

Examining the perceptions of needs, services and abilities of Czech and North Macedonian caregivers of children with autism and trainers

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Effective practices for supporting families with autistic children ensure a match between their needs and the expectations and competencies of the clinician. Applied behavior analysis (ABA) services are a common provision for serving autistic individuals. However, in regions where ABA is in its infancy, like the Czech Republic and North Macedonia, culturally relevant resources, regulations for practice, and standardized coursework are missing. In their absence, it is necessary to investigate the degree to which practitioners in the regions are meeting the behavioral needs of families. Assessing this match can set the stage for establishing more stable and effective services in the areas, as well as neighboring countries with similar historical foundations. Therefore, a survey was conducted to examine the perceptions of caregivers and trainers (those who self-identified as providing support to families with autistic children). A total of 233 caregivers and 204 trainers participated. Analysis of the survey responses verified the lack of behavioral knowledge on the part of the trainers, the apparent lack of access to ABA services for families in both regions, a potential misalignment between family needs and training targets, and the disparities between the two countries. The information evaluated here can be used to guide preservice training, dissemination efforts, and regulations surrounding behavioral practices.

Keywords: Czech Republic; North Macedonia; autism; applied behavior analysis; caregiver training; client-centered planning

Supporting families with autistic children can take on many different forms. For example, assistance can be provided through the different modalities of: In-home services (e.g. Flood and Luiselli 2016), clinic-based sessions (e.g. Handleman and Harris 2005), school services (e.g. Grindle *et al.* 2012), or a telehealth model (e.g. Lindgren *et al.* 2016). However, regardless of the resource delivery method, it is vital that there is a match between the needs of the client (i.e. child, adult, or family receiving services) and the expectations of the clinician. In fact, the research of Chadwell *et al.* (2019) found that clinicians who were receptive to the needs of a client were most valued. In addition, Smith *et al.*

(2006) discussed that client-focused services, such as those using a model of person-centered support, were more likely to be effective in establishing pivotal behaviors. Furthermore, given the heterogeneous nature of autism a one-size-fits-all approach is likely to be ineffective (Stahmer *et al.* 2011).

Applied behavior analysis (ABA) services commonly support families with autistic children. By nature, it targets socially significant behaviors which are important to stakeholders (Baer *et al.* 1968, Heward *et al.* 2022). Although originally considered in opposition to a person-centered approach, it has since been argued that ABA and person-centered approaches target behavior change in the natural environment, are based on underlying principles of behavior, and target observable and measurable change (Holburn 2001). Therefore, behavior analysts practicing ethically are making sure that services are individualized and in alignment with the needs and expectations of the client (Behavior Analyst Certification Board 2020).

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Alignment with this ethos can be seen on the micro level, where direct and indirect assessments of specific client behaviors spearhead the development of treatment planning. It can also be seen in the field's recent advancements in compassionate care and trauma-informed ABA practices which support building models that ensure safety and trust, promote choice and shared governance, and emphasize skill building (Rajaraman *et al.* 2022). However, in regions where behavior analysis is in its infancy, and regulations for practice, licensure, or certification are missing, it can be hard to tell if those tenets are being upheld. Therefore, it is necessary to assess the degree to which practitioners in a region are best meeting the needs of families. Assessing a region's degree of ABA application and client-centered focus can set the stage for developing training and policies surrounding best practice.

Client-centered behavioral services

Best practices for serving families with autistic children frequently mean using some services grounded in the science of behavior. The efficacy of ABA services has been heavily demonstrated (Myers and Johnson 2007, Virués-Ortega 2010, Peters-Scheffer *et al.* 2011, Reichow 2012, Makrygianni *et al.* 2018). ABA services are inherently individualized. In fact, ABA has been recognized for its abilities to uphold compliance with laws surrounding special education services to support children with individualized education programs (IEPs; Bloh and Axelrod 2008), support self-directed IEP participation for older students (Diegelmann and Test 2018), and be a valuable and flexible contributor to targeting behavior change in the home by increasing caregiver well-being (Pennefather *et al.* 2018). As further validation of ABA's individualized nature, much of the empirical literature, several hundreds of studies, have utilized single case experimental designs (Granpeesheh *et al.* 2009). Single case experimental designs are noted for their ability to bridge research to clinical gaps by allowing for the matching of treatment strategies to an individual client and their representation of individual changes in behavior that might otherwise be lost in large-scale studies utilizing group designs (Perdices and Tate 2009). As a result of its individualized and empirically validated nature, it is not surprising that many caregivers of children who are receiving services are satisfied with the outcomes (e.g. Dillenburger *et al.* 2004). ABA services have since been officially recommended for supporting autistic children through numerous scientific, government, and professional organizations, such as the Surgeon General of the United States (Hagopian *et al.* 2015).

Unsurprisingly, ABA services have started to emerge beyond the West, reaching places such as Hong Kong (Greenberg and Chung 2019) and the Middle East (Kelly *et al.* 2016). However, even in the West, beyond North America, it is seemingly less established in places like Austria (DeSouza and Konrad 2021) and France (Turgeon

and Lanovaz 2021); where there are ongoing struggles with access and perception. In fact, despite the widespread use of ABA there is still a research to practice gap plaguing Europe. As thoroughly discussed by Dillenburger (2011), ABA services on the continent are scarce, frequently convoluted with other unvalidated treatments, absent of expert-driven government guidance, and constantly battling misinformation. Even in regions where parents are aware of high-quality ABA services, as in parts of the United Kingdom, it has been found that there is a lack of services and adequately trained staff (Dillenburger *et al.* 2012). Furthermore, in places where teachers and trainers tout that they know about ABA and use it appropriately, a mismatch has been demonstrated between their perceptions and the assessment of their relevant content knowledge (Fennell and Dillenburger 2018). This discrepancy between perceived and actual knowledge may be even more prevalent in areas of the continent that are recently finding their way free from the constraints surrounding education and disability formerly imposed behind Eastern Europe's Iron Curtain (Kingsdorf and Pančochá 2021).

Behavioral services in the Czech Republic

In the area of the Czech Republic in particular, ABA services are known but not widely available. In the 1960s and 1970s, when ABA organizations were developing in Western countries like the United States and the UK, the Czech Republic was working under socialist ideological practices that considered approaches based on behaviorism to be bourgeois or capitalist, and therefore undesirable. After the fall of the Iron Curtain in the late 1990s, the science of behavior started to gain more ground in the country. This was mostly seen in the work of cognitive behavioral therapy (CBT), though, as opposed to behavioral services and ABA-based educational strategies for autistic children. The predominant approaches in education for autistic children became locally developed eclectic systems based on highly structured environments and visual support (Pančochá and Vadurova 2022). In fact, there were almost no ABA practitioners in the country in 2015 (Roll-Pettersson *et al.* 2020). The following six years resulted in exponential growth in the field.

In 2016 the Czech Society of Applied Behavior Analysis (CSABA) was established. Coursework in behavior analysis has been available at a major public university in the Czech Republic, Masaryk University, since 2016. This was followed by the establishment of behavior analysis as a recognized profession in 2017. As a collaboration of the Society and the University the first local behavior analytic conference was held in 2021. However, even with all this forward movement in the field, behavior analytic practitioners in the region continue to struggle to find support and mentorship with limited resources available in the local language

(Kingsdorf and Pančocha 2020a). Additionally, despite the availability of ABA training for educators, there is little being done to require participation in events, check for credentials, or systematically incorporate behavior analytic coursework into preservice teacher training programs (Kingsdorf and Pančocha 2020b). As a result, those working with families of autistic children may have little to no formal training in behavior analysis.

Behavioral services in North Macedonia

Similar hurdles have been experienced in the region of North Macedonia. North Macedonia is an economically developing country with guaranteed access to healthcare and services for its people (Trajkovski 2008). However, the country has limited professional and financial resources (Hansen *et al.* 2017). Therefore, autistic children have historically received services which lag the scientifically proven methods which are trending in North America. These services, partially organized by state institutions and partly by private companies and organizations, are more likely to be based on the eclectic models.

Despite the presence of ABA for numerous decades in Western countries, the use of ABA strategies with autistic children first appeared in Macedonia in 2014. Internationally funded projects allowed for professional development and parental training programs to be held in the country from 2014 to 2020 (e.g. Troshanska 2015). These projects have allowed for the dissemination of ABA to caregivers, teachers from mainstream schools, special educators, psychologists, speech therapists, and social workers. This is crucial, given the fact that very few organizations are available in the country to provide caregiver training services, and there was found to be an overwhelming desire by North Macedonian parents to attend training in several different areas, including ABA (Preece *et al.* 2017). The limited availability of therapeutic behavioral resources was found in the work of Salomone *et al.* (2016) and has prompted work in models like pyramidal parent training (Hansen *et al.* 2017). However, without established education programs and policies in the country it is unclear whether those working to teach, train, and support families with autistic children are upholding best practices.

Research aim

European nations, like the Czech Republic and North Macedonia, have struggled to move away from the medical model of defectology of the past (Iarskaia-Smirnova *et al.* 2015), battled lack of early intervention services (Salomone *et al.* 2016), faced proponents of the unvalidated eclectic model of practice (Dillenburger 2011), and dealt with the slow spread of ABA services (Keenan *et al.* 2015). Similarly, both countries have only recently moved towards supporting families of autistic children under

models of current research and practice. To set the groundwork for more stable and effective ABA services in the regions of the Czech Republic and North Macedonia, a survey was conducted to examine the perceptions of caregivers and trainers.

The Czech Republic and North Macedonia were selected as the countries targeted for the survey given their shared historical context (e.g. impacted by Eastern Europe's Iron Curtain) and progress towards improving options for education by participating in joint research projects targeting autism and ABA with European Union partners (e.g. Erasmus + Positive Parenting, Erasmus + A Class, <https://iviv.ped.muni.cz/projekty>). However, it is anticipated that countries with similar historical foundations (e.g. Slovakia, Latvia, and Lithuania) will benefit from the outcomes.

The survey addressed the following research questions:

- What are the behavioral needs of families with autistic children?
- What are the experiences of trainers (those who self-identified as providing support to families of autistic children) working with families with autistic children?
- Does the work of trainers match the needs of caregivers?

This information can set the stage for developing education and policies surrounding best practices in ABA for supporting families of autistic children in these, and similar, regions.

Method

Study overview

The surveys were initially created as part of a European Union funded Erasmus + project, Positive Parenting (<https://www.muni.cz/en/research/projects/57207>). They served as a tool for mapping the training needs of caregivers in a larger region and were later expanded to include more participants in the targeted countries of the Czech Republic and North Macedonia. These two countries were targeted for an extension of the survey, and therefore this study, due to their shared history and joint participation in recent academic projects promoting services for families with autistic children. The surveys were initially developed by the first author using existing relevant survey research as guidance (e.g. Colizzi *et al.* 2020). They were reviewed and revised in collaboration with partners across the region. Ultimately, two surveys were created: one for the caregivers of autistic children and one for trainers of caregivers of autistic children. For this study, a trainer was defined as any person that self-identified as providing support (i.e. training, in-home services, teaching) to families with autistic children. The support did not need to be ABA specific. The survey and the study were approved by the first and second authors' university.

Study population

The aim of this study was to survey participants in the Czech Republic and North Macedonia who fall within the categories of: (1) caregiver of an autistic child, or (2) trainer of a caregiver of an autistic child. Head practitioners in the field of autism in each country circulated the survey links by posting them on social media platforms frequented by parents of autistic children. These practitioners, the second and third authors in the study, were associated with major universities in the region, and therefore worked with most practitioners at some point during their education. As a result, a total of 144 caregivers and 104 trainers participated from the Czech Republic. A total of 96 caregivers and 100 trainers participated from North Macedonia.

Caregiver survey

All surveys were created using Google Forms. The caregiver survey collected demographic information about the caregivers and their children. These questions were spread throughout the beginning and end of the survey, to combat survey fatigue. However, the focus of the survey was the questions related to their children's behaviors, both challenging and adaptive (as per the survey tool labels), and their confidence with ABA concepts. The questions related to their children's behaviors were based on commonly used behavioral assessment tools, such as the Behavior Problems Inventory (BPI-01; Rojahn *et al.* 2001) and Vineland Adaptive Behavior Scales (Sparrow *et al.* 2016). To clarify, the assessment tools were not used in this study. Rather, the tools were only used to create the behavior categories for the survey. Those tools were selected to guide survey creation given their use in other applications in the regions, with the Vineland I previously translated and validated in the Czech Republic (Kožený 1974) and used in North Macedonian screening and research (e.g. de Bildt *et al.* 2015). The BPI was not systematically validated in the Czech Republic but was used in previous research in the region (Kingsdorf *et al.* under-review). Additionally, steps were taken to validate the survey by establishing the expert panel, systematically creating the questions, reviewing and revising the question pool, preliminary pilot distribution, testing for face validity, and forward and back translating into the local languages (Tsang *et al.* 2017). It is important to note, that it was acknowledged that the terms 'challenging', 'problem', and 'adaptive' may be considered ableist discourse and should be replaced with descriptions of specific behaviors (Bottema-Beutel *et al.* 2021). These were the terms taken from the original assessment tools, but were not the terms used in the surveys, as the surveys were distributed in the local languages, which did not translate the terms in an identical manner. Additionally, the survey aimed to describe

the specific behaviors, as opposed to referring to them with overarching patronizing language. The questions in the ABA concepts section were based on topics covered in common parent training materials, like the RUBI Network Parent Training Manual (Bears *et al.* 2018).

Trainer survey

The trainer survey had 11 questions. The first five questions collected demographic information from the participants. The remaining questions targeted their experience with working with families with autistic children and ABA. Two of the ABA questions required multiple responses that looked specifically at supporting caregivers on specific behaviors. An additional question looked at their confidence in concepts of ABA. The trainer survey was created to align with the questions presented on the caregiver survey and went through similar creation and validation processes. However, only the ABA concept questions were the same in both surveys.

Data collection and analysis

The surveys were distributed to potential participants using the link generated by Google Forms. The survey was available from June to November 2021. Apart from the demographic information, all other questions in both surveys had three answer categories (i.e. 1 = targeted, 2 = not targeted, 3 = not sure; 1 = trained on, 2 = not trained on, 3 = not sure; 1 = usually, 2 = sometimes, 3 = never; 1 = very confident, 2 = somewhat confident, 3 = not confident at all). When the survey ended the raw data were moved to Excel and the frequencies were counted for the number of responses in each category for each group (e.g. the frequency of Czech trainers who indicated that they targeted the behavior of pica, those who did not target, and those who were not sure). Data were calculated by the first researcher and checked by the second. The data were moved to SPSS 21.0 software for statistical analysis. The chi-square independence tests were conducted after verifying its assumptions in order to examine the relationships between: (1) caregivers' nationality and their reports of behaviors, (2) caregivers' nationality and their reports of confidence with ABA concepts, (3) trainers' nationality and their reports of experience with behaviors, (4) trainers' nationality and their reports of confidence with ABA concepts, (5) group association of caregiver or trainer and confidence with ABA concepts for North Macedonia, and (6) group association of caregiver or trainer and confidence with ABA concepts for the Czech Republic. A p-value less than 0.05 (alpha level 5%) indicated statistical significance.

Table 1. Demographic information of the caregivers by country.

| | CZECH <i>n</i> = 144 | NM <i>n</i> = 89 | Combined <i>N</i> = 233 |
|--------------------------------------|----------------------|------------------|-------------------------|
| Age | | | |
| Mean (SD) | 40.8 (6.97) | 40.2 (9.71) | 40.6 (8.11) |
| Gender, <i>n</i> (%) | | | |
| Female | 134 (93%) | 66 (74%) | 200 (86%) |
| Male | 9 (6%) | 23 (26%) | 32 (14%) |
| Other | 1 (1%) | 0 (0%) | 1 (0%) |
| Household income level, <i>n</i> (%) | | | |
| High | 11 (8%) | 4 (4%) | 15 (6%) |
| Medium | 93 (65%) | 77 (87%) | 170 (73%) |
| Low | 40 (28%) | 8 (9%) | 48 (21%) |
| Living situation, <i>n</i> (%) | | | |
| Married/living with a partner | 110 (76%) | 73 (82%) | 183 (79%) |
| Divorced | 11 (8%) | 6 (7%) | 17 (7%) |
| Single parent | 23 (16%) | 10 (11%) | 33 (14%) |
| Age of autistic child, Mean (SD) | 9.5 (5.40) | 9 (4.90) | 9.25 (5.21) |
| Number of siblings, <i>n</i> (%) | | | |
| 0 | 30 (21%) | 30 (34%) | 60 (26%) |
| 1 | 76 (53%) | 42 (47%) | 118 (51%) |
| 2 | 29 (20%) | 11 (12%) | 40 (17%) |
| 3 and more | 9 (6%) | 6 (6%) | 15 (6%) |
| Autistic siblings | | | |
| Yes | 18 (16%) | 8 (13%) | 26 (15%) |
| No | 126 (84%) | 81 (87%) | 207 (85%) |
| Caregiver heard of ABA | | | |
| Yes | 125 (87%) | 26 (29%) | 151 (65%) |
| No | 19 (13%) | 63 (71%) | 82 (35%) |
| Autistic child received ABA | | | |
| Yes | 29 (20%) | 9 (10%) | 38 (16%) |
| Unsure | 13 (9%) | 25 (28%) | 38 (16%) |
| No | 102 (71%) | 55 (62%) | 157 (67%) |

Note: SD, Standard Deviation; ABA, Applied Behaviour Analysis.

Results

Caregiver characteristics

For the purposes of this survey individuals were invited to participate if they identified as the primary caregiver (usually the parent or another family member) of a child with a diagnosis of autism. However, data were not collected on the caregiver’s specific relationship to the child (e.g. grandparent, mother, etc.). Demographic information was able to be collected on their gender, age, household income level, and living situation. Further information was collected on the age of their autistic child, his/her number of siblings, and status of siblings’ diagnoses of autism. If the caregiver reported having more than one autistic child, they were asked to complete the survey in reference to only one child. The results are summarized quantitatively in Table 1.

A total of 233 caregivers participated in the survey (144 from the Czech Republic and 89 from North Macedonia). Most caregivers self-identified their gender as female (86%). In North Macedonia a much higher percentage of males identified as caregivers and completed the survey (26%) than in the Czech Republic (6%). The age of the participants ranged from 25 to 66 with the mean age being 41. The majority (73%) of caregivers across both countries reported a household income level of average. The majority (79%) of caregivers across both countries reported their living situation as married. Regarding their children with autism, the mean age in both countries was about 9; with the majority having one (51%) or no (26%) siblings. Of those with siblings, about

15% also had a diagnosis of autism. Overall, the basic demographic characteristics of the caregivers and families in both countries appeared similar.

Regarding ABA familiarity, though, the difference between the two countries was apparent. Caregivers in the Czech Republic reported greater knowledge of ABA than those in North Macedonia, 87% and 29%, respectively. However, most caregivers and their families in both countries did not currently or previously have access to ABA services (67%).

Caregiver identified experiences and knowledge

The caregivers were asked to report on the prevalence of their children’s behaviors, and their confidence with specific ABA procedures. Given the fact that the ABA procedures/terminology may have been novel to the caregivers (and trainers), in both surveys the terms were translated into the local language by practitioners using layman terminology appropriate to the language/culture. There was also an option to select ‘not sure’ or ‘not confident’ for the ABA related questions, if completely unknown. Descriptive statistics were evaluated, and significant differences were examined using the chi-squared test of independence. The results are summarized quantitatively in Tables 2 and 3.

Specific behaviors which might be categorized as challenging for the family (behaviors taken from the BPI) were rated (across three categories) differently based on country. A chi-squared test of independence

Table 2. Caregiver reports of behaviors.

| <i>N</i> = 233 | CZECH | NM | Chi square tests of independence |
|--|-------|-----|--|
| Highly Prevalent Behaviors | | | |
| Engaging in repetitive body movements. | 37% | 66% | $\chi^2(1) = 19.158,$ $p = <.001^*$ |
| Repeating sounds or phrases. | 44% | 69% | $\chi^2(1) = 13.577,$ $p = <.001^*$ |
| Manipulating objects repeatedly. | 32% | 71% | $\chi^2(1) = 33.332,$ $p = <.001^*$ |
| Physical aggression towards others (e.g. hitting, kicking, pushing, biting, spitting on others). | 14% | 31% | $\chi^2(1) = 10.383,$ $p = .001^*$ |
| Verbal aggression towards others. | 9% | 13% | $\chi^2(1) = 1.140,$ $p = .286$ |
| Property destruction. | 15% | 21% | $\chi^2(1) = 1.770,$ $p = .183$ |
| Self-injurious behavior (e.g. hitting, scratching, biting, own body, pulling own hair). | 14% | 22% | $\chi^2(1) = 2.850,$ $p = .091$ |
| Pica (mouthing or swallowing non-food items). | 13% | 24% | $\chi^2(1) = 4.815,$ $p = .041^*$ |
| Vomiting or rumination. | 3% | 4% | $\chi^2(1) = .155,$ $p = .694$ |
| Highly Prevalent Skill-Specific Behaviors | | | |
| Follows instructions. | 43% | 28% | $\chi^2(1) = 5.264,$ $p = .022^*$ |
| Making requests for wanted/needed items. | 58% | 47% | $\chi^2(1) = 2.415,$ $p = .120$ |
| Engages in self-care tasks (e.g. brushing teeth, getting dressed, using the toilet). | 39% | 33% | $\chi^2(1) = .944,$ $p = .331$ |
| Participates in family meal-times. | 54% | 25% | $\chi^2(1) = 19.470,$ $p = <.001^*$ |
| Entertains him/herself with a leisure activity for at least 10 min. | 44% | 29% | $\chi^2(1) = 5.383,$ $p = .020^*$ |
| Demonstrates awareness of the needs of others (e.g., asking if someone is okay). | 15% | 6% | $\chi^2(1) = 5.010,$ $p = .025^*$ |
| Plays with siblings or other children of a similar age for at least 10 min. | 18% | 11% | $\chi^2(1) = 1.958,$ $p = .162$ |
| Identifying which individuals are strangers and which individuals are family members (safe versus unsafe people/situations). | 51% | 11% | $\chi^2(1) = 37.344,$ $p = <.001^*$ |

Note: % indicate proportion of caregivers, who reported high prevalence of the described behavior in their child with ASD, * statistically significant association.

revealed statistically significant associations in the behaviors of repetitive body movements, repeating sounds or phrases, manipulating objects repeatedly, physical aggression towards others, and pica. They were more often reported as occurring by caregivers in North Macedonia than in the Czech Republic (see Table 2). However, the behaviors reported in both countries as most prevalent still fell into the overarching category of engagement in repetitive, or stereotypic, stimming actions that are most often maintained by reinforcement coming from within the child, or automatic reinforcement.

Regarding the skill-specific (behaviors taken from the Vineland scale) behavior reports, a chi-squared test of independence revealed statistically significant associations in the behaviors of participating in family meal-times, entertaining oneself for at least 10 min, demonstrating awareness of the needs of others (empathy), and identifying safe and unsafe situations. They were significantly more often reported by caregivers as occurring in the Czech Republic than in North Macedonia (see Table 2). In general, it appeared that

most of the skill-specific behaviors reported on by the caregivers need targeting to increase their prevalence to higher levels (current reported prevalence ranging between 15% to 58% in CZ and 6% to 47% in NM).

The caregivers' confidence levels in specific ABA concepts looked at procedures that would commonly be taught by trainers and are effective for behavior change. In general, the North Macedonian caregivers reported much less confidence in their knowledge of ABA procedures. They reported knowledge of functional communication training (working to build a child's communication skills) the highest (11%), followed by chaining and task analyses (9%), and prompting procedures (8%). The caregivers in the Czech Republic reported their highest level of knowledge in the three-term-contingency, or A-B-C, antecedent, behavior, consequence model (39%), followed by reinforcement (38%), and functional communication training (31%). A chi-squared test of independence revealed that Czech caregivers perceived their ABA concept knowledge higher than North Macedonian caregivers in all reported areas (see Table 3). Overall, it appeared that most

Table 3. Caregiver reports of confidence with ABA concepts.

| N = 233 | CZECH | NM | Chi square tests of independence |
|---|-------|-----|--|
| ABA Concepts | | | |
| Reinforcement. | 38% | 4% | $\chi^2(1) = 33.035$, $p < .001^*$ |
| Extinction (planned ignoring). | 28% | 6% | $\chi^2(1) = 17.333$, $p < .001^*$ |
| The ABC model (antecedent, behavior, consequence). | 39% | 3% | $\chi^2(1) = 36.695$, $p < .001^*$ |
| The four functions of behavior (escape, attention, access, automatic). | 25% | 7% | $\chi^2(1) = 12.409$, $p < .001^*$ |
| Proactive intervention strategies (antecedent-based intervention strategies). | 19% | 7% | $\chi^2(1) = 6.524$, $p = .011^*$ |
| Functional communication training. | 31% | 11% | $\chi^2(1) = 12.218$, $p < .001^*$ |
| Chaining using task analyses. | 25% | 9% | $\chi^2(1) = 9.205$, $p = .002^*$ |
| Token economy systems. | 24% | 6% | $\chi^2(1) = 13.508$, $p < .001^*$ |
| Prompting procedures. | 29% | 8% | $\chi^2(1) = 15.028$, $p < .001^*$ |
| Time out. | 19% | 4% | $\chi^2(1) = 9.691$, $p = .002^*$ |

Note: % indicate proportion of caregivers, who reported confidence with the described ABA concept, * statistically significant association.

caregivers in both countries did not feel that they have received adequate training in any ABA concepts (ranging between 19% to 39% in CZ and 3% to 11% in NM).

Trainer characteristics

In this research the decision was made to define a trainer as anyone who stated that they had at least some experience working with caregivers of autistic children. Demographic information was collected on their profession, gender, age, and years in the field. The results are summarized quantitatively in Table 4.

A total of 204 trainers participated in the survey (104 from the Czech Republic and 100 from North Macedonia). The trainers were recruited in each country based on their affiliation with the authors. The authors were associated with local universities, ABA centers, and/or autism support organizations. The trainers identified as either: a classroom teacher (inclusive of special education teachers), assistant teacher, student, consultant, or behavior specialist (inclusive of all levels of behavioral professionals). Any other responses were categorized as other. The two countries differed in their most common professions. In North Macedonia, it appeared that those most often providing training to caregivers of autistic children are classroom teachers (63%). In contrast, in the Czech Republic this was more often split between classroom teachers (30%) and assistant teachers (32%).

Most of the participants identified as female (86%). However, as with the caregiver data, in North Macedonia a much higher percentage of males identified as trainers and completed the survey (20%), than in the Czech Republic (8%). The age of the participants ranged from 20 to 63 with the mean age being 35. The caregivers in the Czech Republic had education levels

that were almost equally divided across the three levels of high school only (34%), bachelor’s degree (38%), and master’s degree (29%). This aligns with the greater number of assistant teachers providing parent training, as assistant teachers can be someone without a completed university degree. In North Macedonia, most of the trainers held a bachelor’s degree (64%). The number of years worked in the field supporting families with autism ranged from 1 to 25 with a mean of 7 years. The North Macedonian trainers had a significantly higher mean than the Czech trainers, 9.4 versus 5.4 years, respectively. Regardless of country, most participants had not received training in ABA (63%) and had not trained others in the use of ABA procedures (83%).

Trainer self-identified knowledge and experience

The trainers were asked to self-identify their knowledge and experience relevant to specific behaviors and ABA. The results are summarized in Tables 5 and 6. Questions looked to assess specific work that they have done with caregivers of autistic children. Differences between countries were examined using the chi-squared test of independence.

Trainers in the Czech Republic reported having much more experience than the trainers in North Macedonia in all areas of behaviors which might be viewed as challenging to the families, except experience with training parents on issues concerning vomiting and rumination. In both countries, trainers had very little experience with these behaviors (8% in the Czech Republic and 5% in North Macedonia). In the case of Czech trainers, their greatest areas of reported experience were addressing the behaviors of physical aggression (86%), property destruction (71%), and stereotypic

Table 4. Demographic information of the trainers by country.

| | CZECH n = 104 | NM n = 100 | Combined N = 204 |
|----------------------------------|------------------|---------------|---------------------|
| Age | | | |
| Mean (SD) | 32.7 (9.65) | 37.5 (9.06) | 35.1 (9.65) |
| Gender, n (%) | | | |
| Female | 95 (90%) | 80 (80%) | 175 (85%) |
| Male | 8 (8%) | 20 (20%) | 28 (14%) |
| Other | 1 (2%) | 0 (0%) | 1 (1%) |
| Education, n (%) | | | |
| Master's Degree or higher | 30 (29%) | 36 (36%) | 66 (32%) |
| Bachelor's Degree | 39 (38%) | 64 (64%) | 103 (50%) |
| High School Diploma | 35 (34%) | 0 (0%) | 35 (17%) |
| Profession, n (%) | | | |
| Classroom Teacher | 31 (30%) | 63 (63%) | 94 (46%) |
| Assistant Teacher | 33 (32%) | 17 (17%) | 50 (25%) |
| Consultant | 1 (1%) | 6 (6%) | 7 (3%) |
| Behavior Specialist | 12 (12%) | 1 (1%) | 13 (6%) |
| Student | 17 (16%) | 1 (1%) | 18 (9%) |
| Other | 10 (10%) | 12 (12%) | 22 (11%) |
| Years in the field | | | |
| Mean (SD) | 5.4 (4.22) | 9.4 (6.61) | 7.4 (5.86) |
| Received Training in ABA, n (%) | | | |
| Yes | 34 (33%) | 22 (22%) | 56 (27%) |
| Unsure | 10 (10%) | 9 (9%) | 19 (9%) |
| No | 60 (58%) | 69 (69%) | 129 (63%) |
| Trained Caregivers in ABA, n (%) | | | |
| Yes | 21 (20%) | 11 (11%) | 32 (16%) |
| Unsure | 0 (0%) | 3 (3%) | 3 (1%) |
| No | 83 (80%) | 86 (86%) | 169 (83%) |

object manipulation (69%). Those percentages are much higher than the North Macedonia data, where trainers did not surpass 26% in targeting any of those behaviors; with physical aggression also being the most common (26%), followed closely by stereotypic body movements (24%), and stereotypic object manipulation (22%), see Table 5.

In looking at their experience with skill building, again, the trainers in the Czech Republic generally reported having much more experience than the trainers in North Macedonia. A chi-squared test of independence revealed that Czech trainers rated all areas of skill building higher than North Macedonian trainers (see Table 5). In the case of Czech trainers, their greatest areas of reported experience were working on following instructions (88%), building communication skills (82%), and teaching self-care activities (77%). Again, those percentages are much higher than the North Macedonia data, where trainers did not surpass 27% in teaching any of the skill building behaviors; with following instructions (27%), building communication skills (82%), and teaching self-care activities (22%) being among the highest.

Similar trends in the disparity between the two countries were observed when looking at the trainers' assessments of their own experience with training caregivers on specific ABA concepts. A chi-squared test of independence revealed that trainers differed significantly between countries in all areas of reported ABA concept knowledge (see Table 6). The trainers in the Czech Republic generally reported having much more experience than the trainers in North Macedonia. Their

greatest area of reported experience was with token economy systems (39%), followed by reinforcement (33%), and extinction (planned ignoring; 29%). This contrasts with North Macedonian trainers with their greatest area of reported experience being in functional communication training (13%), followed by extinction (10%), and the four functions of behavior (hypothesized reasons for engaging in behavior; 9%). However, experience with training caregivers in ABA concepts and procedures was low across both countries (ranging between 21% to 39% in CZ and 7% to 13% in NM).

Relationship between caregiver and trainer perceptions

One goal of this research was to assess the match between the work of the trainers and the needs of the caregivers in each country. It should be noted that the trainers and caregivers are not matched pairs, therefore only general comparisons can be made. Additionally, given the differing roles of the individuals in each group the questions asked were not all identical and did not all allow for statistical testing (only the ABA concept questions were identical and allowed for chi-square tests of independence). Regardless, review of the data raise questions that might be valuable for future research.

Specific behaviors

In looking at the descriptive statistics in Tables 2 and 5, caregivers in both countries reported that stereotypic behaviors (e.g. stimming) were among the most prevalent. It was also the case that caregivers in both countries reported the skill-specific behaviors that need the

Table 5. Trainers reports of experience.

| N = 204 | CZECH | NM | Chi square tests of independence |
|--|-------|-----|---|
| Behaviors Targeted | | | |
| Engaging in repetitive body movements. | 61% | 24% | $\chi^2(1) = 27.885$, $p = <.001^*$ |
| Repeating sounds or phrases. | 69% | 18% | $\chi^2(1) = 54.272$, $p = <.001^*$ |
| Manipulating objects repeatedly. | 70% | 22% | $\chi^2(1) = 47.585$, $p = <.001^*$ |
| Physical aggression towards others (e.g. hitting, kicking, pushing, biting, spitting on others). | 86% | 26% | $\chi^2(1) = 73.575$, $p = <.001^*$ |
| Verbal aggression towards others. | 52% | 12% | $\chi^2(1) = 37.127$, $p = <.001^*$ |
| Property destruction. | 71% | 19% | $\chi^2(1) = 55.902$, $p = <.001^*$ |
| Self-injurious behavior (e.g. hitting, scratching, biting, own body, pulling own hair). | 68% | 20% | $\chi^2(1) = 48.071$, $p = <.001^*$ |
| Pica (mouthing or swallowing non-food items). | 45% | 13% | $\chi^2(1) = 25.448$, $p = <.001^*$ |
| Vomiting or rumination. | 8% | 5% | $\chi^2(1) = .619$, $p = .431$ |
| Skill-Specific Behaviors Targeted | | | |
| Following instructions. | 88% | 27% | $\chi^2(1) = 79.233$, $p = <.001^*$ |
| Making requests for wanted/needed items. | 82% | 27% | $\chi^2(1) = 61.677$, $p = <.001^*$ |
| Engaging in self-care tasks (e.g. brushing teeth, getting dressed, using the toilet). | 77% | 22% | $\chi^2(1) = 61.514$, $p = <.001^*$ |
| Participating in family meal-times. | 47% | 21% | $\chi^2(1) = 15.426$, $p = <.001^*$ |
| Entertaining him/herself with a leisure activity for at least 10 min. | 64% | 19% | $\chi^2(1) = 43.136$, $p = <.001^*$ |
| Demonstrating awareness of the needs of others (e.g., asking if someone is okay). | 47% | 12% | $\chi^2(1) = 29.991$, $p = <.001^*$ |
| Playing with siblings or other children of a similar age for at least 10 min. | 68% | 20% | $\chi^2(1) = 48.071$, $p = <.001^*$ |
| Identifying which individuals are strangers and which individuals are family members (safe versus unsafe people/situations). | 47% | 19% | $\chi^2(1) = 18.134$, $p = <.001^*$ |

Note: % indicate proportion of trainers, who reported experience with delivering parent training focused on the described behavior, *statistically significant association.

most improvement to be demonstrating empathy and playing with a sibling or another child for at least 10 min. In contrast, the skill-specific behaviors being worked on most by trainers in both countries were following instructions and building communication skills. Overall, it might be the case that trainers in both regions need more education in developing client-centered programming.

ABA concepts

Regarding ABA concepts and procedures, most North Macedonian caregivers do not feel confident in applications of any ABA concepts (NM caregiver confidence ranging from 3% to 11%). This was further supported by a chi-squared test of independence which revealed that North Macedonian trainers did not differ significantly from caregivers in any of the investigated areas of ABA concept knowledge. Therefore, the trainers do not appear to have more ABA knowledge than the caregivers (see Table 7).

In the Czech Republic, the caregivers reported greatest confidence in using the three-term-contingency, or A-B-C, antecedent, behavior, consequence model (39%). However, the trainers reported highest

confidence and most experience in training parents on the use of token economies (39%). As with the North Macedonian data, a chi-squared test of independence revealed that Czech trainers did not differ significantly from caregivers in most of the investigated areas of ABA concept knowledge except for the two aforementioned (see Table 8). So, while the overall range of trainer knowledge in the Czech Republic was higher (21% to 29%) than North Macedonia, the Czech trainers do not appear to have much more knowledge than the caregivers in many of the ABA concept areas.

Discussion

Research questions

This study aimed to address research questions investigating: (1) the behavior change needs of families with autistic children, (2) the experiences of trainers working with families with autistic children, and (3) the hypothesized match between the knowledge of trainers and the caregiver needs. In looking at the first question, the data demonstrated that the caregivers in both countries reported high levels of specific behaviors such as stimming and aggression in their children, with the North Macedonian data surpassing the Czech data. A

Table 6. Trainer reports of confidence with ABA concepts.

| N = 204 | CZECH | NM | Chi square tests of independence |
|--|-------|-----|--|
| ABA Concept Targeted | | | |
| Reinforcement | 33% | 7% | $\chi^2(1) = 20.656,$ $p = <.001^*$ |
| Extinction | 29% | 10% | $\chi^2(1) = 11.487,$ $p = <.001^*$ |
| (planned ignoring) | | | |
| The ABC model | 26% | 8% | $\chi^2(1) = 11.572,$ $p = <.001^*$ |
| (antecedent, behavior, consequence) | | | |
| The four functions of behavior | 27% | 9% | $\chi^2(1) = 11.030,$ $p = <.001^*$ |
| (escape, attention, access, automatic) | | | |
| Proactive intervention strategies | 21% | 7% | $\chi^2(1) = 8.375,$ $p = .004^*$ |
| (antecedent-based intervention strategies) | | | |
| Functional communication training | 27% | 13% | $\chi^2(1) = 6.154,$ $p = .013^*$ |
| Chaining using task analyses | 23% | 8% | $\chi^2(1) = 8.762,$ $p = .003^*$ |
| Token economy systems | 39% | 8% | $\chi^2(1) = 27.582,$ $p = <.001^*$ |
| Prompting procedures | 28% | 8% | $\chi^2(1) = 13.576,$ $p = <.001^*$ |
| Time out | 24% | 7% | $\chi^2(1) = 11.190,$ $p = <.001^*$ |

Note: % indicate proportion of trainers, who reported confidence with the described ABA concept.
*statistically significant association.

need to target building skills was also reported throughout. This is an additionally important finding, since skill building can bolster real world outcomes such as educational attainment, independence, and support needs (Moore et al. 2022) with their value very well documented throughout the literature (Scheithauer et al. 2018, Tschida et al. 2021, Montgomery et al. 2014). The questions on the ABA concepts appeared to present totally unfamiliar strategies to the caregivers from North Macedonia, which may explain the higher levels of need reported by the caregivers, since the lack of appropriate strategies for managing behavior based on reinforcement, extinction or even token economy may increase these behaviors (Loughrey et al. 2014, Almutlaq 2021). In addition, caregivers from the Czech Republic appeared to be more knowledgeable about ABA concepts which may have corresponded to the reports of their children’s higher levels of certain skills and consequently lower levels of need (Scheithauer et al. 2018).

The second research question addressed the trainer’s knowledge and experience with specific behaviors and ABA concepts. The confidence level in dealing with behaviors that may be seen as challenging to families was higher in the Czech than the North Macedonian trainers, and these disparities were noticed even more in the field of skill-specific behaviors, which contradicts with the level of education that trainers from North Macedonia reported. Respectively, the education received with the university degrees may not have prepared them to meet the needs of autistic children. Regarding ABA concepts, even though the Czech trainers were more aware of every concept in comparison to the North Macedonian trainers, the overall low percentage highlights the needs for additional trainings,

especially on the use of proactive strategies (Smyth et al. 2019).

The third research question addressed the intersection between the trainers and caregivers regarding ABA concepts and behavioral needs. The gap in knowledge between trainers and caregivers on ABA concepts was very slight. Overall, these results were not surprising. Caregivers cannot have appropriate knowledge on behavioral strategies if there are no trainers knowledgeable to teach them. However, it should also be considered that the level of knowledge needed for a caregiver to report confidence is not the same as that of trainer, since the expectation of a trainer is knowing a skill well enough to not only apply it but teach others. Therefore, making comparisons between the two groups on ABA concepts may pose a challenge.

However, regarding the match in targeted behaviors, trends were like those observed in the research of Tschida et al. (2021). Specifically, the behavior targeted most by trainers in both countries, although not necessarily most important to caregivers, was physical aggression. Again, this aligns with the outcomes of previous surveys (e.g. Almutlaq 2021), and may correspond with the challenges faced by autistic individuals in demonstrating their wants and needs. A possible rationale behind these differing priorities may be that trainers are taught to focus on mediating behaviors that are often viewed as undesirable, as opposed to building skill-specific behaviors, and that physical aggression is a more ethical behavior to work to reduce than stimulating behaviors (Kapp et al. 2019).

Conclusion

In summary, our main findings included the lack of behavioral knowledge on the part of the trainers, the lack of direct service access and training related to

Table 7. Table ABA concepts: comparison of North Macedonian caregivers and trainers.

| <i>n</i> = 189 | Caregivers | Trainers | Chi square tests of independence |
|---|------------|----------|------------------------------------|
| North Macedonia – ABA Concepts | | | |
| Reinforcement. | 4% | 7% | $\chi^2(1) = .539,$ $p = .463$ |
| Extinction (planned ignoring) | 6% | 10% | $\chi^2(1) = 1.238,$ $p = .266$ |
| The ABC model (antecedent, behavior, consequence) | 3% | 8% | $\chi^2(1) = 1.841,$ $p = .175$ |
| The four functions of behavior (escape, attention, access, automatic) | 7% | 9% | $\chi^2(1) = .329,$ $p = .566$ |
| Proactive intervention strategies (antecedent-based intervention strategies) | 7% | 7% | $\chi^2(1) = .005,$ $p = .944$ |
| Functional communication training | 11% | 13% | $\chi^2(1) = .137,$ $p = .711$ |
| Chaining using task analyses | 9% | 8% | $\chi^2(1) = .059,$ $p = .807$ |
| Token economy systems | 6% | 8% | $\chi^2(1) = .417,$ $p = .518$ |
| Prompting procedures | 8% | 8% | $\chi^2(1) = .001,$ $p = .973$ |
| Time out | 4% | 7% | $\chi^2(1) = .539,$ $p = .463$ |

Note: % indicate proportion of Czech caregivers and trainers, who reported confidence with the described ABA concept,
* statistically significant association.

Table 8. Table ABA concepts: comparison of Czech Caregivers and trainers.

| <i>n</i> = 248 | Caregivers | Trainers | Chi square tests of independence |
|---|------------|----------|--------------------------------------|
| Czech Republic – ABA Concepts | | | |
| Reinforcement | 38% | 33% | $\chi^2(1) = .795,$ $p = .373$ |
| Extinction (planned ignoring) | 28% | 29% | $\chi^2(1) = .034,$ $p = .854$ |
| The ABC model (antecedent, behavior, consequence) | 39% | 26% | $\chi^2(1) = 4.532,$ $p = .033^*$ |
| The four functions of behavior (escape, attention, access, automatic) | 25% | 27% | $\chi^2(1) = .117,$ $p = .733$ |
| Proactive intervention strategies (antecedent-based intervention strategies) | 19% | 21% | $\chi^2(1) = .220,$ $p = .639$ |
| Functional communication training | 31% | 27% | $\chi^2(1) = .544,$ $p = .461$ |
| Chaining using task analyses | 25% | 23% | $\chi^2(1) = .122,$ $p = .727$ |
| Token economy systems | 24% | 39% | $\chi^2(1) = 6.493,$ $p = .011^*$ |
| Prompting procedures | 29% | 28% | $\chi^2(1) = .049,$ $p = .826$ |
| Time out | 19% | 24% | $\chi^2(1) = 1.019,$ $p = .313$ |

Note: % indicate proportion of Czech caregivers and trainers, who reported confidence with the described ABA concept.
* statistically significant association.

ABA for families in both regions, a potential misalignment between family needs and training targets, and the disparities between the two countries.

Of major importance here is the fact that only half of the trainers are well-versed in ABA. More structured education is needed for those taking on the roles of training caregivers of autistic children. It is hypothesized that a solid educational foundation in ABA would result in practices by trainers that better support the needs of caregivers of autistic children (Smyth *et al.* 2019). This is supported by the Czech Republic’s availability of coursework beginning in 2016 which appeared to boost access to ABA services in the region. In fact, previously Salomone *et al.* (2016) found that North Macedonia had more behavioral services available than the Czech Republic. Since the Czech

Republic’s recent movement towards education in ABA, legislation, and improved dissemination (Arntzen and Pellón 2021), they have seemingly surpassed North Macedonia in ABA (with more parents having access to services and ABA knowledge, see Tables 1 and 3). Overall, this highlights the urgent need for legislative regulations of service centers to be trained in behavioral concepts, and to prepare preservice students with behavioral knowledge.

Regarding the possible misalignment between needs and practice, trainers do not perceive themselves as more competent than caregivers in ABA concepts and may be training on behaviors that are not client centered. It is interesting to consider this further by evaluating the types of strategies being used by trainers in relation to the families’ most common behavioral needs.

Specifically, if the most prevalent behaviors being targeted are related to stimming (and most likely maintained by automatic reinforcement), then we would expect to see teaching of skill-specific replacement behaviors for stereotypy that relate to increasing self-regulation through conditioning leisure skills (e.g. Nuzzolo-Gomez *et al.* 2002). While increasing communication skills may support this, engaging in leisure activities may have more functional alignment (e.g. Britton *et al.* 2002). Engaging in preferred activities with greater valence results in better self-regulation (Fries *et al.* 2008). However, since the behaviors in both assessed categories are not incompatible, it is not necessarily the case that reported prevalence of certain behaviors would correlate with lower levels of others.

Limitations and future research

When a survey is conducted for the first time in a different cultural context, even if it is extensively research based, it is still impossible to neutralize all the factors that would affect the results. For one, the questionnaires were initially created in English, then forward and back translated into the Czech and Macedonian languages. During these translations, we cannot be sure that there were not different interpretations of some concepts. This is especially the case when considering that ABA has a specific vocabulary, without direct translations, and may be altogether missing from the lexicon of North Macedonia. Additionally, it was carried out online, without the possibility of added explanations. An additional limitation is that information was not gathered on the specific autistic characteristics of the children (e.g. diagnosis, IQ) that were part of the families, or part of the population with which trainers had worked. It might be assumed that this impacted the reports on specific behaviors, since research has shown that higher level of IQ or function is positively correlated to skill-specific behavior and negatively to behaviors such as aggression (Manning *et al.* 2021, McQuaid *et al.* 2021).

Overall, while the self-report data in this study are not without their limitations, the findings contributed valuable information to fill the gap highlighted in the literature review. In North Macedonia and the Czech Republic, ABA therapy is still developing, and this is the first study which explores the perceptions of caregivers and trainers regarding ABA concepts. Future research can be driven by the results here to build better teacher/trainer education programs in both countries, with an emphasis on assessing and meeting the individualized needs of families with autistic children.

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