

Does Parent Networking Enable Transition Planning?

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Target Population:

Parents of youth in grades 7 to 12 who use the Communication & Writing Aids Service at Bloorview Kids Rehab

Background:

- Many youth grow up without critical life skills and future plans – a barrier to full participation in their communities
- Parents of youth with disabilities need support to help them plan and prepare for the future
- Parents benefit from connecting with other parents with similar experiences (Almbinder et al., 1998; Kerr & McIntosh, 2000; Law, King, Stewart & King, 2001)
- Family Facilitator role was created to promote parent-to-parent support focused on growing up ready for adult life (transition) -- Family Facilitator is a parent of a youth with a disability
- Based on in-depth interviews and a needs survey, a Program Logic Model was used to identify objectives, program elements and evaluation strategies

Program Objectives:

- Increase parents' knowledge in accessing resources and services
- Reduce parents' anxiety about transition to adult services
- Increase parents' social support and networking opportunities
- Initiate active preparation for growing up

Program Design:

Family Facilitators offered a pilot networking program including: Parent Networking Sessions, Parent Education Sessions, and 1:1 support

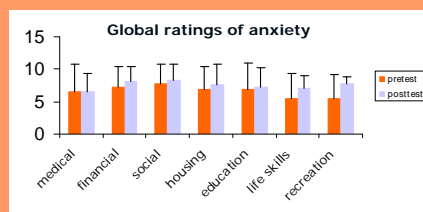
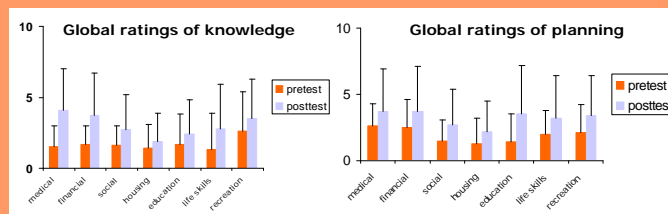
Participants:

- 25 parents participated in the program
- 8 families completed pre/post Transition Planning Questionnaires
- Average of 7 parents attended the 9 Networking Sessions
- 8 parents attended a Focus Group

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Transition Planning Questionnaire Results (n=8)



Specific Actions Taken by Families

- Creating their own circles of support
- Use of programs identified and network contacts shared
- Adding their names to waiting lists and applying for individualized funding
- Formation of a networking splinter group

Methods:

- 12-month program evaluation
- Pre/post-test survey and qualitative descriptions of experience
- Measures included:

Transition Planning Questionnaire: Custom 11-item questionnaire that assesses parents' global levels of anxiety, knowledge and planning in 7 different transition planning domains and their involvement in community and Bloorview-based activities

Networking Sessions Retrospective Notes: The Family Facilitator wrote a summary after each of nine Networking Sessions (held over a one year period in 2005/2006). Notes included comments on the content and mood of the discussion.

Network Self-Review Focus Group: Focus Group held February 2006 with parent networking session participants to reflect on their networking experience

- Thematic analysis of notes from the Networking Sessions and Focus Group by two members of the research team (met with the Family Facilitator to discuss data interpretation and coding)

Themes & Quotes from Networking Sessions and Network Self-Review Focus Group

Sharing Knowledge & Resources

(about funding, housing options, etc.)

"...just different options that come available that I wouldn't know about if I had not joined the group, so I find it very helpful, I don't feel as alone..."

Parent-to-Parent Support

(sharing experiences, problem solving together, etc.)

"Emotional support and knowing that other parents in room have same issues. Things that you can't talk to your friends about – talk openly."

New skills & ways of thinking

(articulating issues, thinking creatively about solutions, etc.)

"Different points of view from other parents has been very helpful in changing our view...not just planning for future but problem solving day to day things – professionals, even family do not understand, not in our skin. This is the difference between parents...we feel it...a connection."

Group process

(sense of comfort and belonging, positive impression of Family Facilitator role)

"Ideas and inspiration, positive energy for this very very challenging time and it keeps you going."

[on parent leadership for program] "Family with a child with a disability regardless of whether the disability is the same is what brings a lot to group."

Discussion:

- Parents who participated in the pilot program reported increased knowledge, preparedness, and a sense of social support. They took a number of concrete actions to help their youth prepare for adult life.
- Parent leadership (by the Family Facilitator) of the networking opportunities was highly valued.
- Self-reported levels of anxiety increased. This appeared to be related to increased understanding of the preparations required. One parent stated, "Got a lot [of information] but need is still too great, so many things to do... Overwhelmed."

Conclusion & Next Steps:

- Participating families benefited from this program focused on growing up ready for adult life. They were strongly supportive of the networking opportunities being led by a parent (the Family Facilitator).
- New Family Facilitators have been hired to work with other clinical groups at Bloorview. With each clinical group, support methods will be tailored to identified needs.