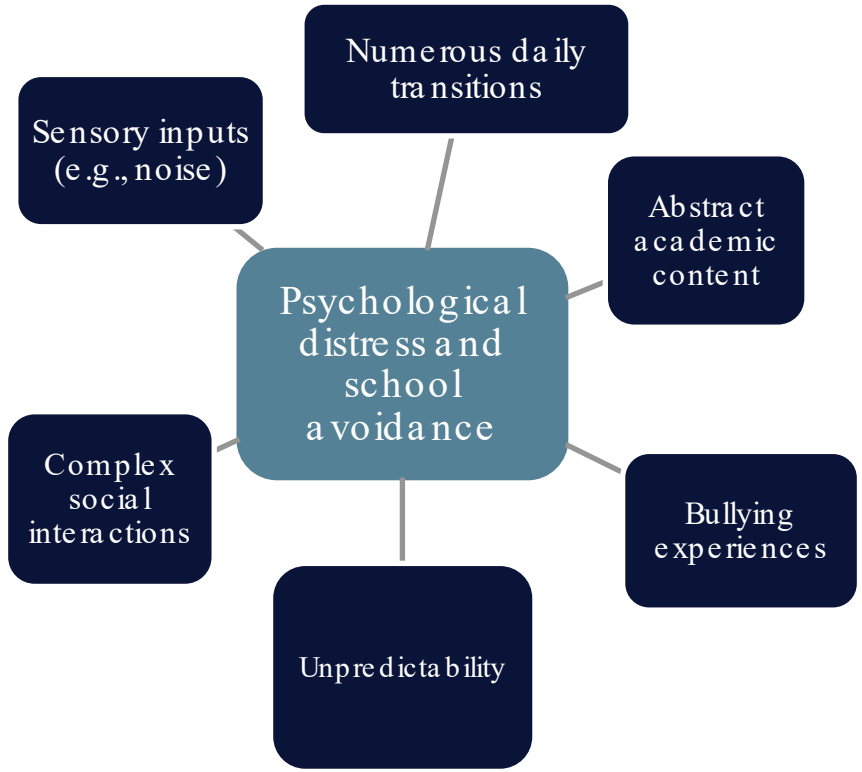
IS BACK2SCHOOL HELPFUL FOR YOUTHS WITH AUTISM SPECTRUM DISORDER? - SIX CASE STUDIES

The 2nd Nordic Conference on School Absenteeism
November 10, 2021

Sarah Jakobsen
MSc in Psychology and PhD fellow,
Aarhus University

WHY LOOK AT AUTISM AND SCHOOL ATTENDANCE PROBLEMS (SAPS)?

- Has received little attention in research
- The need for effective treatment is evident…
  - Greater risk of developing SAPs[1,2]
  - Cases are often complex and challenging with many actors and interrelated problems[3]
- …But core symptoms may challenge techniques used in traditional cognitive behavioral treatment (CBT) protocols [4,5]



[1] Munkhaugen et al. (2017), [2] Hansen & Højmose (2020), [3] Socialstyrelsen (2016), [4] Rapee (2003), [5] Reaven (2011)

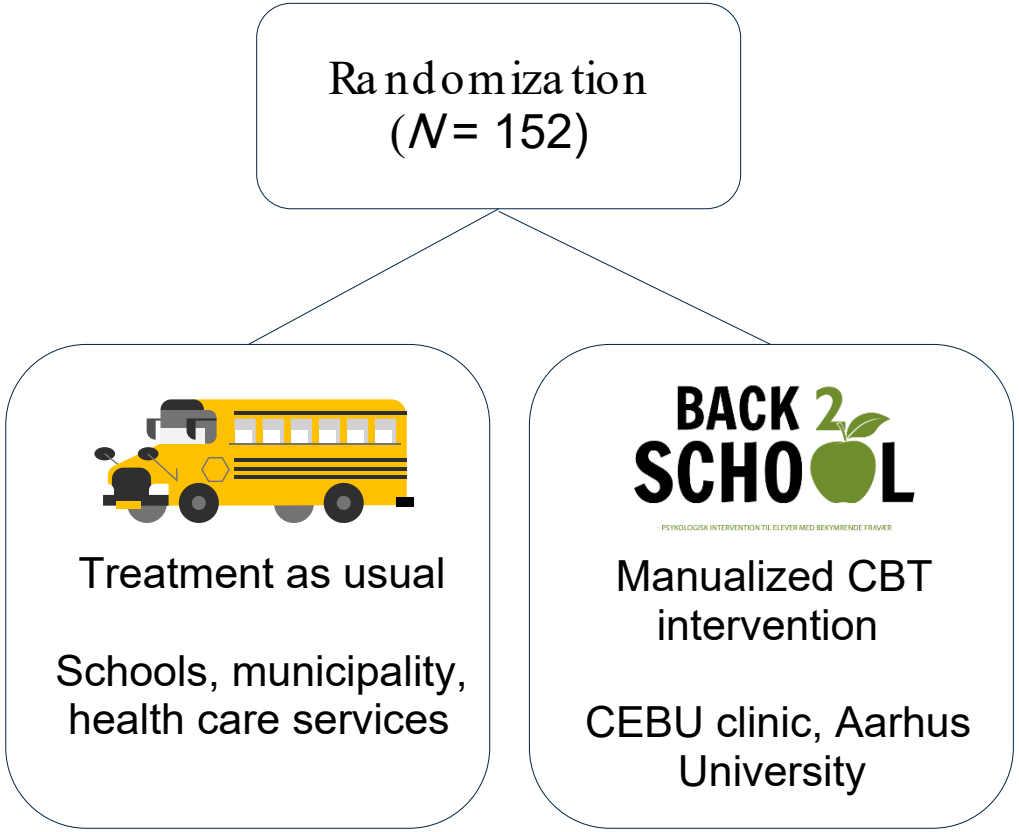
OBJECTIVES AND METHODS

Is B2S helpful for youths with autism and, if so, under what conditions and with which adaptations?

- Case study
  - Study aiming for rich descriptions and pragmatic insights
- Multiple and mixed data sources
  - Absence data
  - Standardized questionnaires (youth's psychological symptoms, experience of service)
  - Video recordings of the sessions
  - Clinical records and meeting minutes
- Description validated by the appointed therapist of each case

RESEARCH CONTEXT

- The cases are drawn from a randomized controlled trial comparing Back2School (B2S) with treatment as usual (TAU)
- Primary outcome: School absence
- Secondary outcome: Youths' psychological symptoms (e.g., anxiety, depression, behavioral problems)



ABOUT BACK2SCHOOL

BACK 2 SCHOOL
- PSYKOLOGISK INTERVENTION TIL ELEVER MED BEKYMRENDE FRAVÆR

- Manualized trans-diagnostic intervention for youths with SAPs
- Based on cognitive behavioral therapy (CBT) principles
- Modular intervention: Evidence-based strategies targeting specific problem-domains (e.g., anxiety) are organized into treatment modules
- Systemic approach involving parents, school and other professionals (parent sessions included)[6]

*the former manual consisted of 10 sessions

[6] Thastum et al. (2019)

THE CLIENTS AT INTAKE

Gender
6 males

Age
7-15 years
M= 11,7 years

Educational setting
2 enrolled in special education

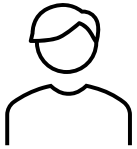
Autism
High functioning autism

Challenged by other diagnoses/ symptoms than their autism (e.g., attention problems)

Psychological symptoms
High scores (almost all of them in the clinical range) for measures of depression, anxiety, emotional and behavioral difficulties and impact

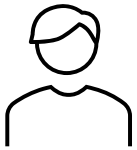
OUTCOME – GOOD RESPONSE

Before B2S



Adam

- 2-3 days of weekly absence
- Often insisted to have his mother with him in school
- Avoided specific situations in school
- Shy, cautious and perfectionistic appearance
- Sleep problems



Nils

- Sporadic absent over a 2-year period (1-2 days)
- Fully absent for 4 months, except a few hours of home instruction and attendance in a support program
- Diffuse somatic complaints
- Socially withdrawn

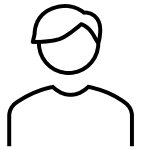
After B2S (3months follow up)

- Full time in school
- The mother's presence almost eliminated
- Sleep problems were reduced
- Appeared less affected by anxiety – less perfectionistic, was presenting to class, attending assembles and project days etc., which were avoided before

- 80 % in school – every day but not every lesson
- School and parents reported that Nils was more happy and comfortable being in school and doing better with peers
- Some anxiety symptoms remained, especially deviations from normal schedule
- Managed to attend school events, birthday parties etc.

OUTCOME – PARTLY GOOD RESPONSE

Before B2S

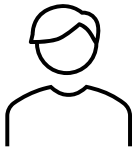


Max

- Severe absence for 1 year and currently fully absent
- Depressed mood
- Worried about being around many people in school and about own academic abilities
- Not motivated for getting back to school

After B2S (3months follow up)

- Transferred to special education between session 10 and booster session
- No attendance during sessions, but approx. 72 % absent at the new school and gradually increasing hours
- Reported greater motivation for school and academic self-confidence
- Mood was improved and more energetic



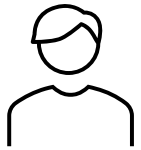
Felix

- Severe absence over a 1,5-year period
- Went to school 2 hours per day
- Primary individual and non-academic content during school hours
- Often insisted to have his mother with him in school
- Transition between home and school was specifically difficult

- Same absence rate
- The mother was still with him in school
- Started to request more school hours and social content
- More academic content
- The school reported fewer conflicts and outbursts
- No difficulties in the transition to school

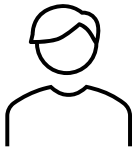
OUTCOME – LIMITED RESPONSE

Before B2S



Oscar

- 80-85 % absence over a year
- Worried about own appearance and about being perceived "odd" by others
- Described as demand avoidant
- Many conflicts at home



Marc

- Severe absence 2+ years
- Currently fully absent
- Socially isolated
- Described as demand avoidant
- Many conflicts at home
- Did not express motivation for school

After B2S (3months follow up)

- Fully absent from school but receiving 4,5 hours of weekly home instruction
- Parents reported increasing social isolation and poorer mental well-being due to the situation
- Conflict level at home were unchanged if not worse
- Referred to special education (still awaiting)
- Awaited getting started with other municipal support programs

- 90% absent (reduced schedule)
- Did not express motivation for school
- High conflict level at home
- Still socially isolated
- Doing well with a support person assigned during B2S
- The family were about to get associated with a psychologist

OUTCOMES – BRIEF SUMMARY

- Only a few significant improvements on the psychological symptom measures – however, trends were observed
  - Depressive symptoms decreased in 4/6 cases
- Many qualitative improvements
- Overall better outcomes in cases with
  - Younger age
  - Less severe SAPs → importance of early intervention
  - When families were engaged and motivated
  - When the collaboration between parents and youth *and* home and school was good
  - When the school placement was "right"

ADAPTATIONSTHATWORKED

- **Reducing the client's participation in sessions**
  - The client participates in 15 minutes and is allowed to sit with his iPad
  - The client stays at his room and is brought out for decisions/ initiatives that concerns himself
  - More sessions are turned into parent sessions
  - Providing time-out possibilities such as a red stop card

- **Provision of external structure and preparation**
  - The client receives a message or picture describing the agenda
  - Using Time-Timer to help focus
  - Visual agenda with checkmarks for overview

ADAPTATIONSTHATWORKED

- **Incorporation of concrete and visual elements**
  - Using the Emotion Thermometer (e.g., floor version)
  - Using figures from Cool Kids ASD[7]
  - Visualizing stepladder by coloring schedule (lessons with distinct colors)

- **Focused motivation work and reward systems**
  - The client receives stickers when completing a task
  - The client receives candy at the end of each session
  - Making use of the client's preoccupied interest(s)

[7] Kilburn et al. (2018)

ADAPTATIONSTHATWORKED

- **Provision of concrete tools – making the options predictable and clear**
  - A step-by-step "manual" for getting out of the car in the morning
  - A structured overview in case of sickness and other somatic complaints – what are the client's options and privileges? (e.g., screen time)
  - Simplifying stepladders by working with one step at a time – the remaining steps are covered to not overwhelm the client

- **Flexibility regarding treatment length and location**
  - In 2 cases were extraordinarily extended
  - Many sessions were moved to the family's home

CASES WITH LIMITED RESPONSE

- **Therapeutic relationship/working alliance**
  - Marc appeared very hard to reach and his motivation for B2S was doubtful (e.g., did not go to the clinic, answered "no"/"I don't know")
  - It was difficult to find solutions that were motivating for Oscar and challenge his fears. He later wrote *"I did not feel fully listened to"*
- **Lack of insight to/understanding of own difficulties**
- **Collaboration and communication between youth and parents**
  - Described as demand avoidant → difficult to engage in homework and implement agreements
- **Parents were "tired" and slightly despondent**

CASES WITH LIMITED RESPONSE

- **Parents requested autism specific knowledge and expertise**
  - *"It was more about our boy's difficulties rather than the program"*
  - *"The therapists were highly professional and emphatic but […] did not posses the specialized knowledge about our son's difficulties, which is crucial. There should be therapists who are able to work targeted on this kind of problems and with the necessary expertise and experience"*
  - *"The problem is that the difficulties are very complex and you feel like it is a box. Somebody says 'you should do this and that' but it may not be what we need"*
  - Answering what could be improved, one parent wrote *"more sessions focusing on the child and more psychoeducation on autism"*

SUMMING UP AND FINAL THOUGHTS

- B2S and the CBT principles seem helpful for youths with autism as long as the premises are accepted (e.g., homework, exposure)
- Maintenance of engagement and motivation, a good collaboration between parents and youth and insight into/acceptance of own difficulties seem to be important to succeed with this
  - But we do not know the severity of their autism symptoms
- Courses may be more time-consuming and demand flexibility and creativity from therapists
  - Some authors recommend extending CBT[8]
- Autism-friendly adaptations are recommended
- As the manual does not (yet) include autism specific tools, it will rely on the therapist's knowledge and skills

[8] Beebe & Risi (2003)

SUMMING UP AND FINAL THOUGHTS

- How should we evaluate effect and outcome within this population?
  - Small improvements might represent large steps
  - Is getting 100 % back to school a realistic goal?
- Standardized questionnaires may not be a good tool for measuring change within this population
  - Core symptoms are argued to overlap with anxiety symptoms[9]

[9] Sukhudolsky et al. (2013)

THANK YOU FOR YOUR ATTENTION!

Feel free to contact me

Sarahjak@psy.au.dk

Follow the Back2School program

https://psy.au.dk/cebu/om-vores-forskning/forskningsprojekter/back2school/

Sign up for CEBU's newsletter

https://psy.au.dk/cebu/nyhedsbrev

DEPARTMENT OF PSYCHOLOGY
AND BEHAVIOURAL SCIENCES
AARHUS UNIVERSITY

REFERENCES

[1] Munkhaugen, E. K., Gjevik, E., Pripp, A. H., Sponheim, E., & Diseth, T. H. (2017). School refusal behaviour: Are children and adolescents with autism spectrum disorder at a higher risk? *Research in Autism Spectrum Disorders*, 41-42, 31-38

[2] Hansen, M. F. & Højmose, G. L. (2020). Skolevægring hos børn og unge med autismespektrumforstyrrelser In: Andersen, M. J. et al (Eds). *Skolens fraværende børn – Årsager og indsatser.* Frederikshavn: Dafolo A/S

[3] Socialstyrelsen (2016). Børn med autisme og skolevægring. Retrieved from: file:///C:/Users/au512178/Downloads/Autisme - skolev%C3%A6gring_Socialstyrelsen%20(1).pdf

[4] Rapee, R. M. (2003). The influence of comorbidity on treatment outcome for children and adolescents with anxiety disorders. *Behaviour Research and Therapy, 41(1)*, 105–112

[5] Reaven, J. (2011). The treatment of anxiety symptoms in youth with high-functioning autism spectrum disorders: Developmental considerations for parents. *Brain Research*, 1380, 255-263

REFERENCES

[6] Thastum, M., Johnsen, D. B., Silverman, W. K., Jeppesen, P., Heyne, D. A., and Lomholt, J. J. (2019). The Back2School modular cognitive behavioral intervention for youths with problematic school absenteeism: study protocol for a randomized controlled trial. *Trials* 20:29

[7] Kilburn, T.R., Sørensen, M.J., Thastum, M. et al. (2018). Rationale and design of cognitive behavioral therapy for anxiety disorders in children with autism spectrum disorder: a study protocol of a randomized controlled trial. *Trials,* 19, 210

[8] Beebe, D. W., & Risi, S. (2003). Treatment of adolescents and young adults with high-functioning autism or Asperger syndrome. In M. A. Reinecke, F. M. Dattilio, & A. Freeman (Eds.), *Cognitive therapy with children and adolescents: A casebook for clinical practice* (pp. 369–401). The Guilford Press

[9] Sukhodolsky, D. G., Bloch, M. H., Panza, K. E., & Reichow, B. (2013). Cognitive-behavioral therapy for anxiety in children with high-functioning autism: A meta-analysis. *Pediatrics*, 132(5), e1341-e1350