INTERTWINING TO FIT IN: A GROUNDED THEORY STUDY OF CAREGIVERS WITH SCHOOL-AGED CHILDREN WITH FASD

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Learning Objectives

• Understand parents’ strategies to help their school-aged children with FASD succeed in the school system

• Identify conditions that influence the ways parents of school-aged children with FASD manage their children’s schooling

• Appreciate the effects of managing their children’s schooling on parents’ self-image

• Implications
Background to Research Question

- Primary and secondary disabilities significantly affect children’s day-to-day functioning in school (Burd, Cotsonas-Hassler, Martsolf, & Kerbeshian, 2003; Streissguth et al., 1997; Timler, Olswang, & Coggins, 2005)

- Secondary disabilities are difficult to prevent (e.g., Chudley et al., 2005; Ryan & Ferguson, 2006a)

- Limitations to studies (e.g., Clark, Hughes, & Jaswal, 2010; Duquette & Stodel, 2005; Duquette et al., 2006, 2007; Ryan & Ferguson, 2006a, 2006b)

- Missing information: Caregivers’ perspectives about managing schooling for school-aged children with FASD
Research Design and Questions

• Qualitative design

• Research Questions
  – How do caregivers of school-aged children with FASD manage their children’s schooling?
  • How do caregivers act as they try to manage their children’s schooling?
  • What contextual factors affect caregivers’ efforts to manage?
  • How do contextual factors affect primary caregivers’ efforts to manage?
Sample

• 17 caregivers, purposively and theoretically sampled
  - 6 biological mothers, 1 biological father, 1 step-mother (who was a biological mother of another child), 2 grandmothers, 5 adoptive mothers, and 2 foster mothers
  - 11/17 participants graduated from secondary school
  - 11 participants were single
  - 1 participant was employed full-time; 6 were employed part-time; 7 were not employed outside the home; 3 participants were part-time students
  - 5 participants indicated that they were receiving “welfare,” “income assistance,” or “disability payments;” 4 participants accessed the food bank
Orchestrating Schooling

Tactics:
- Being on stand-by
- Pitbulling
- Cultivating connections
- Anticipating difficulties

Re-engaging
- Advocating and Educating
- Changing Settings
Conditions Influence Tactics

E.g., Key Workers
...she knows and then she explains it to me later, or right there. And yeah, so I do find that it’s better to have somebody there with me...

E.g., Knowledge of FASD
Things that people take for granted, uniformity of language, was really important. Do you call that “dress up area” or is that “play area”? Do you call that “the toilet” or do you call that “the bathroom”? Things like that could throw him off.

E.g., Open Door Policies
I almost made sure I made friends with the teachers... They had an understanding of what [my] child had been through and what limitations they had so that they could kind of work with it, so they wouldn’t criticize... over criticize or have expectations that were ridiculously high...

Tactics Influence Self-Image

But then I think that’s when the principal finally went, “okay, wait a second. She’s not just a mom with a spoiled kid that misbehaves.” So now I’m not the big bad birth mom that’s causing the problem, I’m the big bad birth mom that’s trying...
Conditions and Tactics Contribute to Critical Junctures

• Hitting Rock Bottom
  So as the years went by, the difference between my daughter and the in-group just got stronger and stronger and more set. ... she had an opportunity to go and play and jump on the trampoline of one of the children of the in-group, who lives just next door. And I noticed that she wasn’t allowed on the trampoline. And then when the movie started... they would not let her sit with them (crying): And that’s after three years of putting it [the goal of social integration] on the IEP, to make any kind of integration meaningful. And so it was a watershed moment (17.1, lines 331-362).

• Islands of Calm
  So I just mean success in terms of that she was able to stay in school, to have some successful days where there wasn’t high levels of frustration or anxiety that lead to, you know, behaviours in the end. And that she actually liked going to school. To me, that’s the better measuring stick than anything, is the fact that she would get up in the morning and be happy and want to go to school (16.1, lines 381-390).
Keeping Up Appearances

Recognition as “good” parent
• intertwined with academic and social success and happiness for children
• a sense of self-actualization or accomplishment beyond the parental identity

Tactics:
• Sharing Information
• Reframing
• Redefining Self

Conditions
Because the principal that was there [said], “the kids got dirty clothes.” But listen ... there was only one washer, two dryers for eighteen apartments. Now when you get family allowance you’ve got to be there early in the morning, because if you’re not you can’t wash your clothes. Now me, two kids, it gets piled up there and ... okay, like Monday they sprayed my place there [for lice], three weeks in a row. I got still twelve loads of laundry to do. But the laundry room is always busy. Do it at the Laundromat, do you know how much it costs at the Laundromat? $1.50 to wash, $1.50 to dry (14.1, lines 620-629).
Implications

• Primary and secondary disabilities undermine goals for children and long-term outcomes for caregivers:
  • Complementary nature of success
  • Emphasize importance of prevention (e.g., Astley & Clarren, 1999; Gurwitch, Mulvihill, & Chaffin, 2003; Malbin, 2002) and complementary nature of success

• Paid employment and children’s success as mutually exclusive; adds new information about living in poverty and children with FASD (Astley et al. 2000); double jeopardy of parents of children with FASD living in poverty

• Mutual support that was identified in a community characterized as impoverished, contributes to understanding of the kinds of supports beneficial to participants
  • Education
    • LEIC Planning Tool (POFASD, 2011)
    • Knowledge of FASD
  • Key workers
    • What constitutes helpful relationships
    • Support groups
Thank you

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References


Clark, E., Hughes, K. & Jaswal, O. (2010, November). *So you have the assessment, now what about the teacher?* Paper presented at the meeting of the British Columbia Association of School Psychologists, Vancouver, BC.


References


