



## “Mindfulness-based Programs for Families with Autism Spectrum Disorders”

Day: Thursday 12th July 2018      Time: 9:00 – 10:15 am      Track: Clinical Applications

Mindfulness-based programs could be beneficial for families living with a child with autism spectrum disorder (ASD). Children with ASD experience neurodevelopmental problems, social communication problems, and increased psychopathology, such as anxiety and behavior problems. Parents are known to experience increased stress levels, related to the large burden to raise a child with ASD and comorbid symptoms. Research shows that mindfulness-based programs could decrease psychopathology and stress in other populations, and recent studies imply that mindfulness is a feasible and promising approach for children with ASD and their parents. In this symposium we will present research from four teams of clinical scientists from different continents around the world, investigating mindfulness-based programs that are tailored for families with ASD. Within this specific clinical application of mindfulness, we will present a variety of study designs, including randomized controlled trials, a repeated measures study, and a qualitative study. Moreover, this symposium will discuss the application of mindfulness for families with ASD in different cultural contexts. The panel will include research on the combination of mindfulness-based practices with a well-established parenting program, and research on the combination of mindfulness training for children and teenagers with ASD with mindfulness training for their parents. Quantitative psychological and behavioral outcomes as well as qualitative data about the experiences of both children and their parents will be evaluated. Thereby, this panel will provide insights into the potential benefits of mindfulness-based programs for children and teenagers with ASD, and their parents.



## Symposium overview

**Presenter 1**     **Mette Elmoose** - MYmind-DK. Investigating the feasibility and effect of MYmind in a Danish context.

**Presenter 2**     **Daisy Dexing Zhang** - MYmind for Chinese adolescents with ASD and their parents: a pilot study

**Presenter 3**     **Anna Ridderinkhof** - MYmind for Autism Spectrum Disorder: A Qualitative Study of the Experiences of Children and Parents

**Presenter 4**     **Nirbhay Singh** - Component Analysis of Stepped Care Mindfulness-based Positive Behavior Support with Mothers of Children with Autism Spectrum Disorder: Randomized Controlled Trial

**Chair:**            ***Esther de Bruin***



## **MYmind-DK. Investigating the feasibility and effect of MYmind in a Danish context.**

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**Background:** High levels of distress and comorbid health difficulties have been reported for persons with autism spectrum disorder (ASD) and their parents. The development and investigation of interventions for persons with ASD is increasing, but there is still a need to expand the type and accessibility of interventions, and to increase the evidence base of these interventions. Especially when applying the interventions in different contexts.

**Objectives:** The study objectives are to investigate the feasibility of the MYmind program for adolescents with ASD and their parents in a Danish context and to investigate the effect of the program on individually specified areas of focus as well as on measures of stress and well-being.

**Methods:** 31 adolescents with ASD and 39 parents from 30 families have currently been enrolled with additional 6-8 families currently being recruited. Data was collected using questionnaires, pre- and, post-training, and 2 and 6 months follow-up. Further, continuous registrations were collected on individually specified areas of interest and general well-being. Information on both adolescent and parental distress and well-being were collected. Moreover, interviews were made with adolescents and parents focusing on their experience with the training.

**Results :** Of the enrolled participants 17 adolescents and their parents (55%) took part in more than 5 sessions. Four participants dropped out just before the training started (13%) and nine dropped out after participating in a few sessions (29%). This dropout was typically ascribed to especially the adolescent, but in some cases also to the parents declaring to be too stressed to attend the training. The preliminary results from the study will be presented focusing both on the feasibility of the training in a Danish context and the effect on adolescent and parental stress and well-being.

**Discussion and conclusion:** Challenges with recruitment and higher dropout rates than previously reported were experienced. The challenges often reflected adolescents struggling to find the energy necessary to participate in the current set-up of the training. This indicates a need to reconsider how best to anchor mindfulness training in a Danish context.



## **MYmind for Chinese adolescents with ASD and their parents: a pilot study**

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**Background and Objectives:** Autism spectrum disorder (ASD) is a lifelong condition associated with significant neurodevelopmental hurdles and behavioural problems. Recent evidence shows that mindfulness training for children with ASD combined with Mindful Parenting is a feasible and promising intervention to benefit both children with ASD and their parents. The objectives of this project are to improve social responsiveness and reduce problem behaviours of adolescents with ASD; and reduce parental stress and improve parenting style of their parents through a mindfulness training programme (MYmind for ASD).

**Methods:** Participants will include 32 adolescents aged 12 to 18 years who had doctor-diagnosed ASD and one of their parents (N=32) who agree to participate. Effectiveness of the mindfulness based intervention will be examined through a pilot randomized controlled trial using a waitlist control. Measures include Social Responsiveness Scale (SRS), the Child Behaviour Checklist (CBCL) and the Behavior Rating Inventory of Executive Function (BRIEF) for adolescents; and Parenting Stress Index (PSI), Parenting Scale (PS), the Interpersonal Mindfulness in Parenting (IM-P), WHO-5 Well-being Index (WHO-5), and the Rumination Response Scale (RRS) for parents. Assessments will be conducted before and after the intervention. Linear mixed models will be used to analyze the data with group, time and the interaction between the group and time treated as fixed effects while an unstructured covariance structure will be employed. Intention-to-treat principle will be applied. A two-sided P value of 0.05 or less will be considered as statistically significant.

**Results:** We had provided the mindfulness training to 16 families with ASD and the pilot is ongoing and expected to complete by February 2018 with results ready by April 2018.

**Discussion and Conclusion:** The project can provide evidence of the feasibility and potential effectiveness of mindfulness for ASD within the Chinese family context.



## **MYmind for Autism Spectrum Disorder: A Qualitative Study of the Experiences of Children and Parents**

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**Background and objectives:** Although children with autism spectrum disorder (ASD) are known to experience socio-emotional problems and their parents experience heightened distress, effective psychosocial interventions are sparse. Mindfulness-based programs are promising to benefit children with ASD and their parents. Mindfulness is primarily an internal experience, targeting the way people relate to their internal thoughts, feelings, bodily sensations, and action tendencies. Therefore, this study will use a qualitative approach to explore which processes lead to what outcomes from a mindfulness-based program, as perceived by children with ASD and their parents.

**Methods:** Participants were 11 children with ASD, aged 9 till 17 years, and 22 parents (mothers and fathers) that took part in the mindfulness-based program MYmind. MYmind consisted of nine weekly parallel sessions for children and parents of 1.5 h, and a booster session after two months. Interviews were conducted within six weeks after the booster session and lasted between 30 and 60 minutes. Children and parents were interviewed separately. The interviews were transcribed and incorporated into ATLAS.ti. Guidelines of grounded theory were followed to analyze the data.

**Results:** Main categories that emerged from the preliminary analyses are acknowledging feelings and thoughts, mindfulness in daily situations, increased calmness, and improved relating to the needs of the child. Several processes seem to lead to the experienced benefits. Participants described that acknowledging feelings or thoughts leads to choosing how to respond rather than responding automatically, which leads to responding calmly. Also, acknowledging their own feelings leads to acknowledging feelings of and towards others, which leads to constructive solutions in parent-child interactions. Furthermore, taking a moment for mindfulness leads to increased calmness, which helps to respond less emotionally, to improve school work, or to better fall asleep. Parents and children seem to describe the same constructs, with the parents presenting more depth and color in their explanations.

**Discussion and conclusion:** Children with ASD and their parents provided valuable insights into the experienced benefits following from MYmind and the processes of change underlying them. This study provides a participants' perspective on how mindfulness-based programs might work for children with ASD and their parents.



## **Component Analysis of Stepped Care Mindfulness-based Positive Behavior Support with Mothers of Children with Autism Spectrum Disorder: Randomized Controlled Trial**

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**Background and Objectives:** Parents of children with autism spectrum disorder (ASD) face added stress in their daily lives given the challenging behaviors of their children. While positive behavior support (PBS) has been the mainstay of interventions parents use to control the challenging behaviors of their children, implementing the PBS programs often adds to their stress. Mindfulness-based interventions have been used to decrease stress in caregivers in multiple contexts. Combining mindfulness practices with PBS (i.e., mindfulness-based positive behavior support; MBPBS) offers a synergistic approach to reducing parental stress and in controlling the challenging behaviors of the children. The objective of this study is to determine the component effects of MBPBS on the stress levels of the mothers and the challenging and compliance behaviors of their children with ASD.

**Methods:** In a three-arm randomized controlled trial, mothers were randomized into one of the following conditions: mindfulness-based (MB) practices, positive behavior support (PBS), or MBPBS. Outcome measures included self-reported ratings of maternal stress and objective measures of the children's behavior. Experimental and long-term followup outcome data will be presented.

**Results:** The results are being analyzed but very preliminary data analyses indicate that all three interventions were effective, but in different ways. The MB intervention was effective in reducing maternal stress, PBS was effective in reducing the children's challenging behaviors and in increasing compliance behaviors, and the MBPBS was effective in reducing maternal stress and the children's challenging behaviors and in increasing compliance behaviors.

**Discussion and Conclusion:** A dismantling of the MBPBS procedure may show the effects of each component on selected variables.