

# Stability of emotional and behavioral problems in autistic children and adolescents during the COVID-19 pandemic

Clemens Boy, Femke L. Truijens, Anneke Louwerse, Kirsten Visser, Dennis Bastiaansen, Wietske A. Ester, Elisabeth H.M. Van Rijen, Ruth Van der Hallen and Linda P. Dekker

(Information about the authors can be found at the end of this article.)

## Abstract

**Purpose** – *The lasting impact of the COVID-19 pandemic on autistic children and adolescents remains uncertain. Disruptions to routines, social communication and support systems presented unique challenges. The existing body of research has produced inconclusive results, necessitating further investigation to elucidate this ambiguity. This study aims to provide clarity regarding the emotional and behavioral functioning of autistic youth in response to COVID-19 related lockdowns. We further explore distinct subgroups of Autism Spectrum Disorder (ASD), investigating the socially inflexible and demand avoidant profile.*

**Design/methodology/approach** – *To surpass short-term outcomes, this study examined emotional and behavioral problems (EBPs) by means of the Brief Problem Monitor in 69 autistic youth before, during and after a national lockdown in the Netherlands. Using individualized measurement (Reliable Change Indices), group-level changes were discerned. An exploratory analysis compared individuals from the socially inflexible and demand avoidant profile.*

**Findings** – *Both on a group and individual level, this findings suggest stability of EBPs in response to the COVID-19 pandemic and its corresponding measures. However, while the demand avoidant profile showed significantly more EBPs compared to the socially inflexible profile prior to the pandemic, the two profiles showed similar EBPs levels during and post-pandemic. Taken together, autistic youth and their families may have exhibited unique adaption strategies toward challenges caused by the pandemic and managed them better than initially expected.*

**Originality/value** – *The findings urge to look beyond group level functioning, and rather into nuances in ASD profiles to tailor interventions and support to the needs of autistic youth and families. A novelty of the study consists in having identified two different autism profiles to explain differences among subgroups of ASD.*

**Keywords** *Autism spectrum disorder, COVID-19 pandemic, Emotional and behavioral problems, ASD profiles, Child and adolescent psychiatry*

**Paper type** *Research paper*

## List of abbreviations

ASD = Autism spectrum disorder;  
EBPs = emotional and behavioral problems;  
BPM = brief problem monitor;  
SRS = social responsiveness scale; and  
RCI = reliable change index.

The COVID-19 pandemic is considered a difficult period for most people, although assumed particularly challenging for children and adolescents diagnosed with Autism

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Spectrum Disorder [1] (ASD) and their families, given the diagnostic criteria and comorbidities (Colizzi *et al.*, 2020). Previous research has reported diagnostic stability of ASD diagnoses (Woolfenden *et al.*, 2012) and high rates of comorbidity (Morgan *et al.*, 2003). For instance, autistic children and adolescents experience more emotional and behavioral problems (EBPs) compared to normative groups (Schroeder *et al.*, 2011). EBPs can comprise externalizing problems (e.g. verbal or physical aggression, tantrums, self-injury or property destruction) and internalizing problems (e.g. anxiety, depressive and somatic symptoms) that can negatively impact daily functioning and quality of life (Achenbach *et al.*, 2016). The presence of multiple comorbidities, such as a higher likelihood of experiencing EBPs, along with the vulnerability of autistic individuals, could both be factors contributing to alterations in EBPs during the COVID-19 pandemic. However, it is unclear if the pandemic has led to increased EBPs during and after the pandemic.

EBPs may be exhibited in an attempt to reduce their anxiety, distress and frustration from unpredictable transitions (Brewer *et al.*, 2014). Furthermore, three contexts may trigger EBPs in individuals with ASD: transitions, termination of preferred activities and the presence of a feared stimulus (Cale *et al.*, 2009). Amidst the COVID-19 pandemic, various circumstances can be considered as transitions that result from the sudden implementation of protective measures. These transitions may involve moving from one activity or place to another. The termination of preferred activities refers to the abrupt cessation of school routines or face-to-face treatments and support systems. Finally, feared stimuli in this context may include certain sensory or environmental triggers that cause anxiety, such as the virus itself. COVID-19 lockdowns have caused these circumstances to be omnipresent. Increased EBPs have been related to negative clinical outcomes (Cale *et al.*, 2009) and parental anxiety (Colizzi *et al.*, 2020). High rates of co-occurring EBPs in ASD individuals (Zaidman-Zait *et al.*, 2014) and the importance of early intervention (Horner *et al.*, 2002) underline the importance to investigate how EBPs are modulated by external factors such as the COVID-19 pandemic.

The COVID-19 pandemic represents a highly distinctive challenge, resulting in far-reaching changes and impact on mental health, as individuals navigate the various physical, social and economic consequences of the pandemic. Due to the outbreak of the COVID-19 virus, many countries implemented national lockdowns, leaving most public life closed while introducing social distancing and hygiene rules (Terpstra *et al.*, 2021). Common daily routines and structure such as schools, therapies or free time activities were closed by the government. These protective measures against the COVID-19 virus were highly unpredictable as they depended on various factors such as the daily COVID-19 infection or immunization rates. These rapid changes related to the COVID-19 pandemic have caused distress among young ASD individuals due to their vulnerability to changes and unpredictability (Colizzi *et al.*, 2020). Furthermore, the COVID-19 pandemic has disrupted usual therapies and support systems for families with someone with ASD, posing a potential risk factor (White *et al.*, 2021) for increased EBPs. Despite the challenges autistic youth have faced as a result of the COVID-19 pandemic, the impact on the extent to which they experienced EBPs remains unclear.

Due to their specific set of symptoms, the impact of the COVID-19 pandemic on individuals with ASD is considered twofold. On the one hand, previous research implies relief for ASD individuals during the COVID-19 pandemic (Lugo-Marín *et al.*, 2021). Governmental regulations (e.g. school closings) reduced challenging social interactions and sensory overstimulation (Mumbardó-Adam *et al.*, 2021). On the other hand, ASD individuals were vulnerable to drastic changes (Colizzi *et al.*, 2020) during the COVID-19 pandemic, which offers a unique opportunity to study vulnerability to unpredictable events.

Since the onset of the COVID-19 pandemic, a handful of studies have been conducted amongst the ASD population with some indicating a rise in EBPs (Colizzi *et al.*, 2020) while others report a decrease in the prevalence of EBPs (Siracusano *et al.*, 2021). These studies

have signaled more frequent EBPs (Colizzi *et al.*, 2020) and more restricted and repetitive behaviors or sleep disturbances (Renzo *et al.*, 2020). Interestingly, some previous research has also suggested a positive impact of the pandemic in terms of a reduction of psychopathological symptoms (Lugo-Marín *et al.*, 2021) and increased family cohesion (Neece *et al.*, 2020). Moreover, others have failed to find any detrimental effects in response to the pandemic (Bouter *et al.*, 2021) or worsening of EBPs or repetitive behavior in ASD individuals (Siracusano *et al.*, 2021). Taken together, the results differ between available literature which suggests the presence of both protective and risk factors within ASD individuals in light of the COVID-19 pandemic. Currently, it remains unclear if indeed there are increases in EBPs and, if so, how these develop over time, as previous studies lack pre-pandemic or follow-up data.

At the root of these mixed findings may be the theoretically known difference between the *socially inflexible* and *demand avoidant* ASD profiles (Buhr and Dugas, 2009; Leung *et al.*, 2016). These distinct profiles suggest that ASD individuals can present with pronounced, differential characteristics and preferences. Individuals ASD may exhibit features of both the *socially inflexible profile* and the *demand avoidant profile*, and while there may be shared areas of potential benefit, each individual may have a more prominent expression of one profile over the other.

ASD individuals with a *socially inflexible profile* react strongly to uncertain social situations and events (Buhr and Dugas, 2009; Leung *et al.*, 2016), for example, interactions with strangers or small talk. They often struggle with understanding and appropriately responding to social cues, such as facial expressions. They may have difficulty initiating and maintaining conversations, making and keeping friends and understanding social norms and expectations (Leung *et al.*, 2016). As social encounters were generally restricted during lockdowns, such a reduction of uncertain social situations might have been beneficial to individuals with this profile. Lockdown restrictions have compelled individuals to spend an increased amount of time with a limited number of people, including friends or close relatives. This has given rise to new social challenges, particularly in terms of altered family dynamics such as living in confined spaces.

On the contrary, ASD individuals with a *demand avoidant profile* react emotionally to routine demands and express anxiety or distress in the context of demands and missing routines (Newson, 2003). This profile is characterized by individuals who avoid routine demands, struggle with processing requests, resist following instructions and may engage in manipulative behavior to avoid tasks and stay in control (O'Nions *et al.*, 2021). As such, these individuals might be particularly vulnerable to the constantly changing demands of the COVID-19 pandemic. Furthermore, school and therapy routines were omitted by many individuals. This potential range in both behavior and emotional challenges depending on ASD individuals' profile, might be particularly important to consider to understand fluctuations in EBPs as a result of the COVID-19 pandemic.

This study aims to investigate the long-term effects of the COVID-19 pandemic on children and adolescents with ASD. Specifically, we aim to investigate (1) how EBPs develops over time (pre-pandemic, during a lockdown, post-lockdown), (2) if changes over time reflect clinically relevant changes and lastly (3) in an exploratory analysis, if two distinct ASD profiles may serve as potential or protective factors in EBPs fluctuations as a result of the COVID-19 pandemic. Previous studies have largely been conducted directly following the first COVID-19 outbreak. However, due to a lack of pre-pandemic data or follow-up possibilities, it remains unclear if and how individuals with ASD may be affected by the COVID-19 pandemic long-term. As the majority of studies have shown a negative impact of the pandemic among healthy and mentally ill samples, combined with the specific vulnerability posed by ASD symptomatology, in this study, an increase of EBPs on both the group and individual level is hypothesized over the course of COVID-19 regulations. Moreover, we hypothesize both ASD profiles react differently to the COVID-19 pandemic in

terms of EBPs. Given the complexity of demarcating profiles, no hypothesis is posited regarding the impact of profile differences in this exploratory analysis.

## Method

### *Procedure and sample*

Prior to the study, parents of children with ASD who received pre-pandemic care were contacted and asked for their participation to collect information about their children. A total of 69 parents of children and adolescents diagnosed with ASD gave informed consent to partake in our study. The examined children and adolescents with ASD were between 4 and 20 years of age at T0 before a national lockdown (pre-pandemic March 2019 – March 2020). At T0, these individuals with ASD were in care at one of three large mental healthcare institutions around Rotterdam so some pre-pandemic clinical data (March 2019 until March 2020) was available. The sample was gathered based on open and voluntary participation (self-selection). Financial compensation was provided to participants in recognition of their participation in the study. The compensation scheme was graded based on the timing of data collection activity and comprised of a €10 incentive for completing the T1 survey, €25 for completing the T2 survey. This approach was implemented to incentivize continued engagement in the study and mitigate the likelihood of participant attrition. Pre-pandemic clinical (T0) data on ASD symptoms [Social Responsiveness Scale (SRS)] was available for 45 participants whereas data on EBPs [brief problem monitor (BPM)] was available for 41 participants. The BPM was first sent out in the Spring of 2021 (T1: January to May; during the second Dutch national lockdown) and returned by 52 parents. In Fall 2021 (T2: September to December; after the second national lockdown), the BPM was filled in by 39 participants. The Medical Ethics Committee (METC) of the Erasmus MC, Rotterdam, the Netherlands provided medical ethical approval for this study (MEC-2020-0720). For more information about the sample and procedure of the study, see the study protocol by Dekker and colleagues (2022).

Recruitment phases were limited in time to lockdown and non-lockdown phases to allow a comparison of the impact of regulations which led to missing values among the sample. Accordingly, data were imputed for missing BPM and SRS questionnaires in SPSS based on all given data from each participant. Multiple imputation was found to be the most appropriate technique to deal with missing data, superior to listwise deletion (Manly and Wells, 2015). Based on the original data set containing missing values, missing values are replaced with plausible estimates (see Results – multiple imputation).

### *Materials*

*Brief problem monitor.* To measure EBPs, the BPM (Achenbach *et al.*, 2011) was used. The BPM is a shortened version of the Child Behavior Check List (CBCL) consisting of a total score, an externalizing and internalizing domain, as well as attention. The BPM uses a three-point Likert scale ranging from 0 (“not at all”) to 2 (“clearly”). Consisting of 19 items, possible BPM total scores range from 0 to 38. Higher scores indicate more frequent internalizing, externalizing and attention problems. The BPM was found to have a high internal consistency ( $\alpha = 0.72-0.86$ ) and correlates strongly with the original CBCL (Piper *et al.*, 2014). Items include statements about the child’s or adolescent’s behavior such as “Unhappy, sad or depressed”, “Threatens people” or “Inattentive or easily distracted” (Achenbach *et al.*, 2011).

*Social responsiveness scale.* The SRS was developed by Constantino and Gruber (Constantino and Gruber, 2005) and comprises 65 items. There are different forms available to be filled in by a teacher, parent or relative, also adjusted by age. The SRS quantifies ASD traits, reciprocal social behavior and communication in children and adolescents. All items are rated on a four-point Likert scale ranging from 0 (“not true”) to 3 (“almost always true”).

To establish the *socially inflexible* and *demand avoidant profiles*, 14 items from the SRS questionnaire were used to develop two scales with seven items each. Profile scales were constructed based on previous research (Buhr and Dugas, 2009; Chowdhury et al., 2016; Newson, 2003; O’Nions et al., 2021), definitions from literature, qualitative insights from the larger mixed-method study and confirmed by evaluating the internal consistency. The *socially inflexible profile* scale reflects the struggle with socially challenging and novel situations and intolerance of uncertainty (Chowdhury et al., 2016). It consists of SRS items 1, 6, 18, 33, 36, 37 and 64, containing items such as “Seems much more fidgety in social situations than when alone” or “Would rather be alone than with others”. The *demand avoidant profile* scale reflects demand avoidance, routine request and the need for control (O’Nions et al., 2021). It consists of SRS items 4, 8, 19, 24, 30, 61 and 62, containing statements such as “When under stress, the child seems to go on auto-pilot” or “Has more difficulty than other children with changes in his/her routine”.

### Statistical analyses

For descriptive purposes, means and standard deviations were computed for age, BPM total scores at T0, T1 and T2, gender and mean scale scores on the SRS *socially inflexible* and *demand avoidant profile*. The internal consistency of the *socially inflexible* and *demand avoidant profile* scale was evaluated using Cronbach’s alpha and identified as good (see Table 1 for more details). The item-total correlation was set to a minimum of  $\alpha \geq 0.30$ , indicative of the fact that items indeed measured the same construct (Field, 2013). Items were deleted in case the removal of the item increased Cronbach’s alpha more than 0.10 (Field, 2013).

To assess changes in EBPs in youth with ASD and the influence of ASD profiles and gender, the following analyses were conducted:

1. *Mean Level Change*. A repeated measures ANOVA was conducted with BPM total scores as the dependent variable and time as the independent variable. The latter had three levels consisting of the three time points (T0, T1 and T2) at which the BPM was administered.

**Table 1** Internal consistency

| <i>n</i>                           | SRS item | M   | SD  | Item-total correlation | Cronbach’s alpha | Cronbach’s alpha if item deleted |
|------------------------------------|----------|-----|-----|------------------------|------------------|----------------------------------|
| <i>Socially inflexible profile</i> |          |     |     |                        |                  |                                  |
| 69                                 |          |     |     |                        | 0.85             |                                  |
|                                    | 1        | 1.7 | 0.9 | 0.64                   |                  | 0.82                             |
|                                    | 6        | 1.3 | 0.8 | 0.46                   |                  | 0.85                             |
|                                    | 18       | 1.5 | 0.9 | 0.60                   |                  | 0.83                             |
|                                    | 33       | 1.2 | 0.8 | 0.63                   |                  | 0.82                             |
|                                    | 36       | 1.0 | 0.8 | 0.69                   |                  | 0.81                             |
|                                    | 37       | 1.5 | 0.8 | 0.62                   |                  | 0.82                             |
|                                    | 63       | 1.5 | 0.9 | 0.59                   |                  | 0.83                             |
| <i>Demand avoidant profile</i>     |          |     |     |                        |                  |                                  |
| 69                                 |          |     |     |                        | 0.83             |                                  |
|                                    | 4        | 1.9 | 0.9 | 0.62                   |                  | 0.80                             |
|                                    | 8        | 1.3 | 0.8 | 0.62                   |                  | 0.80                             |
|                                    | 19       | 1.4 | 0.9 | 0.60                   |                  | 0.80                             |
|                                    | 24       | 2.1 | 0.8 | 0.61                   |                  | 0.80                             |
|                                    | 30       | 1.8 | 1.0 | 0.49                   |                  | 0.82                             |
|                                    | 61       | 1.8 | 0.9 | 0.50                   |                  | 0.82                             |
|                                    | 62       | 1.2 | 0.9 | 0.60                   |                  | 0.80                             |

Notes: Cut-off Cronbach’s alpha = 0.7; cut-off item-total correlation = 0.3 (Field, 2013)

Source: Authors’ own work

2. *Reliable Change Indices (RCI)*. To assess whether the change of each participant over time is clinically significant, individual differences were assessed using three RCIs. The RCI gives information about whether a change is clinically significant across time (Ferguson *et al.*, 2025).

The formula includes the change score divided by the standard error of each participant, thereby separating true change from measurement error (31). Scores indicated whether the EBPs of ASD individuals has decreased, increased or remained stable over time. Change scores larger than one SD (i.e.  $\pm 1.96$ ) are considered clinically significant. Our study assessed clinically relevant changes in the EBPs of children and adolescents with ASD at (1) T0 to T1, (2) T0 to T2, as well as compared EBPs at (3) T1 to T2:

3. *Profile Analysis*. To ascertain the profile that would be most suitable for each participant, mean scores on both scales for the *socially inflexible* and *demand avoidant profiles* were computed and compared per individual. Participants were assigned to the profile they had the highest mean score on. Although participants may have met criteria for both profiles, our approach enabled the determination of each participant's primary challenge or difficulty. In our exploratory analysis, the allocation of profiles with minimal differences on the profile scales is deemed acceptable, as our primary focus lies in identifying overarching patterns of profile distinctions, and it would therefore be counterproductive to further fragment our sample into three distinct groups. Following the allocation, a total of three independent sample t-tests were conducted to compare both groups. The mean of change scores between T0 and T1, T1 and T2 and T0 and T2 were used to identify concrete differences between the two profiles in their reaction to the COVID-19 lockdown in terms of EBPs.

### ***Community involvement statement***

Given the time sensitivity of the study, it was not feasible to involve clients in the development of the research question and the design, however we did use (non-academic) publications of autistic individuals or their parents about their experiences with COVID-19 and the related measures (e.g. den Houting, 2020; Van den Bosch, 2020). In addition, key stakeholders (i.e. clinicians at three large mental health care institutions in the region of Rotterdam who provide specialized care to families with children with ASD) were involved already during the funding application for the study. The stakeholders helped developing the research question, study design, measures, implementation of the study and interpretation and dissemination of the findings. The stakeholders shared their experiences with clients to finetune our research question prior to the study. Furthermore, (preliminary) findings, e.g. communication desires from the clients, were directly relayed to the clinicians leading to adaptations in their communication and treatment approaches with clients already during the study. In addition, (preliminary) findings have been shared in several newsletters suitable for a non-specialist audience sent to participants, clinicians and other interested parties throughout the project, as well as several Dutch non-academic publications, two webinars and a website on COVID-19 projects in the Netherlands to reach a large audience. Based on client and clinician input, some output was specifically created throughout the project, for example visualizations of the outcomes of the study.

## **Results**

### ***Sample description***

Descriptive statistics for all relevant variables (i.e. age, gender, BPM T0, BPM T1, BPM T2, profile scales) are displayed in Table 2.

**Table 2** Descriptive statistics

| Variable                                 | n        |          |           |     |     | %  |
|------------------------------------------|----------|----------|-----------|-----|-----|----|
| <i>Gender</i>                            |          |          |           |     |     |    |
| Male                                     | 49       |          |           |     |     | 71 |
| Female                                   | 16       |          |           |     |     | 23 |
| Missing                                  | 4        |          |           |     |     | 6  |
|                                          | <i>n</i> | <i>M</i> | <i>SD</i> | Min | Max |    |
| Age                                      | 69       | 12       | 4.6       | 4   | 20  |    |
| BPM T0                                   | 69       | 17.6     | 4.5       | 7   | 33  |    |
| BPM T1                                   | 69       | 16.7     | 6.7       | 1   | 32  |    |
| BPM T2                                   | 69       | 15.9     | 5.7       | 0   | 28  |    |
| <i>Socially inflexible profile scale</i> | 69       | 1.6      | 0.6       |     |     |    |
| <i>Demand avoidant profile scale</i>     | 69       | 1.4      | 0.6       |     |     |    |

**Notes:** BPM = brief problem monitor; T0/1/2 = timepoint 0/1/2  
**Source:** Authors' own work

### Multiple imputation

Data on the ASD symptoms at T0 (SRS) was imputed for 24 of the 69 participants. BPM total scores were imputed for 28 cases at T0, 17 at T1 and 30 cases at T2 as data was not available for all participants at all timepoints. Multiple imputation has demonstrated effective performance in small sample sizes, with as few as 50 observations, even in the presence of up to 50% missing data in the dependent variable (Graham, 2009). Important to note, an analysis of the missing data showed a random pattern, and multiple imputations, therefore, seemed suitable. Multiple imputation was performed using the AUTO method with a total of five imputations. A fully conditional specification, an iterative Markov Chain Monte Carlo method, was used as it showed to be the most appropriate for monotone as well as non-monotone missing patterns.

### Mean-level emotional and behavioral problems change

The results of the repeated measures ANOVA indicated no significant change of EBPs across the three time points,  $F(1.82, 123.65) = 1.78$ ,  $p = 0.17$ ,  $\eta^2 = 0.025$ . This suggests that the COVID-19 lockdown did not affect EBP levels in children and adolescents with ASD across the periods before, during and after the lockdown.

### Reliable change indices

For each participant, RCI were calculated relating to their change of EBPs between T0 and T1, T0 and T2, as well as T1 and T2. The results indicated that 92.8% of participants (64 out of 69) did not exhibit a clinically significant change in EBPs from T0 to T1. Simultaneously, 5.8% of the participants (4 out of 69) demonstrated an increase in EBPs, and 1.4% (1 out of 69) showed a decrease. This suggests that for a vast majority of children and adolescents with ASD, EBPs remained stable from before to the onset of the COVID-19 lockdown. A similar pattern was found between T0 and T2: 91.3% of the participants (63 out of 69) showed no clinically significant change in EBPs, with 7.2% (5 out of 69) exhibiting a decrease in EBPs and only 1.4% (1 out of 69) showing increased levels of EBPs across the COVID-19 lockdown. Similarly, for the change in EBPs between T1 and T2, 94.2% (65 out of 69) demonstrated no clinically significant change. 5.8% (4 out of 69) further decreased their EBPs, while no participant increased their EPBs upon lifting the national lockdown. In conclusion, also on individual level, the vast majority of individuals with ASD demonstrated stable EBP levels across all phases of the COVID-19 lockdown, with no significant fluctuations observed between pre-lockdown, during-lockdown and post-lockdown periods.

## Profile analysis

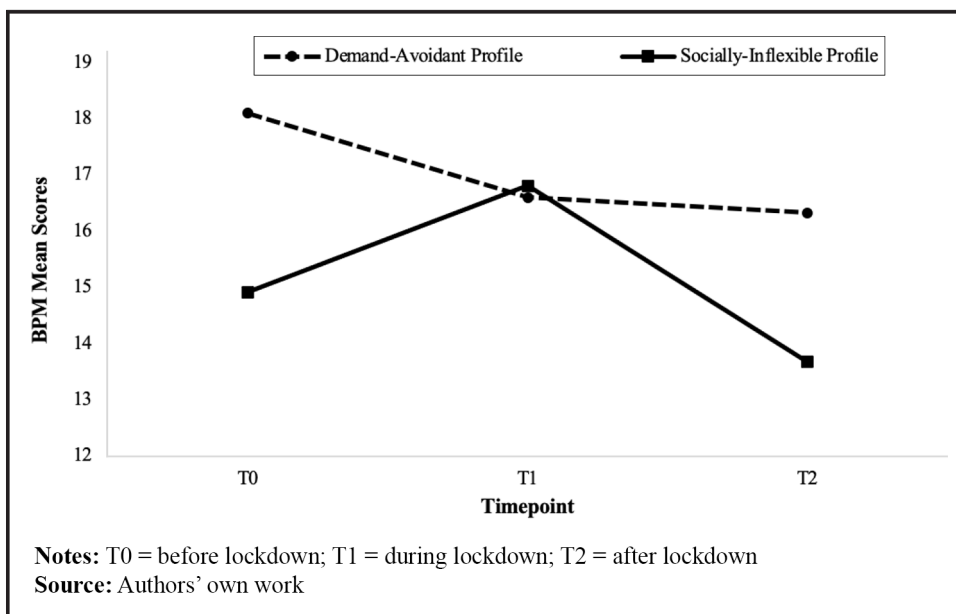
Following the aforementioned method of comparing mean scores (see Method), participants were allocated to one specific profile. Twelve participants (17.4%) were assigned to the *socially inflexible profile*, and 57 participants (82.6%) were assigned to the *demand avoidant profile*. The results of independent t-tests are shown in Table 3 and profile trends among the sample are displayed in Figure 1. EBPs scores at T0 differed significantly between the groups,  $t(67) = -2.27, p = 0.03, d = -0.72$ . This indicates that prior to the pandemic, EBPs were significantly higher among the *demand avoidant profile* compared to the *socially inflexible profile*. At T1, EBPs levels were equal for both groups,  $t(67) = 0.10, p = 0.92, d = 0.03$ . This suggests that, with the onset of the COVID-19 lockdown, the demand-avoidant profile experienced a decrease in EBPs, while the socially inflexible profile showed an increase, resulting in a reduction of the overall group difference from before the lockdown during the COVID-19 period. EBPs scores at T2 were again similar for both profiles,  $t(67) = -1.48, p = 0.14, d = -0.47$ , as observed at T1. This suggests that after the COVID-19 lockdown was lifted, there was no significant EBP difference between both profiles. In sum, EBP levels differed between the *socially inflexible* and *demand avoidant profiles* before the COVID-19 pandemic but these differences diminished during the COVID-19 lockdown with more similar EBP levels at the end of the lockdown.

**Table 3** Profile analysis (t-tests)

| Timepoint | Socially inflexible profile <sup>a</sup> |     | Demand avoidant profile <sup>b</sup> |     |
|-----------|------------------------------------------|-----|--------------------------------------|-----|
|           | M                                        | SD  | M                                    | SD  |
| BPM T0    | 14.9                                     | 4.5 | 18.1                                 | 4.4 |
| BPM T1    | 16.8                                     | 4.5 | 16.6                                 | 7.1 |
| BPM T2    | 13.7                                     | 6.1 | 16.3                                 | 5.6 |

Notes: <sup>a</sup> $n = 12$ ; <sup>b</sup> $n = 57$ ; BPM = Brief problem monitor  
Source: Authors' own work

**Figure 1** BPM Scores of ASD profiles



## Discussion

To our knowledge, this is the first study to investigate the long-term impact of COVID-19 on EBPs in children and adolescents with ASD. Prior findings on the pandemic's impact on ASD individuals have shown mixed results, suggesting both positive (Mumbardó-Adam *et al.*, 2021) and negative effects (Colizzi *et al.*, 2020). However, previous studies lacked pre-pandemic data, and follow-up data from multiple time points throughout the pandemic. The current study assessed EBPs at three timepoints: before, during and following the first national lockdown in the Netherlands. Previous research did not account for the etiological and clinical heterogeneity among ASD samples (Lenroot and Yeung, 2013). To extend prior research, our study differentiated group-level changes using individualized measurement and compared newly adapted ASD profiles.

To summarize our results, both on a group and individual level, EBPs levels remained stable over time and were not affected by the implementation or lifting of the COVID-19 lockdown measures. Comparing two ASD profiles, the *socially inflexible* and *demand avoidant* profile, we found a substantial nuance. EBPs were more prevalent for the *demand avoidant profile* prior to the pandemic. During and after the lockdown, the two profiles did not differ significantly in terms of expressed EBPs. Across all timepoints of the COVID-19 lockdown, the *socially inflexible profile* showed a general increase in EBPs. Conversely, the *demand avoidant profile* demonstrated a decline in EBPs, which suggests a potential resilience in this group.

A key finding was the overall stability in EBPs during the COVID-19 pandemic among the ASD population. Our findings align with previous research, indicating that COVID-19 lockdowns were not related to significant increases in problem behavior (Siracusano *et al.*, 2021) as well as indicative that EBPs generally seem to remain stable (Bilancia and Rescorla, 2010). Participants with an ASD diagnosis handled the lockdown better than expected (Colizzi *et al.*, 2020). Some studies show they participated more frequently in family routines and were generally more communicative (Mumbardó-Adam *et al.*, 2021) which may have buffered against EBPs. Other studies found additional improvements, such as a reduction of psychopathological symptoms and decreased stress levels, most prominently among younger participants compared to adults (Lugo-Marín *et al.*, 2021). Although, COVID-19 related measures were challenging for ASD individuals (Renzo *et al.*, 2020), previous and our current findings indicate that the COVID-19 lockdown did not lead to significant changes in emotional and behavioral functioning. In addition, our study extends these findings with follow-up data after the COVID-19 lockdown suggesting stability of EBPs without a negative long-term impact.

We consider three possible explanations for the overall stability of EBPs, drawing from previous research and insights gathered through our mixed-method study (Dekker *et al.*, 2022). It is important to note that these explanations serve as plausible interpretations aimed at contextualizing the observed patterns, rather than offering definitive explanations. One reason may be that also in other periods EBPs has proven to be relatively stable in various populations. Research into EBPs prior to the pandemic indicates longitudinal stability of EBPs in healthy children and adolescents (Verhulst and Van der Ende, 1992). Similarly, even in light of major changes in day-to-day life, EBPs remained stable over time in a normative sample of 834 children (Bilancia and Rescorla, 2010). Added to that, previous research pointed out that short periods such as the COVID-19 lockdown “may not represent a consistent time trend in certain” EBPs (Duijnhof *et al.*, 2015). In summary, EBPs have shown to be highly stable over time, even in the face of major life events such as the COVID-19 pandemic.

A second possible explanation for the overall stability of EBPs may be that the pandemic may enabled ASD individuals to behave according to their preferred behavior patterns (Reicher, 2020), minimizing the impact of the COVID-19 pandemic and stabilizing EBPs.

Due to governmental regulations, ASD individuals may have experienced less overstimulation as there was no need to tolerate social interaction and managing sensory environment, which could have reduced the triggers for EBPs (Cale *et al.*, 2009; Mumbardó-Adam *et al.*, 2021). The lockdown situation could have suited their characteristic of typical shyness and withdrawal from social interaction (Lugo-Marín *et al.*, 2021). Taken together, the stability of EBPs during the COVID-19 pandemic could be attributed to new routines, such as telehealth and part-time schooling, which likely reduced overstimulation and social interactions.

A third potential explanation for the stability of EBPs in reaction to the COVID-19 pandemic is that family context may have played an important protective role in the emotional and behavioral functioning of ASD individuals. The environment significantly changed with governmental COVID-19 protective measures, such as social distancing and remote learning, which required adjusting to changes in the environment (Baweja *et al.*, 2021) as well new forms of social interaction (Pellicano *et al.*, 2022). Potentially, the family context may have buffered against negative outcomes. Individuals with ASD may have benefitted from increased quality family time which allowed them to learn new skills in terms of communication and autonomy (Mumbardó-Adam *et al.*, 2021) without stressful exposure at school as well as reduced transitions between home and external places (Berard *et al.*, 2021). Furthermore, parents of children with ASD may have already been more prepared for the challenges the COVID-19 pandemic posed. Prior to the pandemic, ASD families were already used to the living circumstances present during the COVID-19 pandemic. This may include working part-time, having reduced social contacts and spending much time at home in a safe environment. Taken together, the positive influence of family context with increased quality time and already established routines may have stabilized EBPs.

A second important finding to discuss are our initial insights into different trends in EBPs among the *socially inflexible* and *demand avoidant profile*. The present study showed that the *demand avoidant profile* had significantly more EBPs than the *socially inflexible profile* prior to the pandemic. During and after the COVID-19 lockdown, these groups aligned their EBPs levels and subsequently did not show significant differences. However, the ASD profiles showed EBPs level trends that were contrary to each other and earlier observed stability of EBPs in the sample might be explained by the fact that the EBPs scores of both profiles seem to balance each other out. During the lockdown, scores aligned as EBPs for the *socially inflexible profile* increased while EBPs for the *demand avoidant profile* showed a decrease. The *socially inflexible profile* tended to increase their EBPs in reaction to the COVID-19 pandemic which might be explained by new social obstacles. Some studies reported social relief during the COVID-19 pandemic, but also noted the inability of many ASD individuals to properly socialize with others. More interactions with caregivers and siblings might have imposed a burden on them (Colizzi *et al.*, 2020). Next to that, online education and distanced face-to-face interactions required more active outreach which has been suggested to pose a significant challenge to ASD individuals (Mumbardó-Adam *et al.*, 2021). EBPs for the *demand avoidant profile* seemed to decrease during the COVID-19 pandemic. Everyday demands from parents and teachers also decreased due to the national lockdown, which might have been particularly beneficial for this subgroup (Riese and Mukherjee, 2022). After lifting the lockdown, both subgroups shifted toward baseline level, showing no significant group difference post-lockdown. Taken together, although EBPs was higher for the *demand avoidant profile* in every day pre-pandemic life, EBPs of the *socially inflexible profile* was especially vulnerable during the COVID-19 pandemic in light of new social challenges. To summarize, while the exploratory nature of this study limits the ability to draw definite conclusions, the observed differences and trends support previously discussed but overlooked suggestions about ASD profiles.

Our findings imply valuable practical implications with suggestions for therapeutic interventions and support strategies for ASD individuals and caregivers. First, given that

EBPs were found to be stable over time, as well as serving a risk factor for affective disorders (Roza *et al.*, 2003), caregivers should offer early identification and intervention for children with elevated EBP. Early and sustained support is key to prevent elevated EPB levels and long-term mental health issues. Second, incorporating some of the beneficial routines from the pandemic, such as telehealth and part-time schooling, into everyday life can support emotional and behavioral well-being. Furthermore, it seems crucial to improve family quality time and routines by raising awareness within families and actively involving them in the therapeutic process. Our findings underline the importance of identifying a client's profile to focus therapeutic interventions on their specific challenges and strengths, particularly during a crisis like COVID-19 but also in general. The *socially inflexible profile* may need specific support with navigating social interactions, especially during disturbances like safety measures, and with managing increased family time. The *demand avoidant profile* may require tailored support to address everyday demands, including considering the potential benefits of reducing these demands even beyond the COVID-19 context.

There are some notable strengths to our study. First, this was the first COVID-19 study to consider three different time points, namely before, during and after a national lockdown. This has allowed us to study the effects of the ongoing pandemic and guaranteed the availability of pre-COVID-19 data, such as the BPM and SRS. Second, collecting data from three different mental health care institutions also poses a strength by increasing the external validity of our findings. We included participants from different institutions in Rotterdam and the surrounding area, representing the diversity of the ASD population as seen in clinical practice. Third, although strong diversity among the ASD population is well known (Lenroot and Yeung, 2013) and different ASD profiles have been suggested in previous research, this is one of the first studies to investigate this diversity. Developing different ASD profiles based upon an already validated questionnaire (SRS) allowed us to reach very high internal consistency.

Simultaneously, the findings of this study have to be considered in light of some limitations. First, due to the short duration of the lockdown phases, the time constraints on participant recruitment resulted in sample-related limitations. The comparably small number of participants reduces the generalizability of our results, particularly as self-selection bias might have led to the inclusion of families who coped relatively well during the COVID-19 pandemic. The small and homogeneous sample may have resulted in an underrepresentation of the socially inflexible profile, thereby limiting the statistical power for profile comparisons. The geographic and institutional specificity of the sample limits its ability to fully represent the diversity of experiences across varying cultural, socioeconomic and healthcare contexts. Second, RCI results strongly depend on measurement error and the cut-off for clinical change is statistically rather high. One should be aware of the high heterogeneity among the ASD population, when interpreting these individual differences based on RCI. Third, while our newly developed ASD profiles are grounded in exploratory analysis, further empirical and theoretical validation is needed to strengthen their justification.

Future research is needed to gain a comprehensive understanding of the long-term effects of the COVID-19 pandemic on EBPs in children and adolescents with ASD, possibly in longitudinal studies. EBPs was found to remain stable over time and has previously been found to predict mood disorders at later stages which makes it crucial to examine effective interventions and find possible protective factors. Moreover, given the promising trends in EBPs among individuals within the socially inflexible profile, and conversely, the potential vulnerability of those within the demand avoidant profile, further research is warranted to better understand differences between these two ASD profiles. Such research may inform the development of targeted interventions to support the mental health and well-being of children and youth, particularly those with ASD. Our newly created ASD profile scales

require further validation and improvement, possibly by including other questionnaire items than the SRS items. Also, in this case, a more longitudinal approach seems reasonable as both profiles showed promising differences prior to and during the pandemic and future research might offer valuable clinical implications.

## Conclusion

Our work provides an understanding for the impact that the COVID-19 pandemic has had on the emotional and behavioral functioning of children and adolescents with ASD. Taken together, ASD individuals may have managed the challenges of the pandemic better than expected with seemingly stable EBPs across the COVID-19 lockdown. Possible explanations are offered by supportive family context, general stability of EBPs and reduced overstimulation and social interactions. Finally, different ASD profiles seem to exhibit distinct strengths and weaknesses, leading to heterogeneity in regards to the reaction to the COVID-19 pandemic. Our findings urge to look beyond group level into nuances in ASD profiles in an attempt to adjust interventions and support unique ASD youth and family needs.

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*Ethics approval:* All procedures were performed in line with the principles of the Declaration of Helsinki. Approval for the study was granted by the local medical ethics committee (MEC 2020 0720).

*Consent to participate:* Informed consent was obtained from all individual participants.

*Author contributions:* All authors contributed to the study design. CB processed the data and conducted all the analyses. CB, FT, RVH, LPD drafted the first version of the manuscript. The clinical partners, AL, KV, WE, DB, helped in data collection and data management. All authors participated in editing the manuscript and approved the final manuscript.

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*Data, materials and/or code availability:* All materials, methods and syntaxes are available for sharing via open science framework. Quantitative and pseudonymized qualitative data can be shared under the conditions outlined in the Data Management Plan (Creative Commons license CC BYNC-SA 4.0 Attribution-NonCommercial-ShareAlike 4.0 International). Requests for sharing data can be addressed to the Principal Investigator.

## Note

1. Due to the missing consensus regarding identity-first or person-first language, a mix is used throughout this paper as proposed by Buijsman and colleagues (Buijsman *et al.*, 2022).

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## Author affiliations

Clemens Boy is based at Erasmus School of Social and Behavioural Sciences, Erasmus University Rotterdam, Rotterdam, The Netherlands.

Femke L. Truijens is based at the Erasmus School of Social and Behavioural Sciences, Erasmus University Rotterdam, Rotterdam, The Netherlands and the Rotterdam Autism Consortium (R.A.C.), Rotterdam, The Netherlands.

Anneke Louwse is based at Department of Child- and Adolescent Psychiatry and Psychology, Erasmus MC -Sophia, Rotterdam, The Netherlands and the Rotterdam Autism Consortium (R.A.C.), Rotterdam, The Netherlands.

Kirsten Visser is based at the Department of Youz Child-Adolescent Psychiatry, SARR Expert Centre for Autism, Parnassia Psych-Medical Centre, Rotterdam, The Netherlands and the Rotterdam Autism Consortium (R.A.C.), Rotterdam, The Netherlands.

Dennis Bastiaansen is based at the Department of Yulius Academie, Dordrecht, The Netherlands and the Rotterdam Autism Consortium (R.A.C.), Rotterdam, The Netherlands.

Wietske A. Ester is based at the Department of Youz Child-Adolescent Psychiatry, SARR Expert Centre for Autism, Parnassia Psych-Medical Centre, Rotterdam, The Netherlands; The Rotterdam Autism Consortium (R.A.C.), Rotterdam, The Netherlands; Department of Child- and Adolescent Psychiatry, Curium-LUMC, Leiden, The Netherlands and ParnassiaBavo Academie, The Hague, The Netherlands.

Elisabeth H.M. Van Rijen, Ruth Van der Hallen and Linda P. Dekker are all based at Erasmus School of Social and Behavioural Sciences, Erasmus University Rotterdam, Rotterdam, The Netherlands and the Rotterdam Autism Consortium (R.A.C.), Rotterdam, The Netherlands.

### Corresponding author

Linda P. Dekker can be contacted at: [l.p.dekker@essb.eur.nl](mailto:l.p.dekker@essb.eur.nl)

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