Informal and Formal Community Supports for Parents: A Pilot Study To Assess Information Sharing in Connecticut Schools

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Parents of children with special needs are resilient, strong, persistent and steadfast advocates for their children.

They are the experts that guide policy makers, advocates, and all service providers in their practice.

As resilient as parents are, parenting children with special needs presents challenges that may challenge parents' resiliency and self-efficacy.

Mothers of children with special needs often experience increased stress related to caring for their child that can have a significant impact on a parent's psychological well being (Hendriks, DeMoor, Oud, & Savelberg, 2000; Lessenberry & Rehfeldt, 2004; Rowlands, 2005; Smith, Oliver, & Innocenti, 2001).

Parent Community Supports

“What lies behind us and what lies before us are tiny matters compared to what lies within us” (Ralph Waldo Emerson)
It is well documented that family context is highly influential on child development and outcome (Bruder, 2000; Dunst, 1999).

High levels of parent stress may adversely impact the child with a disability and place the family at risk for family maladjustment (Plant & Sanders, 2007; Havens, 2005).

Lower levels of parenting stress may serve as a protective factor on the social-emotional health of children and directly influence healthy child adjustment (Raikes & Thompson, 2005).

Informal and formal supports in the community can help parents maintain their resiliency.

It is imperative for parents to be aware of the informal and formal supports that are available to them in the community.

To complement parents’ knowledge, schools can also be a resource to parents and share information about the available supports.
Informal Supports Defined

- Consists of family, faith, & friends
- Example: Community parent support groups run by parents for parents
- Parent Reports: Significant long-term alleviant of stress!
  - when in crisis, families seek out social networking supports
  - these are the supports that are sustained long term
  - the act of sharing experiences is comforting

Formal Supports Defined

- Provided by organized networks
- Examples: parent education, parent matching programs, behavioral training, therapy, respite care services

**Together, these supports help reduce parent stress, increase coping and foster better child outcomes!**
Informal and Formal Parent Supports for Optimal Child Development
Significance To LEND

**Family Centered Practice**
- Information sharing is empowering
- Assists families to make informed decisions, gain feelings of personal control that has direct impact on positive child outcomes *(Dunst et al, 1988)*
- Values: Sharing information on *all* community supports fosters home-school collaboration; positive academic outcomes *(National Association of School Psychologists, 2002)*

**Interdisciplinary Practice**
- Conversations between team members and parents offer insight into struggles that may impact the child at school
- Information sharing among team members, *(with parent consent)* based on conversations with parents, ensures teams are united and informed
- When all members are informed, comprehensive supports can be implemented using a synergistic team approach
Resource for Parents

- Dr. Ann Turnbull: Parents of children with special needs are at increased risk of stress (Beach Center on Disability, 2008).
- A combination of supports ameliorate parents’ distress and increases confidence (Beach Center on Disability, 2008).
- Informal support emphasized for greater long term support
- Knowledge/Value: School service providers must know about the existing supports to be a resource!!

**NASP Professional Standards: School Psychologists as Resources for Parents**
As part of our LEND training, we are committed to children and families.

Schools also share this commitment that should be reflected in their relationships with parents...

“The way schools care about children is reflected in the way schools care about the children's families” (Epstein et al. 2007, p. 7)
Family Centered Practice

Schools must use family centered practices to ensure family choice of all available supports to facilitate parents’ capabilities and competence (Trivette & Dunst, 2005)

Problem Statement

- Schools are struggling to provide family centered care; tendency to decrease with school progression from pre-school to high school (Dunst, 2002)
- This may be related to the child’s increased independence/decreased parental role over time but we still need to be practicing family centered care in schools regardless to optimally support children and families

- There is a gap in the literature to measure family centered practice in schools, especially related to information sharing about informal and formal community supports for parents
Interdisciplinary Practice

Interdisciplinary Practice = Expertise in Partnership (Power, 2003)
**Without Interdisciplinary practice, partnership is compromised

Problem Statement
- Schools value interdisciplinary practice but are struggling to utilize it regularly and consistently and have different definitions of what constitutes best practice
- There is a lapse in the literature about information sharing with teams in schools in relation to sharing information on the informal and formal parent supports
- **Result: All team members not informed; teams not working synergistically; creates an “inner circle” of care where members are excluded!!**
Study Purpose & Significance

**Purpose: Survey School Psychologists**
- Knowledge of informal and formal parent supports & of school’s procedures for sharing information
- Values of sharing information
- Needs for further training

**Study Significance: Explore Practice in CT Schools**
- There is little information about family centered care and interdisciplinary practice in school systems in the area of sharing information about parent community supports from the perspective of a school psychologist
Research Questions: Family Centered Care

What are the barriers for parents to access information from schools about the available parent community supports to make more informed decisions about the supports that are best for them?

- **Knowledge**: Are school psychologists aware of the community supports available to parents? Do school psychologists know the current school procedures for sharing information?
- **Values**: Do school psychologists believe that sharing information with parents about community supports is valuable?
- **Training**: Would they benefit from training or a resource document?
Research Questions: Interdisciplinary Care

What are the barriers that parents experience to receive interdisciplinary care in relation to the school sharing information with other team members?

- **Knowledge**: Do school psychologists know the current school procedures for sharing information with other interdisciplinary team members? What are the current practices for sharing information with team members in Connecticut schools?
- **Values**: Do school psychologists believe that sharing information with other interdisciplinary team members, with parent consent, is valuable?
- **Training**: Would they benefit from additional training?
Hypothesis

School psychologists value sharing information with parents about the informal and formal community supports and with other team members.

- The barriers to provide information to parents are potentially related to school psychologists’ knowledge of these supports, especially informal supports.
- Barriers exist in the school’s procedures or lack thereof to provide information on some, rather than on all supports.
- Schools would benefit from training and a resource document.
Methodology

Participants
- Practicing School Psychologists in Connecticut, members of the Connecticut Association of School Psychology (CASP) listserv
- IRB Review: Expedited (no human risks/concerns)

Instruments
- 30 item survey generated via Survey Monkey to CASP listserv in April, 2011
- Featured Sections: Values, Current Practice, Demographics & Training Resources
- Participation was voluntary; responses anonymous, confidential
Results Summary

Demographics (n=16)
- 73% of respondents were specialist level practitioners
- 66%: 1-10 years in practice
- 13%: 11-21 years in practice
- 60% practice in elementary schools, 33% in high schools, 7% in K-12 settings

Values
- Formal Support - 88% agree/strongly agreed that sharing information with parents is part of evidence based practice
- Informal Support - 100% agree/strongly agreed that sharing information with parents is part of evidence based practice
- 93% agreed that sharing information with parents is part of their role
- 100% agreed that sharing information with parents is important
Results Summary

Knowledge

- **Formal Support**: 86% of respondents were aware of these supports, 86% learn from their own research, 93% share regularly
  - 60% were aware of their school’s procedure for sharing this information
- **Informal Support**: 60% were aware of these supports, 93% learn from parents, 66% share regularly
  - Only 20% responded that all school personnel share: In 80% of schools, only a few individuals share this information (e.g. social worker, school psychologist)
  - 54% were aware of their school’s procedure for sharing this information

Need for Training/Resources

- 100% would benefit from additional training on these supports
- 93% would benefit from a resource document to share with parents
- 93% would benefit from additional training in interdisciplinary practice
“The educational system is supposed to be part of wraparound and system of care. Often schools do not know this and are not part of these community-based concepts. This survey is timely as schools are a great resource for sharing resources.”
Conclusions

- School psychologists are knowledgeable of formal supports but are not as familiar with informal supports.

- The procedures for sharing information with parents should be made clear by schools and reviewed by staff.

- Sharing is transactional between school psychologists and parents, where parents are educating schools on informal supports.
Conclusions

- Most often, information is shared verbally with parents making it difficult to ensure that parents are provided all options to make choices that are best for them.

- A resource document should be developed by the district or school to share with parents.

- All school personnel should be resources for parents by being aware of community supports and share with parents in a resource document, when applicable.
Future Impact: Psychology & Policy

Initial Step Towards Advocacy & Awareness

- The current pilot is an initial step towards advocating for parents in schools throughout Connecticut and serves to bridge the gap and foster more trusting relationships between schools and parents.

- Results emphasized a need for further research in this area and to establish a definition of what constitutes a complete resource list.

- Results may serve to impact policy on a state level; guide CASP to develop a (i) training program and/or (ii) resource template for schools to share with parents.

- Results may raise awareness about: (i) family centered care and interdisciplinary practices related to community parent supports in schools, and (ii) the University of Connecticut Center for Excellence in Developmental Disabilities LEND Fellowship Program.
“Progress in partnerships is incremental…a process, not a single event.” (Epstein, 1995)