)	33.3%	20%	7.1%
Below average (71–85)	0%	6.7%	14.2%
Intellectual disability (< 70)	0%	35.6%	50.0%
IQ unknown ^b	9.1%	31.1%	14.3%
Current education			
None	84.8%	55.6%	82.1%
Regular	15.2%	2.2%	3.6%
Special	0%	33.3%	14.3%
Other	0%	8.9%	0%
Highest level of education			
Primary education	21.2%		42.9%
Secondary education	33.3%		3.6%
Higher education	45.4%		3.6%
Different or none			50.0%
More than one diagnosis	72.7%	35.6%	50.0%

^aSome participants have 2 nationalities. ^b disharmonious IQ or no IQ test taken (yet)

We included questions about interventions that are directly related to ABA and are offered in the Netherlands: Applied Behavior Analysis (ABA); Pivotal Response Treatment (PRT; (Koegel et al., 1987; Lei et al., 2017; Verschuur et al., 2014); Verbal Behavior (VB; (Barbera, 2007; Carr et al., 2005); Discrete Trial Training (DTT; (Smith, 2001; Vismara et al., 2010); Natural Environment Training/Teaching (NET; (Halle, 1982); Early (Intensive) Behavioral Intervention (EIBI; (Vismara et al., 2010); Incidental Teaching and Precision Teaching ((Hart et al., 1975, 1980; McGee et al., 1983); Picture Exchange Communication System (PECS; (Bondy & Frost, 1998; Charlop-Christy et al., 2002); Functional Communication Training (FCT; (Carr et al., 2005; Cooper et al., 2020; Ghaemmaghami et al., 2021); and (School Wide) Positive Behavior Support (Hieneman, 2015; Horner et al., 2015). As with the focus groups, participants were asked to report on interventions explicitly named as ABA or its derivatives to ensure familiarity with the intervention.

Quantitative Study: Data Analyses

Chi-squared tests and independent t-tests were used to analyze differences in experiences (satisfaction, results, goals and effect on daily functioning) between groups of participants and differences between interventions (satisfaction and components).

A multinomial logistic regression analysis was conducted to examine the association between type of intervention and intervention satisfaction, with the satisfaction score being the predictor and the type of intervention the outcome variable. The reference category for the outcome variable was “Other ABA intervention”.

Multiple regression analyses were conducted to determine the relationship between the number of years since the intervention was used and the level of satisfaction (per group of informants), as well as the relationship between the number of reported positive and negative elements of the intervention and the intervention satisfaction level.

Quantitative Study: Results

Offered ABA and Derivative Techniques

A total of 106 autistic adults, parents and legal representatives reported a sum of 263 separate ABA interventions. The most common types were: Applied Behavior Analysis (61.3%); Pivotal Response Treatment (33.0%); Early Behavioral Intervention (26.4%) and Discrete Trial Training (20.8%) (see Tables 3 and 4, Appendix C). ABA intervention goals included expanding social and play skills, increasing communication skills, promoting language development, and promoting self-reliance and daily living skills (see Table 5 in Appendix C). Most healthcare professionals reported parent involvement in ABA interventions, but 20% of adults and parents/representatives said parents were not involved (see Table 6 in Appendix C).

Experiences with ABA and Derivative Techniques

On average, participants (autistic adults and parents/representatives) rated their ABA intervention a 6.31 out of 10 (*SD*=2.95) (see Table 7 in Appendix C). About half of the participants (45.7%) reported their ABA intervention contained at least one negative component such as “forcing the child to perform tasks or exhibit certain behavior (e.g., making eye contact)” (mentioned by 29.3%) and “forced/involuntary time-out or isolation” (26.1%). Most participants (90.2%) reported positive components like “rewards” (76.1%), “aligning with interests and motivation of the child” (68.5%) and “comprehensive behavioral

analysis (i.e., studying the behavior)” (66.3%) (see Table 8 in Appendix C).

A quarter of autistic adults reported the intervention had a negative effect on their daily life functioning at the time, while 11.3% of parents/legal representatives reported this. 22.2% of adults reported a positive effect on their daily functioning while 61.3% of parents/legal representatives reported a positive effect on their child’s daily functioning (see Table 9 in Appendix C).

Differences in Experiences Between Groups

Autistic adults rated their satisfaction with the intervention significantly lower on a scale from 1 to 10 ($M=5.0$, $SD=2.7$) compared to parents ($M=6.8$, $SD=3.0$; $t(76) = -2.67$, $p=.009$) and legal representatives of autistic individuals ($M=7.0$, $SD=2.8$; $t(59)=2.87$, $p=.006$).

Autistic adults, parents and legal representatives less often reported positive results compared to healthcare professionals (72.7%, 86.7% and 82.1% vs. 100%, respectively; $\chi^2(3, N=217)=25.669$, $p<.001$). Parents, legal representatives and healthcare professionals less often reported negative results compared to autistic adults (48.9%, 32.1% and 48.7% vs. 75.8%, $\chi^2(3, N=217)=12.341$, $p=.006$). See Table 10 in Appendix C for all positive and negative results that were reported.

Intervention goals most reported by autistic adults and parents/legal representatives were ‘increasing communication skills’ (70.8%), ‘expand social skills’ (69.8%) and ‘promote self-reliance and daily skills’ (64.2%). Healthcare professionals mentioned ‘increasing communication skills’ (73.5%), ‘promote language development’ (72.6%) and ‘expand social skills’ (72.6%) most often (see Table 5 in Appendix C). Autistic adults and parents/legal representatives more frequently reported ‘reducing self-stimulatory behavior’ as an intervention goal compared to healthcare professionals (20.8% vs. 5.3%; $\chi^2(1, N=217)=11.367$, $p<.001$). Healthcare professionals more often reported ‘returning to school’ (38.9% vs. 10.4%; $\chi^2(1, N=217)=24.537$, $p<.001$), ‘reducing aggressive behavior’ (39.8% vs. 20.8%; $\chi^2(1, N=217)=9.137$, $p=.003$), ‘promote language development’ (72.6% vs. 52.8%; $\chi^2(1, N=217)=8.581$, $p=.003$) and ‘regulate or reduce self-injurious behavior’ (41.6% vs. 15.1%; $\chi^2(1, N=217)=18.443$, $p<.001$).

Differences in Experiences Between Interventions

Satisfaction ratings did not differ significantly between ABA interventions. Parents reported their child received intervention 3.5 years ago ($SD=2.4$) at the age of 5.8 years ($SD=2.4$). Parents of autistic children were more satisfied with interventions that were followed longer ago ($B=0.459$,

$p<.001$). Autistic adults received their ABA interventions on average 21.5 years ago ($SD=13.23$) at the age of 16.1 ($SD=9.3$). They were less satisfied with interventions that were followed longer ago ($B=-0.080$, $p=.003$). Legal representatives reported the person with autism received intervention 20.6 years ago ($SD=12.0$) at the age of 6.7 ($SD=3.0$). For this group, satisfaction level was not associated with recency of the intervention.

There were no significant differences in reported positive or negative elements per ABA intervention. However, a higher number of positive elements was positively associated with intervention satisfaction ($B=0.495$, $p<.001$) and a higher number of negative elements was negatively associated with satisfaction ($B=-0.706$, $p<.001$).

Discussion

This study examined the experiences of autistic individuals, parents and healthcare professionals with ABA interventions using a sequential mixed methods design (focus groups followed by a survey). Overall, results showed varying experiences. Participants had different interpretations of ABA and interventions varied in intensity, duration, parent involvement, goals and components. Autistic adults were generally less satisfied with the ABA interventions than parents and healthcare professionals. Parents of autistic children both expressed positive and critical views about ABA, while healthcare professionals were mostly positive. Often mentioned positive effects were learning new skills and heightened independence, whereas often mentioned negative effects included masking autistic traits and overstimulation.

Quantitative findings showed contrasting views on the impact of ABA on daily functioning and well-being (as mentioned in the theme ‘Positive experiences’), highlighting the variability in how different stakeholders perceive ABA’s benefits and challenges. Most parents/legal representatives reported positive effects, whereas autistic adults reported mixed experiences. Qualitative insights echoed concerns about negative impacts on well-being and psychological outcomes (as mentioned in the theme ‘Concerns About ABA’) consistent with previous literature (Anderson, 2023; Graber et al., 2023; Kupferstein, 2018). This paper highlights the discrepancy between parents’ views and those on the receiving end of the intervention. Satisfaction with ABA interventions varied by stakeholder group with autistic adults generally being less satisfied and more critical than parents and professionals. These findings emphasize the importance of including the autistic voice, as it can differ significantly from parental and professional perspectives (Anderson, 2023).

It is important to note that autistic adults reported on interventions they received on average about 21 years ago at the age of 16.1, whereas parents reported on interventions their child had received on average 3.5 years ago at the age of 5.8. Also, adults were less satisfied with interventions received longer ago, whereas parents were more satisfied with interventions received longer ago. Timing of the intervention (early '00 versus '20) may have contributed to different experiences of autistic adults and parents or perhaps adults have had more time to experience the long-term effects of ABA.

Participants were less satisfied with ABA interventions when they included more negative (e.g. forced time-outs) or fewer positive (e.g. aligning with interests and motivation of the child) components. However, no differences in satisfaction were found between the different types of ABA-interventions (e.g. PRT, DTT, NET, etc.). ABA theory emphasizes the use of positive reinforcement and not the use of negative components (Cooper et al., 2020). It seems that the *quality* of the ABA-intervention (higher quality is assumed in case of more positive and fewer negative components) rather than the *type* of intervention is associated with intervention satisfaction. This is reinforced by the qualitative data which called for improved training and quality control to ensure ethical and correct practice (as shown in the theme 'Quality Control').

Both quantitative and qualitative data highlighted the importance of parental involvement in ABA interventions. Parental involvement is a key factor in the correct implementation of ABA, as shown in the theme 'The use of ABA'. However, a notable portion of participants reported limited or no parental involvement, suggesting a variability in implementation and quality of the ABA interventions which is consistent with criticism on the implementation of ABA in Europe (Keenan et al., 2015, 2023).

Overall, the findings align with previous research showing mixed outcomes of ABA interventions. On the one hand, participants reported concerns about the ethical application of ABA and its potential negative impact on the psychological well-being of autistic individuals (Anderson, 2023; Graber et al., 2023; Kupferstein, 2018) as 75.8% of the autistic adults and 43.5% of the parents reported negative results from the intervention. On the other hand, participants also mentioned the short-term effectiveness of ABA in improving communication skills and reducing problematic behaviors as described in prior studies (Gitimoghaddam et al., 2022; Rosen et al., 2016; Virués-Ortega, 2010).

Strengths and Limitations

Both quantitative and qualitative data mostly converged, with qualitative data adding additional depth to the survey and showing relatively more negative experiences. This

highlights the importance of using mixed methods for a holistic understanding of ABA experiences. The inclusion of perspectives from parents, healthcare professionals and autistic adults enriched the findings, offering nuanced insights into the complexities of ABA experiences.

However, the study has several limitations. Autistic adults with ABA experience were underrepresented in the focus groups and survey. Recruiting autistic adult participants with ABA experience was challenging. Possible explanations for this low participation rate include difficulty remembering or recognizing the exact intervention or intervention name, or being suspicious of scientific research. Furthermore, ABA has only more recently been widely adopted in the Netherlands (2000s vs. 1970s in the US) (Keenan et al., 2023) which means there might be a limited number of individuals who are currently adults who have received it. Additionally, it was easier to find participants with positive experiences. Possibly those with negative experiences might prefer not to recall or discuss their experiences. This limits the ability to generalize the findings to all autistic individuals. The self-reported nature of the data may introduce bias. As the survey relied on the names of ABA-derived interventions without providing standardized definitions, some participants may not have recognized or accurately identified the interventions they received. Additionally, as the study was conducted within the Netherlands, the findings may not be fully generalizable to other contexts, particularly the US. Differences in regulation, training, and certification—such as the strict standards in the US compared to more variable practices in Europe—likely shape the experiences and perceptions of stakeholders.

Implications

The findings have several implications for practice. Firstly, better training and certification processes for ABA practitioners are needed to ensure consistent and ethical application of ABA principles. Implementing a protected title and a register for ABA practitioners, similar to the system in the U.S., could improve service quality (Keenan et al., 2015, 2023). Secondly, enhancing parental involvement in the intervention process may contribute to better outcomes. Lastly, addressing potential negative consequences of ABA is essential, as individuals may experience psychosocial problems following intervention. Appropriate aftercare, should be provided to those who need it.

This study underscores the importance of ongoing evaluation and refinement of ABA practices to address diverse stakeholder concerns and optimize outcomes for individuals with autism. Future research should focus on longitudinal studies to assess the long-term impact of ABA interventions on the quality of life and psychological well-being of autistic

individuals. Additionally, comparative studies between different countries could provide insights into how variations in regulation and training standards affect the outcomes of ABA interventions (Keenan et al., 2015).

Conclusion

This study highlights the complex and varied experiences with ABA-derived interventions among autistic individuals, their caregivers, and healthcare providers. Participants raised significant concerns that merit attention alongside the noted benefits of ABA. By improving training and ensuring ethical practices and monitoring whether people adhere to these guidelines, the potential of ABA to positively impact the lives of autistic individuals can be maximized.

Appendix A: ABA Survey Details

The questionnaire consisted of questions about:

- Demographic data of the person with autism or healthcare professional (age, nationality, biological sex, IQ, education level).
- Demographic data of the parent or legal representative (biological gender, relationship to the child, highest level of education).
- Diagnoses (autism diagnosis, intellectual disability and other psychiatric diagnoses).
- Experiences with ABA interventions (autistic adults, parents and legal representatives).
 - Details per ABA intervention (type of ABA intervention, satisfaction, age during intervention, duration and intensity of intervention).
 - Details about the content (who was the practitioner, what training did he have, what goals were set, were the parents involved, which components were included in the intervention).
 - Details about the effects (positive/negative results, effect on daily functioning).
- Experiences with ABA interventions (healthcare professionals).
 - Details about the ABA intervention (type of intervention, years of experience, duration and intensity of intervention, training completed, financing).
 - Details about the content of the interventions (who is involved in the intervention, what are the goals, what behavior is encouraged, what does the target group look like, components of ABA interventions).
 - Details about the effects of the intervention (positive and negative results).

The questionnaire asked about experience with different types of ABA interventions:

- Applied Behavior Analysis (ABA);
- Pivotal Response Treatment (PRT);
- Verbal Behavior (VB);
- Discrete Trial Training (DTT);
- Natural Environment Training (NET);
- Early Intensive Behavioral Intervention (EIBI);
- Early behavioral intervention;
- Incidental Teaching and Precision Teaching;
- Picture Exchange Communication System (PECS);
- Functional Communication Training (FCT);
- (School Wide) Positive Behavior Support (PBS).

Appendix B: Main Themes, Subthemes and Illustrative Quotes

Main theme	Sub-theme	Illustrative quotes
1. The Theory and Definition of ABA	The theory of ABA	Parent: <i>"But I find it really bizarre. I don't think it has anything to do with ABA, punishment."</i>
	The current definition of ABA	Healthcare professional: <i>"On the one hand you have the studies in which those principles have been identified and on the other hand you have the implementation."</i>
	Normality	Healthcare professional: <i>"Because what is the part that belongs to the child, to autism and indeed, what is the part that we can simply accept together, that that it is what it is? And is that also diversity? And can we all be different? Versus when you can no longer live the life you want, maybe you learn in a different way and we can help you in a different way, step by step, so that you understand the world around you better, can exert more influence on the world around you and can do things yourself, because you also want to learn them yourself."</i> Autistic adult: <i>"you have to fit into the school system, and you have to show desired behavior and you have to fit into society. And yes, many characteristics of these children must make way for this and be erased."</i>
2. The Use of ABA	Customization	Parent: <i>"And if it is used in a child-friendly way (...) then it is just fine. But then they have to say: we only do it with a certain type of child. So indeed, with children who are non-verbal, for example (...) But if we also apply this to children with normal intelligence, higher intelligence and punish these children, punish them really seriously because they cannot be social, then you are really doing the wrong thing and that should simply disappear."</i>
	Good healthcare is collaboration	Healthcare professional: <i>"We don't do it alone, we do it with parents, we do it with other professionals who are involved, together we decide what is good within the intervention"</i>
	Improper application of ABA	Parent: <i>"And I think ABA is conditioning, and that is at the same time a very big danger, because your child is completely conditioned to ABA and comes to an institution or a residential facility or a school where this is not available. Yes, then it collapses like a house of cards, precisely because of that conditioning and I think that is a danger of ABA."</i> Healthcare professional: <i>"Because then those tokens were added and there is a point of discussion, I think, about: is the child going to do it for those sweets or for those nice things they will get later? Or is the behavior really fixed in the child itself?"</i>
3. Positive Experiences	ABA is helpful	Parent: <i>"For me it is a guideline, for me it is a support. Yes, I am- I am extremely grateful that it is there and that the institutions are there."</i>
	General daily living skills	Parent: <i>"The ABA he went to felt like home and he developed there so much that he is now a bit more independent. He can talk, there is less frustration and actually at age five I couldn't handle him anymore. And now he is fourteen years old, he is as tall as I am. And now I can handle him again. "</i> Healthcare professional: <i>"All children also progress in development. So, I have no doubts about what ABA can provide for these children, because I see it every day. I see how the children are progressing and how happy the families are."</i>

Main theme	Sub-theme	Illustrative quotes
4. Concerns About ABA	Overburdening of the child	Parent: <i>"ABA is a boot camp for those children, and not all children can handle it and it is not suitable for all children, just like a sports boot camp is not suitable for everyone, right? I mean ABA is crazy, crazy hard work for the children, but also for the parents."</i>
	Psychosocial problems	Parent: <i>"Afterwards the child only became even more anxious. Even less social, he absolutely no longer dares to go into the bedroom with the - he doesn't dare to close the bedroom door, all doors have to be wide open. Well, I think that's quite intense, and it has an impact on school. He has been to a lot of schools now; he no longer trusts adults. (...) He is always afraid that he will be locked up."</i>
	Criticism of ABA	Parent: <i>"If it were up to me, it would just disappear completely, it's that simple. I think there are much kinder ways than ABA. And anyway yes, no, I'm actually 100% against that. In my experience, it should just disappear completely."</i>
5. Healthcare	Dissatisfied with the healthcare system	Parent: <i>"The principle of Dutch healthcare has become that it should cost as little as possible. So, you have to have a child who fails everywhere before you finally get the funding to get your child to a super specialized ABA center. And then you've already lost a lot of years."</i>
	ABA as the only option	Parent: <i>"Our son, who actually did not develop in any other way, with ABA, is now starting to make very small steps."</i>
	Criticism of schools	Parent: <i>"At one point our eldest had a lot of externalizing behavior and four adults sat on top of him. They pushed him on the floor, they called it fixation, and afterwards he resisted authority, against adults, for a long period of time. So, I, yes, I just don't recognize this from ABA, but from a primary school that should actually be specialized but where they do not deal with children the right way."</i>
6. Quality Control	Training	Parent/Professional: <i>"Nine Saturdays indeed, all of which can be attended as a parent, yes, and then something is discussed, but it is not the real training. (...) If you look back at how I sometimes did things, for example, I think: yes, well, that's not at all the way it should be done."</i> Parent: <i>"I think that for me it would feel good if not everyone with an ABA education worth 1,600 euros were allowed to give training (...) but that there are certain requirements imposed on diplomas and training."</i>
	Monitoring and control	Healthcare professional: <i>"I am a big supporter of quality assurance and forming the professional association for a form of protection of the title: I do ABA."</i> Parent: <i>"Inspection simply does nothing, and inspection has been to this institution several times, but still nothing."</i> Parent: <i>"That's what I really think is lacking. On supervision, on clear frameworks within which institutions that ABA prevails must adhere to. (...) I think that there is a task for the government to ensure that there is a form of supervisor within the specific ABA."</i>

Appendix C: Additional Results

See Tables 3, 4, 5, 6, 7, 8, 9 and 10.

Table 3 Intervention use amongst participants

	Autistic adults	Parents	Legal representatives	Healthcare professionals
Applied behavior analysis (ABA)	39.4%	84.4%	50%	89.4%
Pivotal response treatment (PRT)	12.1%	57.8%	17.9%	38.1%
Verbal behavior (VB)	18.2%	17.8%	17.9%	31.0%
Discrete trial training (DTT)	3.0%	22.2%	39.3%	54.9%
Natural environment training (NET)	12.1%	15.6%	14.3%	49.6%
Early intensive behavioral intervention (EIBI)	9.1%	8.9%	14.3%	12.4%
Early behavioral intervention	30.3%	13.3%	42.9%	16.8%
Incidental teaching and precision teaching	6.1%	8.9%	3.6%	10.6%
Picture exchange communication system (PECS)	6.1%	15.6%	32.1%	49.6%
(School Wide) positive behavior support	9.1%	17.8%	17.9%	9.7%
Functional communication training	27.3%	8.9%	21.4%	16.8%
Other ABA intervention	9.1%	0%	17.9%	6.2%

Table 4 Intervention duration and intensity

	Duration in months	Hours per week
Applied behavior analysis (ABA)	25.5 (25.8)	15.0 (11.7)
Pivotal response treatment (PRT)	14.5 (19.6)	7.7 (9.2)
Verbal behavior (VB)	33.2. (32.6)	9.6 (8.8)
Discrete trial training (DTT)	28.4 (31.2)	12.8 (10.6)
Natural environment training (NET)	36.3 (34.2)	11.2 (10.2)
Early intensive behavioral intervention (EIBI)	19.5 (23.8)	11.0 (10.2)
Early behavioral intervention	17.4 (17.6)	5.1 (5.8)
Incidental teaching and precision teaching	33.9 (24.3)	6.6 (7.2)
Picture exchange communication system (PECS)	24.7 (22.1)	9.3 (10.1)
(School Wide) positive behavior support	20.1 (14.6)	7.9 (8.7)
Functional communication training	14.2 (15.7)	5.6 (7.5)
Other ABA intervention	38.5 (43.9)	9.3 (13.6)

Table 5 Goals of the intervention

	Autistic adults and parents/legal representatives	Healthcare professionals
Expand social skills	69.8%	72.6%
Improve attention and concentration	46.2%	35.4%
Help in dealing with and processing sensory stimuli	41.5%	39.8%
Reducing self-stimulatory behavior	20.8%*	5.3%*
Regulate or reduce self-harming behavior	15.1%*	41.6%*
Regulate emotions appropriately	47.2%	51.3%
Promote language development	52.8%*	72.6%*
Promote self-reliance and daily skills	64.2%	70.8%
Increasing communication skills	70.8%	73.5%
Reducing aggressive behavior	20.8%*	39.8%*
Returning to school	10.4%*	38.9%*
I don't know	5.7%	1.8%
Other	8.5%	4.4%

*Significant difference between groups

Table 6 Parent involvement in the intervention

	Autistic adults and parents/legal representatives	Health-care professionals
Yes, the parents are actively involved and can contribute ideas about the intervention goals	47.2%	69.9%
Yes, the parents are involved in carrying out the intervention, for example by applying techniques at home.	49.1%	69.0%
Yes, parents receive regular updates on progress and discuss this with the practitioner.	45.3%	63.7%
Yes, the parents are involved, but this involvement is limited to receiving information or an occasional conversation.	17.9%	5.3%
No, the parents are not actively involved in the intervention.	20.8%	0%
I do not know	1.9%	1.8%

Table 7 Satisfaction with interventions per participant group

	Autistic adults	Parents	Legal representatives
Applied behavior analysis (ABA)	4.7 (3.8)	7.2 (3.1)	6.7 (3.7)
Pivotal response treatment (PRT)	5.8 (2.6)	5.7 (3.5)	7.4 (3.8)
Verbal behavior (VB)	5.8 (3.9)	7.5 (2.6)	9.2 (0.4)
Discrete trial training (DTT)	—	5.1 (3.9)	7.6 (3.1)
Natural environment training (NET)	5.5 (3.4)	8.1 (2.9)	9.5 (0.6)
Early intensive behavioral intervention	5.3 (0.6)	6.8 (3.2)	6 (3.4)
Early behavioral intervention	5.5 (2.2)	4.2 (4.4)	6.7 (2.8)
Incidental teaching and precision teaching	6 (2.8)	4 (3.7)	8 (—)
Picture exchange communication system (PECS)	6 (2.8)	8.6 (1.3)	7.1 (3.3)
(School Wide) Positive behavior support	6 (3.6)	3.6 (3.5)	5.4 (2.3)
Functional communication training	5.9 (1.3)	6.8 (3.6)	7 (3.2)
Other ABA intervention	5 (4.4)	—	6.8 (4.3)

Satisfaction ratings did not differ significantly between ABA interventions

Table 8 Reported treatment components

	Autistic adults and parents/legal representatives
Negative components	
Forcing to perform tasks or exhibit certain behavior (e.g., making eye contact)	29.3%
Forced/involuntary time-out or isolation	26.1%
Exposure to unpleasant stimuli such as annoying sounds or lights	18.5%
Taking away freedom	18.5%
Holding or touching involuntarily	17.4%
Yelling or saying mean things	15.2%
Taking away objects	15.2%
Restraint (limiting freedom of movement)	14.1%
Physical punishments (e.g., hitting, pinching)	10.9%
Positive components	
Rewards	76.1%
Aligning with interests and motivation of the child	68.5%
Comprehensive behavioral analysis (i.e., studying the behavior)	66.3%
Playing games	62.0%
Adapting the environment to individual needs of the child	53.3%
Gentle physical contact (e.g., hugging or stroking)	45.7%
Nice food after good behavior (e.g., candy or cookies)	35.9%
Voluntary time-out	33.7%

Positive and negative components were categorized based on the general opinion within the focus groups

Table 9 Did the intervention have an effect on daily functioning?

	Autistic adults	Parents	Legal representatives
Yes, the intervention had a negative effect on my daily functioning	25.9%	12.8%	8.7%
Yes, the intervention had a positive effect on my daily functioning	22.2%	59.0%	65.2%
Yes, the intervention had both a negative and positive effect on my daily functioning	25.9%	20.5%	8.7%
I do not know	25.9%	7.7%	17.4%

Differences between groups were not analyzed because more than 20% of the cells had expected values below 5, which violates the assumptions of the Chi-square test

Table 10 Positive and negative results from the ABA intervention

I/the child...	Autistic adults	Parents	Legal representatives	Healthcare professionals
Positive results				
Showed no positive results	27.3%	13.3%	17.9%	0%
Went back to school/showed improved school performance	3.0%	13.3%	14.3%	52.2%
Was able to talk/say what I thought better	18.2%	42.2%	46.4%	70.8%
Could interact better with peers	21.2%	20.0%	25.0%	50.4%
Showed less aggressive behavior	12.1%	15.6%	39.3%	4.4%
Was more independent	24.2%	37.8%	42.9%	61.9%
Was happier, more relaxed and felt my/their life was going better	18.2%	35.6%	39.3%	61.1%
Learned new skills	42.4%	57.8%	53.6%	73.5%
Showed less self-harming or -stimulating behavior	15.2%	22.2%	32.1%	53.1%
Was less often overstimulated	21.2%	26.7%	28.6%	35.4%
Negative results				
Showed no negative results	24.2%	51.1%	67.9%	51.3%
Attended school less often or showed worse school performance	0%	4.4%	7.1%	1.8%
Was less able to talk/say what I thought worse	21.2%	6.7%	3.6%	1.8%
Could interact worse with peers	6.1%	6.7%	3.6%	0.9%
Showed more aggressive behavior	3.0%	8.9%	3.6%	1.8%
Was less independent	9.1%	17.8%	0%	1.8%
Was less happy, and more tense	21.2%	13.3%	3.6%	3.5%
Showed more self-harming or -stimulating behavior	6.1%	8.9%	3.6%	3.5%
Was more often overstimulated	24.2%	15.6%	3.6%	4.4%
Showed more anxiety or anxious behavior	24.2%	11.1%	3.6%	1.8%
Showed signs of trauma or symptoms of PTSD	21.2%	8.9%	7.1%	0.9%
Trusted adults less or was suspicious	18.2%	13.3%	3.6%	0.9%
Was too dependent on approval or instructions from adults	24.2%	17.8%	0%	20.4%
Started masking my/their autism symptoms	39.4%	8.9%	3.6%	2.7%

Differences between groups were not analyzed for each positive or negative result due to low expected values per cell and to avoid multiple testing

Acknowledgements We would like to acknowledge the financial support from the Dutch Ministry of Health, Wellbeing and Sports (Grant No. 16-6028-33751). Our sincere thanks go to the advisory team for their invaluable contributions to this study. Their insights and advice, drawn from their personal experiences and professional expertise, were crucial in shaping our research. We also extend our gratitude to the broader autistic and autism community for their ongoing support and input through the Netherlands Autism Register (NAR). This collaborative effort has greatly enriched our study.

Declarations

Conflict of interest The authors declare that they have no competing interests.

Open Access This article is licensed under a Creative Commons Attribution 4.0 International License, which permits use, sharing, adaptation, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons licence, and indicate if changes were made. The images or other third party material in this article are included in the article's Creative Commons licence, unless indicated otherwise in a credit line to the material. If material is not included in the article's Creative Commons licence and your intended

use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder. To view a copy of this licence, visit <http://creativecommons.org/licenses/by/4.0/>.

References

- Anderson, L. K. (2023). Autistic experiences of applied behavior analysis. *Autism*, 27(3), 737–750. <https://doi.org/10.1177/13623613221118216>
- Barbera, M. L. (2007). *The verbal behavior approach: How to teach children with autism and related disorders*. Jessica Kingsley.
- Behavior Analyst Certification Board (2020). *Ethics code for Behavior Analysts*. <https://www.bacb.com/wp-content/uploads/2022/01/Ethics-Code-for-Behavior-Analysts-230119-a.pdf>
- Bondy, A. S., & Frost, L. A. (1998). The picture exchange communication system. *Seminars in speech and Language*, 19(4), 373–424. <https://doi.org/10.1055/s-2008-1064055>
- Campbell, J. L., Quincy, C., Osserman, J., & Pedersen, O. K. (2013). Coding in-depth semistructured interviews: Problems of unitization and intercoder reliability and agreement. *Sociological Methods & Research*, 42(3), 294–320. <https://doi.org/10.1177/0049124113500475>

- Carr, J. E., & Firth, A. M. (2005). The verbal behavior approach to early and intensive behavioral intervention for autism: A call for additional empirical support. *Journal of Early and Intensive Behavior Intervention*, 2(1), 18–27. <https://doi.org/10.1037/h0100297>
- Charlop-Christy, M. H., Carpenter, M., Le, L., LeBlanc, L. A., & Kellert, K. (2002). Using the picture exchange communication system (PECS) with children with autism: Assessment of PECS acquisition, speech, social-communicative behavior, and problem behavior. *Journal of Applied Behavior Analysis*, 35(3), 213–231. <https://doi.org/10.1901/jaba.2002.35-213>
- Cooper, J. O., Heron, T. E., & Heward, W. L. (2020). *Applied behavior analysis* (3rd ed.). Pearson.
- Creswell, J. W., & Clark, V. L. P. (2017). *Designing and conducting mixed methods research* (3rd ed.). Sage.
- Eldevik, S., Hastings, R. P., Hughes, J. C., Jahr, E., Eikeseth, S., & Cross, S. (2009). Meta-analysis of early intensive behavioral intervention for children with autism. *Journal of Clinical Child & Adolescent Psychology*, 38(3), 439–450. <https://doi.org/10.1080/15374410902851739>
- Fuentes, J., Hervás, A., & Howlin, P. (2021). ESCAP practice guidance for autism: A summary of evidence-based recommendations for diagnosis and treatment. *European Child and Adolescent Psychiatry*, 30(6), 961–984. <https://doi.org/10.1007/s00787-020-01587-4>
- Ghaemmaghami, M., Hanley, G. P., & Jessel, J. (2021). Functional communication training: From efficacy to effectiveness. *Journal of Applied Behavior Analysis*, 54(1), 122–143. <https://doi.org/10.1002/jaba.762>
- Gitimoghaddam, M., Chichkine, N., McArthur, L., Sangha, S. S., & Symington, V. (2022). Applied behavior analysis in children and youth with autism spectrum disorders: A scoping review. *Perspectives on Behavior Science*, 45(3), 521–557. <https://doi.org/10.1007/s40614-022-00338-x>
- Graber, A., & Graber, J. (2023). Applied behavior analysis and the abolitionist neurodiversity critique: An ethical analysis. *Behavior Analysis in Practice*, 16(4), 921–937. <https://doi.org/10.1007/s40617-023-00780-6>
- Halle, J. W. (1982). Teaching functional Language to the handicapped: An integrative model of natural environment teaching techniques. *Journal of the Association for the Severely Handicapped*, 7(4), 29–37. <https://doi.org/10.1177/154079698200700404>
- Hart, B., & Risley, T. R. (1975). Incidental teaching of Language in the preschool. *Journal of Applied Behavior Analysis*, 8(4), 411–420. <https://doi.org/10.1901/jaba.1975.8-411>
- Hart, B., & Risley, T. R. (1980). In vivo Language intervention: Unanticipated general effects. *Journal of Applied Behavior Analysis*, 13(3), 407–432. <https://doi.org/10.1901/jaba.1980.13-407>
- Hieneman, M. (2015). Positive behavior support for individuals with behavior challenges. *Behavior Analysis in Practice*, 8(1), 101–108. <https://doi.org/10.1007/s40617-015-0051-6>
- Horner, R. H., & Sugai, G. (2015). School-wide PBIS: An example of applied behavior analysis implemented at a scale of social importance. *Behavior Analysis in Practice*, 8(1), 80–85. <https://doi.org/10.1007/s40617-015-0045-4>
- Howitt, D. (2016). *Introduction to qualitative methods in psychology* (3rd ed.). Pearson.
- Kapp, S. K., Gillespie-Lynch, K., Sherman, L. E., & Hutman, T. (2013). Deficit, difference, or both? Autism and neurodiversity. *Developmental Psychology*, 49(1), 59–71. <https://doi.org/10.1037/a0028353>
- Keenan, M., Dillenburger, K., Röttgers, H. R., Dounavi, K., Jónsdóttir, S. L., Moderato, P., Schenk, J. J. A. M., Virués-Ortega, J., Roll-Pettersson, L., & Martin, N. (2015). Autism and ABA: The Gulf between North America and Europe. *Review Journal of Autism and Developmental Disorders*, 2(2), 167–183. <https://doi.org/10.1007/s40489-014-0045-2>
- Keenan, M., Dillenburger, K., Konrad, M. H., Debetencourt, N., Vukšan, R., Kourea, L., Pancocha, K., Kingsdorf, S., Brandtberg, H. J., Ozkan, N., Abdelnour, H., Da Costa-Meranda, M., Schuldt, S., Mellon, R., Herman, A., Tennyson, A., Ayvazo, S., Moderato, P., Attard, N., & Gallagher, S. (2023). Professional development of behavior analysts in europe: A snapshot for 21 countries. *Behavior Analysis in Practice*, 16(3), 709–729. <https://doi.org/10.1007/s40617-022-00754-0>
- Kirkham, P. (2017). The line between intervention and abuse’—autism and applied behaviour analysis. *History of the Human Sciences*, 30(2), 107–126. <https://doi.org/10.1177/0952695117702571>
- Koegel, R. L., O’Dell, M. C., & Koegel, L. K. (1987). A natural Language teaching paradigm for nonverbal autistic children. *Journal of Autism and Developmental Disorders*, 17(2), 187–200. <https://doi.org/10.1007/BF01495055>
- Kupferstein, H. (2018). Evidence of increased PTSD symptoms in autistics exposed to applied behavior analysis. *Advances in Autism*, 4, 00–00. <https://doi.org/10.1108/AIA-08-2017-0016>
- Leaf, J. B., Cihon, J. H., Leaf, R., McEachin, J., Liu, N., Russell, N., Unumb, L., Shapiro, S., & Khosrowshahi, D. (2022). Concerns about ABA-based intervention: An evaluation and recommendations. *Journal of Autism and Developmental Disorders*, 52(6), 2838–2853. <https://doi.org/10.1007/s10803-021-05137-y>
- Lei, J., & Ventola, P. (2017). Pivotal response treatment for autism spectrum disorder: Current perspectives. *Neuropsychiatric Disease and Treatment*, 13, 1613–1626. <https://doi.org/10.2147/ndt.S120710>
- Lerner, M. D., Gurba, A. N., & Gassner, D. L. (2023). A framework for neurodiversity-affirming interventions for autistic individuals. *Journal of Consulting and Clinical Psychology*, 91(9), 503–504. <https://doi.org/10.1037/ccp0000839>
- Lord, C., Brugha, T. S., Charman, T., Cusack, J., Dumas, G., Frazier, T., Jones, E. J. H., Jones, R. M., Pickles, A., State, M. W., Taylor, J. L., & Veenstra-VanderWeele, J. (2020). Autism spectrum disorder. *Nature Reviews Disease Primers*, 6(1), 5. <https://doi.org/10.1038/s41572-019-0138-4>
- Mathur, S. K., Renz, E., & Tarbox, J. (2024). Affirming neurodiversity within applied behavior analysis. *Behavior Analysis in Practice*, 17(2), 471–485. <https://doi.org/10.1007/s40617-024-00907-3>
- Matson, J. L. (2021). *Functional Assessment for challenging behaviors and mental health disorders*. <https://doi.org/10.1007/978-3-030-66270-7>
- McGee, G. G., Krantz, P. J., Mason, D., & McClannahan, L. E. (1983). A modified incidental-teaching procedure for autistic youth: Acquisition and generalization of receptive object labels. *Journal of Applied Behavior Analysis*, 16(3), 329–338. <https://doi.org/10.1901/jaba.1983.16-329>
- Medavarapu, S., Marella, L. L., Sangem, A., & Kairam, R. (2019). Where is the evidence? A narrative literature review of the treatment modalities for autism spectrum disorders. *Cureus*, 11(1), e3901. <https://doi.org/10.7759/cureus.3901>
- O’Connor, C., & Joffe, H. (2020). Intercode reliability in qualitative research: Debates and practical guidelines. *International Journal of Qualitative Methods*, 19, 1609406919899220. <https://doi.org/10.1177/1609406919899220>
- Pellicano, E., Fatima, U., Hall, G., Heyworth, M., Lawson, W., Lilley, R., Mahony, J., & Stears, M. (2022). A capabilities approach to Understanding and supporting autistic adulthood. *Nature Reviews Psychology*, 1(11), 624–639. <https://doi.org/10.1038/s44159-022-00099-z>
- Peters-Scheffer, N., Didden, R., Korzilius, H., & Sturmey, P. (2011). A meta-analytic study on the effectiveness of comprehensive ABA-based early intervention programs for children with autism

- spectrum disorders. *Research in Autism Spectrum Disorders*, 5(1), 60–69. <https://doi.org/10.1016/j.rasd.2010.03.011>
- Reichow, B., Hume, K., Barton, E. E., & Boyd, B. A. (2018). Early intensive behavioral intervention (EIBI) for young children with autism spectrum disorders (ASD). *Cochrane Database of Systematic Reviews*, 5. <https://doi.org/10.1002/14651858.CD009260.pub3>
- Roberts, K., Dowell, A., & Nie, J. B. (2019). Attempting rigour and replicability in thematic analysis of qualitative research data; a case study of codebook development. *BMC Medical Research Methodology*, 19(1), 66. <https://doi.org/10.1186/s12874-019-0707-y>
- Rosen, T., Connell, J., & Kerns, C. (2016). A review of behavioral interventions for anxiety-related behaviors in lower-functioning individuals with autism. *Behavioral Interventions*, 31. <https://doi.org/10.1002/bin.1442>
- Sandoval-Norton, A. H., Shkedy, G., & Shkedy, D. (2019). How much compliance is too much compliance: Is long-term ABA therapy abuse? *Cogent Psychology*, 6(1), 1641258. <https://doi.org/10.1080/23311908.2019.1641258>
- Seida, J. K., Ospina, M. B., Karkhaneh, M., Hartling, L., Smith, V., & Clark, B. (2009). Systematic reviews of psychosocial interventions for autism: An umbrella review. *Dev Med Child Neurol*, 51(2), 95–104. <https://doi.org/10.1111/j.1469-8749.2008.03211.x>
- Shea, V. (2004). A perspective on the research literature related to early intensive behavioral intervention (Lovaas) for young children with autism. *Autism*, 8(4), 349–367. <https://doi.org/10.1177/1362361304047223>
- Shiyanbola, O. O., Rao, D., Bolt, D., Brown, C., Zhang, M., & Ward, E. (2021). Using an exploratory sequential mixed methods design to adapt an illness perception questionnaire for African Americans with diabetes: The mixed data integration process. *Health Psychology and Behavioral Medicine*, 9(1), 796–817. <https://doi.org/10.1080/21642850.2021.1976650>
- Smith, T. (2001). Discrete trial training in the treatment of autism. *Focus on Autism and Other Developmental Disabilities*, 16(2), 86–92. <https://doi.org/10.1177/108835760101600204>
- Verschuur, R., Didden, R., Lang, R., Sigafoos, J., & Huskens, B. (2014). Pivotal response treatment for children with autism spectrum disorders: A systematic review. *Review Journal of Autism and Developmental Disorders*, 1(1), 34–61. <https://doi.org/10.1007/s40489-013-0008-z>
- Virués-Ortega, J. (2010). Applied behavior analytic intervention for autism in early childhood: Meta-analysis, meta-regression and dose–response meta-analysis of multiple outcomes. *Clinical Psychology Review*, 30(4), 387–399. <https://doi.org/10.1016/j.cpr.2010.01.008>
- Vismara, L. A., & Rogers, S. J. (2010). Behavioral treatments in autism spectrum disorder: What do we know? *Annu Rev Clin Psychol*, 6, 447–468. <https://doi.org/10.1146/annurev.clinpsy.12.1208.131151>
- Willig, C. (2021). *Introducing qualitative research in psychology* (4th ed.). Open University Press.
- Yu, Q., Li, E., Li, L., & Liang, W. (2020). Efficacy of interventions based on applied behavior analysis for autism spectrum disorder: A meta-analysis. *Psychiatry Investig*, 17(5), 432–443. <https://doi.org/10.30773/pi.2019.0229>

Publisher's Note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.