

# Hearing young children's perspectives on life with a parent with bipolar disorder using the In My Shoes interview

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Presenter: David Glasgow



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# Young children's experiences of living with a parent with bipolar disorder: Understanding the child's perspective

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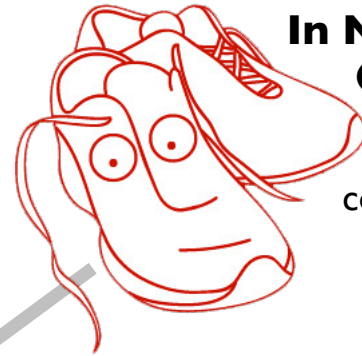
<sup>4</sup>The University of Manchester, UK

# In My Shoes system

- In My Shoes is a computer/tablet based toolkit for child interview and assessment
- Developed from analysis of children's representations/drawings
- Elicits accounts of experiences, emotions, thoughts, settings and relationships
- Evaluated in many contexts & with wide age range



# In My Shoes system



## In My Shoes (IMS) (1993 → present)

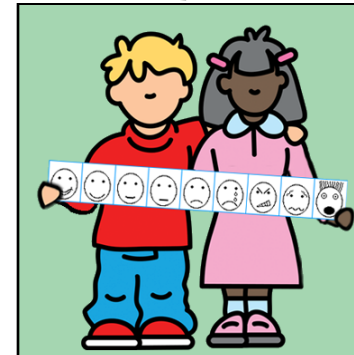
- a comprehensive  
communication toolkit-  
(Mac OS X & Windows)



### This Much! (2013)



### Backdrop (2014)



### This Feeling (2015)

IMS inspired apps for iPad, Windows tablets Mac OS and Windows

*An Interactive Visual Analogue Scale (VAS):*

- Establish capacity
- Express & prioritise goals/ preferences
- Evaluate relationships
- Quantify symptoms, wishes & preferences

*A Draw-&-Tell tool:*

- Build rapport
- Enhance communication
- Establish capacity
- Scaffold narrative
- Record wishes and fears
- Describe experiences

*A feelings (emotions & sensations tool)*

- Locate & explore sensations (inc. pain)
- Attribute causes to injury, (including perpetrator)

Based on the drawings and extensive pilot studies developed & refined standardised symbols of:

- Sensations, especially Pain
- Feelings (i.e emotions)
- People
- Places
- Thought
- Speech
- Commentary/messages/narrative
- Degree/intensity/comparison

These have all the benefits of drawn symbols & toys, but remove vast majority of task demands and ambiguity of them

# Attention & interaction with IMS



# Animated or video Guides:

- Structure and standardise conversation
- Enhance collaborative interaction
- Offer cultural and/or linguistic localisation
- Improve accessibility to children with a disability



English



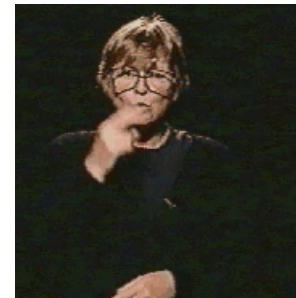
Swedish



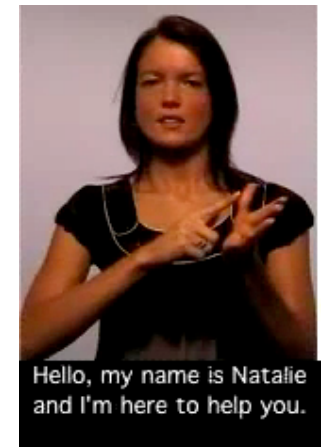
Black English woman



Spanish



Sign Supported  
English

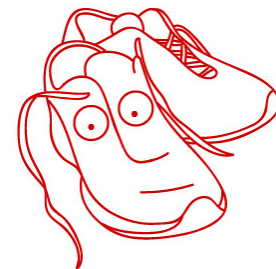


British Sign  
Language

(Also Norwegian & Turkish)



The Swedish studies:  
**VALIDITY OF CHILDREN'S  
ACCOUNTS USING IN MY SHOES**





Child Abuse & Neglect  
58 160-172 (2016)



UPPSALA  
UNIVERSITET

Child Care Health and  
Development  
47 42(1) 87-89 (2015)

# Two recent publications on In My Shoes



Contents lists available at [ScienceDirect](#)

Child Abuse & Neglect



Research article

In My Shoes – Validation of a computer assisted approach  
for interviewing children



Karin Fångström<sup>a,\*</sup>, Pär Bokström<sup>a</sup>, Anton Dahlberg<sup>a</sup>, Rachel Calam<sup>b</sup>,  
Steven Lucas<sup>a</sup>, Anna Sarkadi<sup>a</sup>

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Brunswick Street, Manchester M13 9PL, United Kingdom

Child: care, health and development

Original Article

doi:10.1111/cch.12293

**'I felt a little bubbly in my tummy': eliciting pre-schoolers' accounts of their health visit using a computer-assisted interview method**

P. Bokström,\* K. Fångström,\* R. Calam,† S. Lucas\* and A. Sarkadi\*

## Fangstrom, Bokstrom, Sarkardi, Lucas, Dahlberg, Calam et al

- Series of studies in Uppsala, Sweden looking at validity and properties of IMS
- Young children attending annual routine health centre visit
- All the visit activities, people and interactions video recorded, eg nurse giving injection, signs of the child's emotional states
- Children interviewed using IMS or a standard forensic interview procedure

## Sweden: Methods

Children aged 4–5 years were interviewed 2–5 weeks after a video-recorded Child Health Centre visit.

Randomised to IMS or “gold standard” forensic interview (FI) procedure.

**Feasibility:** qualitative analysis of IMS-interviews ( $n=23$ ).

**Validity:** compared accurate and complete statements elicited by IMS and FI ( $n=54$ ).

**Suitability:** analysed change in verbal and nonverbal responsiveness during the interview by inhibition and interview condition ( $n=60$ ).



# Feasibility

*"I felt a little bubbly  
in my tummy"*

All children gave accounts about  
their subjective experiences.

96 % of the children actively made  
use of and interacted with IMS.



# Validity

The IMS interviews generated  
equally high accuracy as  
FI ( $\beta = -0.02$ ,  $p = .682$ ).

Further, the IMS interviews yielded  
more complete statements about  
people present at the visit  
( $\beta = 0.11$ ,  $p = .030$ )



# Suitability

Quieter, more inhibited children interviewed with IMS showed a greater increase in verbal responsiveness compared to when interviewed with FI,  $F(1, 55) = 6.28, p = .015$ .

In uninhibited children, the interview method did not affect responsiveness.



# **PARENTING AND PARENTAL SERIOUS MENTAL ILLNESS**

# Parenting and parental mental health

- Adult and child services are usually separate
- Children's needs often go unrecognised
- Some research on parenting and depression, particularly postpartum, but rarely bipolar disorder or schizophrenia/psychosis



# Parenting and serious mental illness

- Large scale HTA commissioned systematic review on quality of life
- High quality research on enhancing parenting skills in families with a parent with bipolar disorder or schizophrenia/psychosis is rare (Bee et al 2014)



**The clinical effectiveness, cost-effectiveness and acceptability of community-based interventions aimed at improving or maintaining quality of life in children of parents with serious mental illness: a systematic review**

*Health Technology Assessment, No. 18.8*

Penny Bee, Peter Bower, Sarah Byford, Rachel Churchill, Rachel Calam, Paul Stallard, Steven Pryjmachuk, Kathryn Berzins, Maria Cary, Ming Wan, and Kathryn Abel.

# Children are often overlooked

- Research shows older children and young people living with parents with SMI have a lot to say; many children make significant adaptations and may be young carers (Bee et al)
- How can we best hear the views of very young children?

# Children's experiences of living with a parent with bipolar disorder

- Qualitative interviews with children aged 4-10 using the “In My Shoes “ computer-assisted interview
- Thematic analysis

Backer et al *Psychology and Psychotherapy: Theory, Research and Practice* (2016)

- Purposive sampling to recruit eight parents with bipolar disorder via a UK user-led bipolar disorder organisation through quarterly publication sent to all group members
- Six parents agreed, 10 children overall
- Child assent and parental consent was required for participation
- The researcher did not mention the parent's mental health or bipolar unless the child did

# *Child's Perception of Parents*

- *“Bipolar” Parent.* All children were able to describe their parent and the symptoms of bipolar, whether they knew about the illness or not
- Children of all ages used a variety of terms to describe their parent: *depressed, sad, happy, giddy, irritable, angry, worried, stressed, “funny face” and “naughty”*

# *“Well” Parent*

- Children in two parent families often described their perception of the parent without bipolar and their role within the family

*“Erm freefalling. Dad’s not a care in the world he’s, he enjoys what’s happening now and doesn’t worry about the future which is what me and mummy do.”*

# *“Well” Parent*

- Having a supportive “well” parent appeared to have a “buffering” effect on children and enabled them to cope with the “bipolar” parent’s symptoms in a more manageable way
- Having a consistent parent provided routine and predictability alongside an otherwise “unpredictable illness”.
- Often the “well” parent was more prominent in the child’s life

# *Knowledge and Awareness of Bipolar Disorder*

- *Communication About Illness:* All of the children above 7 years discussed hearing about their parent's bipolar from their parent
- One child discussed how his father only talked to him about his bipolar when he became worried that the child had bipolar too:

*"Well erm he thought I had it. Cos I was getting more and more, I was having more and more things to do with Bipolar and he's told me that I might have it. And that's when he told me about what it does."*



*Description of Illness.* Children's knowledge and awareness of their parent's bipolar disorder often depended on the child's age. Five of the older children (aged 7 to 10), knew that their parent had a mental illness called "bipolar".

- “When she’s unwell she gets she sleeps for the whole day...and then she gets more sleep at night” (Connor, aged 6)

# *Managing Family Life With a 'Bipolar' Parent*

- *Emotional Effects on Child.* Children described a variety of emotions they experienced as a result of family life, and many were in direct response to their parent with bipolar. The two prominent emotions were “sad” and “anger”. Over half of the children expressed sadness that their parent was “ill” or “unwell” and described feeling upset

- *'Independent' Child*: Older children (aged 7 to 10) discussed doing tasks independently in the absence of their parent when they were either in bed or not feeling well:  
*"I go I go downstairs, play for a little bit, decide when I have my breakfast, make the breakfast. If I want some more I just make as much as I like and when I've done that I normally wait until daddy's down, then most of the time playing."*
- The oldest child referred to looking after their mum  
*"I feel happy because I like helping her, so and I help her like make things and make my own tea, and if she wants something I'll go fetch from the shop, I'll go and fetch it."*

# Main findings

- Children of all ages had some knowledge and understanding of their parent's illness
- Both positive and negative experiences were described
- Four year old children could discuss their parent's mood and behaviour

- Children older than seven could reflect about the impact on themselves both emotionally and practically
- Older children were better at making sense of their parent's illness and its impact, rather than seeing it as their fault

- The findings represent an important step in examining directly the experiences of young children whose parents have bipolar disorder
- Additional research into children's perspectives and what support they think they and their family would benefit from would enhance the development of appropriate services and interventions

# Conclusions

- IMS provides a way of helping young children talk about their experience of living in a family with a parent with a serious mental illness
- Even very young children had awareness and expressed opinions on what is needed
- In separate, quantitative studies, IMS show good validity
- We should implement new methods to enable children's authentic voices to inform planning and services





# Links

[In My Shoes Website](#)

<http://bit.ly/1vdNkXi>

[Child & Family Training  
Communication & Assessment Apps](#)

<http://bit.ly/1PDxsXx>