

ACT for the psychological well-being of mothers raising a child diagnosed with an autism spectrum disorder

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Educational Objectives

- ✓ To give a short summary on research we have done on ACT in group-format.
- ✓ And the main objective is to give you ideas about how to set up a study to investigate effects of ACT for parents that has children with special needs, like autism, ADHD or chronic illnesses.



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Studies we have done on a manualized group-format of ACT in Sweden

- ✓ These studies are made on a group-format close to Frank Bond et als "ACT at work".
- ✓ Most of them are randomized, controlled trials (RCTs).
- ✓ Interesting in this context because this is the intervention used for the parents to children with autism.



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What is already done on ACT-groups?

- Summary of studies

Summary: 10 studies completed, 6 ongoing on right. Done:

1. RCT on 230 upper-secondary students, 2004 & 2006 (Livheim 2004, Jacobson & Wellin, in preparation)
2. RCT, ACT for stressed teachers, 2007 (Altbo & Nordin)
3. ACT for youth at alcohol clinic & BUP 2008 (Stavenow)
4. RCT on 106 social workers 2009 (Brinkborg et al, published 2011)
5. RCT for 32 screened 14-16 year olds in school (submitted 2012, F. Livheim, L. Hayes et al)

What is already done on ACT-groups?

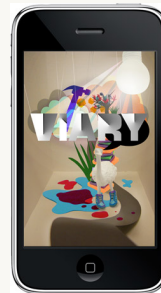
- Summary of studies

Summary: 10 studies completed, 6 ongoing on right. Done:

6. RCT for 24 screened 14-16 year olds in school (Biörklund & Wall 2010)
7. Tested in large company (Andemark & Rasmussen 2011)
8. RCT for 54 stressed teachers (Hydman & Larsson 2010)
9. Pilot study for parents of children with severe autism (Holmberg-Bergman & Lappalainen)
10. RCT for 113 student-nurses at Karolinska Institute (Djordjevic, Frögéli et al, in preparation)

Tested ACT via Iphone

Now revised and tweaked more as behavioural activation and follow up homework (www.hoastoolshop.com)



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Going on right now...

Ongoing:

1. National Institute of Public Health replicates the school study from 2004 & 2006
2. Being tested in Child and Adolescent Psychiatry (slightly revised version)
3. Being tested in the National Board of Institutional care (slightly revised version)
4. Tested by the University of Linköping for chronic pain.
5. Being tested in primary care as 1st-line psychiatry.
6. More studies are planned (Denmark? Finland? etc...)



And now...

ACT for the psychological well-being of mothers raising a child diagnosed with an autism spectrum disorder

Authors: Tiina Holmberg Bergman, Raimo Lappalainen & Fredrik Livheim



Background

- ✓ Autism Spectrum Disorders (ASDs) has increased remarkably (1/10 000 year 1980 to 1/100 children now, Baron-Cohen, 2008)
- ✓ Parenting a child with an autism diagnoses is a great challenge to parents. Several studies indicate very high stress levels and high rates of depression (Tobing, 2005; Estes et al., Tomanik, Harris & Hawkins, 2004; Mungo et al., 2007; Baker-Ericzén & Brookman-Frazee, 2005).
- ✓ Many children with ASD do not spontaneously share emotions or activities with their parents, or seek them for consolation (Zander, 2005, Norton & Drew 1994), this type of "rejection" can be hard and also lead to parents questioning their skills as parents (Schieve et al. 2007, Ohlsson, 2008).



Background

- ✓ ACT has proved to be effective for parents to children with Autism Spectrum Disorders, this was via a 2 day workshop (Blackledge & Hayes 2006)
- ✓ Parents with greater mindfulness skills bring compassion and nonjudgmental acceptance to their parenting situations (Duncan, Douglas & Greenberg, 2009).



Objectives

- ✓ The purpose of this study is to find out whether a 4 session (total of 14-hour) ACT group has a positive effect on the psychological well-being of mothers raising a child diagnosed with an Autism Spectrum Disorder
- ✓ Would ACT lead to?:
 - a) increase in psychological flexibility
 - b) greater mindfulness skills
 - c) decline in eventual depression
 - d) increase in the quality of life



Methods

Recruitment:

- ✓ A letter of invitation to participate in an ACT group was sent to 235 mothers, who had children with ASD that had been in treatment at the Stockholm Autism centre and had a child born during 2004-2005.
- ✓ 24 mothers were interested in participating.
- ✓ Those were Randomized to ACT = 12, to waitlist = 12



Intervention:

THEMES	GOALS
1. Stress and language	To understand the effects of stress To understand the role of rule governed behavior and language in suffering To explore the struggle and control aspects
2. Life compass	Identify core values Explore barriers
3. Barriers and flexibility	To understand that it is the process that matters To find the observing self To be mindful To accept feelings, thoughts, and situations Turn down the autopilot To decenterize oneself
4. Empathy and committed action	To forgive, have empathy and to be together To learn to say "yes" and "no"

- ✓ 4 sessions á 3 hours, based on Livheims protocol "ACT to cope with stress and increase health".
- ✓ Delivered by group leaders that got 4 days of training.
- ✓ CD for mindfulness (available in English, Spanish, Arabic & Swedish)



Outcome measures

- ✓ AAQ-II (Acceptance Action Questionnaire)
- ✓ MAAS (The Mindfulness Awareness Attention Scale)
- ✓ BDI (Becks Depression Inventory)
- ✓ QOLI (Quality of Life Inventory)
- ✓ Feedback form for consumer satisfaction



Results

- ✓ Results based on analyses of 9 ACT participants (9 out of 13 dropped out in control).
- ✓ Assessments before, after and 3 month follow up



Results at 3 month follow up

- ✓ AAQ-II Yes, significantly improved ($p < 0.05$)
- ✓ MAAS Yes, significantly improved ($p < 0.05$)
- ✓ BDI Yes, significantly improved ($p < 0.05$). 66% depressed before intervention, 33% depressed after.
- ✓ QOLI Getting better, but not statistically significant.
- ✓ Feedback form, consumer satisfaction Yes, 100% satisfied



Results: Consumer satisfaction

Question: "- Has the ACT intervention had an effect on your relationship to your child?"

- ✓ *Through that I now better accept my feelings, I am able to be more mindful and really there in the moment with my child. I have more patience.*
- ✓ *I have got new skills that help me to relate to all this shit and my own bad consciousness. I have learned to relate to my thoughts in a new way.*
- ✓ *I now see my child as what he is, an individual, not just the diagnosis.*
- ✓ *I have done good progress in accepting things and situations as they are. I see my child's positive characteristics now- and they are so many!*



Results: Consumer satisfaction

Question: "- If you were to recommend this ACT course to other parents, why would that be?"

- ✓ *All the mothers- with and without children with diagnoses should learn what ACT is all about. Even this mindfulness is very important to everybody. It gives a fantastic tool for one's positive development, and is a good thought awakener. One gets a sort of calm and insight.*
- ✓ *I have much to say on this, would love to do it again, with more time in hands. A super course! Thank you!*
- ✓ *I don't anymore want to change everything all the time. I have become better at accepting things as they are. I am more mindful.*



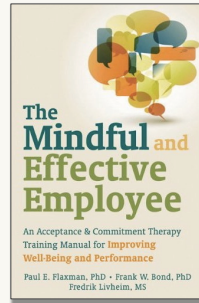
Conclusion and suggestions

- ✓ The ACT-intervention worked well in this pilot-trial and support earlier studies (Hayes & Blackledge 2006).
- ✓ ACT a valuable “add on” to “traditional” Parent management Training (PMT).
- ✓ It is a challenge to involve fathers, try harder with this!
- ✓ Future intervention could also focus on depression (besides stress and life in large).
- ✓ Worth testing in larger randomized, controlled trials.



The Mindful and Effective Employee:

- An Acceptance and Commitment Therapy Training Manual for Improving Well-Being and Performance



By: Paul Flaxman,
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New Harbinger

Thank you!

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