

## Research executed by Dr. Elena V. Syurina and Stephan van de Ven with support of Rosanne Verdegaal, Chantal Luijten and Lisan Kooijmans

### Introduction

Autism Spectrum Disorder is a complex neuro-developmental condition that has been getting increasing attention in the last decencies. There is an increasing need for new interventions that would help integration of children and adolescents with ASD and will contribute to the improvement of their quality of life. In 2017 researchers from the Vrije Universiteit Amsterdam have performed an initial scientific evaluation of the BB tool, developed by Stephan van de Ven. The research focused on the collection of experiences and opinions of Dutch health professionals and the parents with children with ASD, who implemented BB in the past. The research was performed under supervision of Dr. E.V. Syurina, Assistant professor Global Mental Health at the Athena Institute, VU, Amsterdam.

Four independent research lines were executed. Three of the data collection projects were focused on the inventory of experiences of the health professionals (psychologists, orthopedagogical workers, social workers and others) and one project compiled initial data on the parents experiences with BB. Each of the research branches will be described separately below.

### Experiences of health professionals

This branch of research consisted of addressing 3 research questions:

1. What are the initial thoughts of health professionals about BB?
2. What are the ways the health professionals currently apply BB in their daily practice?
3. What are the opinions of the health professionals about the Brain Blocks is explained and presented during the workshop?

#### 1. Opinions of the health professionals about the Brain Blocks.

The first explorative part of the study looked at the general opinions and beliefs of the health professionals about the BB (from here onwards called Study 1). The sample of 17 Dutch professionals (14 females and 3 males) included: 6 ambulatory counsellors, 3 coaches for people with ASD, 2 pedagogical workers, 2 system therapists, 2 supervisors at a living community, a psychologist and psycho-motoric therapist. All except one participant followed all three BB workshops that are currently offered in the Netherlands. One of the interviewees followed only workshops one and three. All participants had a varied experience with the BB: while 7 interviewed professionals have followed all the workshops in the last 12 months, 3 people participated in workshops in the period between 12 and 24 months and the remaining 5 followed the more than 24 months ago.

The outcomes of the study covered the following topics: the route how the professionals started using BB, opinions about strengths and limitations of the tool and the current use of BB in daily practice.

*Route to start using BB*

When talking about the reasons that brought people to the first BB workshop it is important to distinguish between the reasons to participate in the workshop and how people found out about the BB.

Most people found out about the BB either from their enthusiastic colleagues or, in case of one participant, from the client with Autism. The participants often noted a high level of enthusiasms of the ambassadors of BB and people who told them about the tool, which sparked their curiosity. Another important dissemination route for the BB was the internet (in particular Twitter). Some people have mentioned: "I saw it come by on Twitter some time. I went looking for it and it seemed interesting".

Among the most named reasons to investigate the BB by signing up to the first workshop were: the fact that other tools did not totally fulfil their needs, the appeal of a simple and highly visual tool, search for a more flexible and integrated tool; and the curiosity after enthusiastic recommendations from colleagues.

### *Opinions on the BB tool*

#### *Strengths*

It is important to state that all 17 participants were enthusiastic about the use of BB tool and were quite unanimous about its strengths: ease of comprehension, flexibility and contribution to destigmatisation. All participants agreed that the fact that BB is so visual and tactile (with the use of colors and blocks) is an undeniable benefit of this tool compared to the alternatives that are known to them. This is further strengthened by the fact that the tool aims to establish the same language for all stakeholders which facilitates the communication. "I find the visual aspect very strong...and everyone speaks the same language... that is very strong there is a lot of recognition from the children and the parents". Another strength highlighted in the interviews was the fact that BB does not use specialized terminology, but rather a common language that can easily be adapted depending on the situation and cognitive strengths of the child and family. Additionally it contributes to destigmatiation of Autism: "We do not talk about a disorder anymore because then it becomes a problem. We talk about a different brain, it works different for you".

#### *Improvement points*

The possible improvement points tackled two aspects: the application of the BB tools and more practical aspects of physical form of the tool.

Regarding the application of BB several aspects were noted. Interestingly, the most noted weakness of the BB was directly linked to one of its strengths: multiple individuals had difficulties when implementing BB due to the uncertainty of use. "I sometimes miss the translation to *What is next?*". It seems that the professionals do not have clarity about how to use the BB tool in the therapy setting, while these problems are not prevalent when talking about psychoeducative application. Next, the respondents noted that BB would benefit from a stronger ongoing link with the latest scientific advances. They suggested that as the research gets more and more insight into the underlying reasons for autism and precise pathologies, this should be reflected in the tool. Some missed the explanation of

the executive functioning and theory of mind aspects of BB. The last improvement point tackles the issue of BB being a tool for ASD alone. Several professionals suggested expanding the use to other neurodevelopmental disorders, i.e. ADHD.

When talking about physical form of the BB, the respondents noted two aspects: the size of the box (too large to carry around) and the variety of blocks being offered (preferred broader variety).

## 2. Current use of the BB tool

The current use of the BB tool was investigated in the study discussed above<sup>1</sup> as well as in the second explorative study, which used a mixed methods approach. This study used a questionnaire (n=164) and semi-structured interviews (n=14) to look into the daily use of the BB by varied health professionals. From here onwards called Study 2.

Within the realms of the current use of the BB several aspects were discussed: the application method/goal of the BB and the application target group.

### *Application method*

In general there are three application ways that were discussed during the interviews: psycho-education, communication and psychotherapy.

In the study 1, while all 17 respondents used BB for psychoeducative purposes, only 2 used it for this purpose alone. Four respondents predominantly used the tool for therapy and six professionals noted that psychoeducation and communication side of BB was the most useful for their daily practice.

Study 2 showed that a vast majority predominantly used the psycho-educative approach when offering BB (n=160, 97.6%). On the other hand, 36% of the respondents (n=59) admitted not using BB for treatment at all currently for different reasons (not enough experience, not enough confidence etc). The ways of implementation compared to those showed during the BB workshops varied: 81.7% of respondents (n=134) admitted that they adapt the implementation of BB depending on the situation (child's profile, family situation etc). However, a considerable number of professionals told that they use BB exactly in a way it is presented in a manual (n=63, 38.4%) and as showed at the workshops (n=60, 38.4%).

### *Target group*

The BB tool was used both for the children and adolescents with Autism and the representatives of their environment.

The application target group description varied between 2 executed studies. This shows the flexibility of the tool and breadth of application.

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<sup>1</sup> The sample of 17 Dutch professionals (14 females and 3 males) included: 6 ambulatory counsellors, 3 coaches for people with ASD, 2 pedagogical workers, 2 system therapists, 2 supervisors at a living community, a psychologist and psycho-motoric therapist.

Study 1. According to the respondents they mostly used the tool for children with ASD who were within normal IQ range, however, three applied BB to children with predominantly low intelligence. But this was mostly because of the profiles of the patients they saw in their practice. Most professionals (n=10) applied BB to children and adolescents under the age of 21, however six professionals worked both with children and adults and only one treated adults alone. According to the professionals the tool was used not only for patients with ASD alone, but also for those with other co-morbidities or disorders (ADHD, attachment disorder) and two of them stated that they use BB for various clients if they feel that they can benefit from a visual intervention. "Many clients that are very visual, they find [Brain Blocks] very pleasant".

Study 2. According to the distributed questionnaire, majority of respondents (n=123, 75%) used BB or children with average or higher intelligence levels and mostly in home setting (n=92, 56.1%).

The tool was not used for clients alone, but also for the representatives of their direct environment. The most common use was to assist the parents and other family members with understanding the person with ASD and create interventions that could help to strengthen their relationships. However, some professionals involved the parents only during the psycho-education part of the intervention and worked with the child alone afterwards: "They are not always present, it depends. Some [Parents] say it is just of him [child]". Others make a strong argument for involving the parents at all stages: " But sometimes there are children that have difficulties with coming up with examples. A parent can provide real life examples to clarify".

Among other stakeholders to benefit from BB the following were named: school, friends, partners (for adults), employers (for adults) and UWV (Dutch Employee Insurance Agency).

The importance of use of BB by both clients and environment was underlined in multiple interviews as it is important to give them all the same language to use and contribute to improved mutual understanding. "We make a language together, so that you understand what each of you talks about".

### Professionals' practical experiences with BB tool

The study 2 showed that a vast majority of participants like using BB and find it a useful tool for their practice. It was discovered that the more participants like the tool and more happy they are with the way they use it. Which suggests a learning and experiential curve for BB use. Based on their personal daily practice experiences 160 participants (97,6%) shared that they believe BB to help patients with autism. The results also suggest that the continuous practice of BB and increasing complexity of application of the tool is also significantly linked to the overall content with the tool.

### 3. Experiences with the workshops on BB

In the third study of the series we investigated: How intention of health professionals to use BB is influenced by attending the workshops? What are their strengths and limitations? This was a mixed methods study, which analyses the outcomes of the evaluation questionnaire distributed after the workshops and the semi-structured interviews with workshop participants. The data set consisted of 224 questionnaires (with close to equal distribution per workshop) and 11 semi-structured interviews.

In general the analysis of the questionnaire data showed that participants were satisfied with all three workshops, which is supported by high scores on questions about novelty of information, its perceived richness and applicability for practice (all grades above 3,5 on a 4-point scale). On the one hand, the respondents noted a broader use of more active learning methods in workshops 2 and 3 compared to workshop 1. On the other hand, they also wished for more passive learning moments linked to theoretical background in workshop 3. These results were also supported by the outcomes of the semi-structured interviews.

During the interview collection process attention was paid to the practical organization of the workshops: room for questions, use of video materials and role-play situation, group size and duration of the workshops. The respondents felt that there was sufficient room for asking the questions and clarification of certain aspects of the BB. But they would appreciate a more active approach to learning with trainers asking more questions to the participants and involving them in discussions. There was a strongly positive reaction to the presentation of the video materials and use of role-plays. It was noted that it could be beneficial to have video materials that would feature different professionals using the BB. And there was a general trend towards requesting more video materials to be available during the workshop. "I would advise ... to show more videos in which the reaction of children is showed. Videos not just showing ... handling these situations, but also other health professionals." Several respondents highlighted the benefits of making workshop 2 obligatory for those following workshop 1. "I think that everybody is obliged to attend the second workshop, everybody will have all information. Right now, people are just using the material self which can be nice. However, there is a greater chance the goal of the use of BB is not met. That should be a shame..." Regarding the duration of the workshops, respondents were content with current duration of the workshops, however it was highlighted that it could be beneficial to have a period of 2 to 6 months between each workshop to get the best out of it. "It would be nice to have about two to three months in between the first and second workshop... the two weeks I have had are too short to train with application of BB".

One recurrent suggestion regarding the workshop organization was a wish for introduction of the fourth workshop to discuss the overarching themes of all workshops, provide better link between practical application and theoretical background as well as provide ample opportunities to tackle possible difficulties in real life cases. The following is an example of the situation to be addressed in workshop 4: "How do I deal with the expectations of the client and client's parents when these expectations are different from your vision. A fourth person in a role-play who plays a parent would be a great exercise in a 4<sup>th</sup> workshop". Participants also noted that workshop 4 would be a good place to hear about other people's experience with BB application and mutual experiential enhancement.