



Family-centered services for children with ASD and limited speech: the experiences of parents and speech-language pathologists

Kelsey Mandak, MA, CCC-SLP, Doctoral Candidate, Penn State University
 Janice Light, PhD, Penn State University



Acknowledgements

- This project was supported, in part, by funding from the:
 - Penn State AAC Leadership Project, a doctoral training grant funded by U.S. Department of Education Grant #H325D110008;
 - Hintz Family Endowed Chair in Children’s Communicative Competence;
 - Rehabilitation Engineering Research Center on Augmentative and Alternative Communication (The RERC on AAC), funded by Grant #90RE5017 from the National Institute on Disability, Independent Living, and Rehabilitation (NIDILRR) within the Administration for Community Living (ACL) of the U.S. Department of Health and Human Services (HHS).
- The authors would like to thank the Interactive Autism Network (IAN) Research Database at the Kennedy Krieger Institute, Baltimore for their assistance in the recruitment of parents.
 
- The authors have no conflict of interest

Aim of Study

- To investigate the degree of family-centeredness and the identification of specific family-centered behaviors from the perspectives:
 - Families of children with ASD and CCN
 - SLPs who serve children with ASD and CCN

- Families living with ASD**
 - Have to shoulder tremendous responsibilities in raising their children.
 - The need for services and supports often occurs daily and for the entirety of their lives.
 - More likely to report financial problems, need additional income for the child’s care, reduce or stop work because of the child’s condition, and spend greater than 10 hours per week providing or coordinating care (Kogan et al., 2008).
 - Given the impact that ASD has on the child and family, **it is clear that the needs of the whole family must be addressed in clinical service provision.**
- Family-centered services**
 - Families are given choice over treatment decisions as they are the constant in their child’s life and best know the child’s needs (Woodside et al., 2001).
 - FCS promotes a partnership—characterized by trust, respect, and open communication—where families and professionals work together to make decisions in the best interests of the child.
 - Family-centeredness has been linked to many **positive parent, family, and child outcomes.**
- Family-centered AAC services**
 - The successful introduction and use of AAC to support communication depends on the family’s full involvement and support and the development of a successful family-professional partnership.
 - Parents of children who use AAC have repeatedly expressed the **challenges of family involvement and the consequent impact on both the family and child.**

Skill sets necessary for family-centered practices

- **Relational skills**
 - Clinical skills (e.g., active listening, compassion, empathy, respect, and effective communication)
 - Beliefs about and attitudes toward families
- **Participatory skills**
 - Responsivity to family priorities and concerns
 - Inclusion of families in decision making

Both skill sets are necessary to provide family-centered services.

(Dunst and Trivette 1996; Dunst et al. 2007)

SLPs

ASD
 More than 90% of SLPs in educational settings work with children with ASD.
 Children with ASD account for 20%–25% (medians) of the pediatric caseloads of SLPs in outpatient clinics and offices

Family-centeredness (ASHA)
 SLPs should “recognize the essential role that families play in all aspects of service, from assessment through treatment, and the role that families and individuals play as key decision makers, recognized for their knowledge and skills”
 It is the role and responsibility of SLPs to engage families in planning, decision making, and program implementation for children of all ages

Despite the call for a family-centered approach, current practices do not always reflect this ideal or best practice.

- Parents have repeatedly reported the challenges of family involvement.
- Studies reveal that professional beliefs often do not match their practices with regards to family-centered services.

Research Questions

Regarding the family-centeredness of their child’s speech and language services:

1. What are the perceptions of parents of children with ASD and limited speech?
2. What are the perceptions of SLPs who serve children with ASD and limited speech?
3. How do the perceptions compare?

Participants

99 parents

- Majority were white (80%) and biological mothers (83%)
- Average age of child was 11 years
- Children used a range of communication methods
- 40% of children received services for 9+ years
- 81% of children received services in school setting

211 SLPs

- Majority were white (95%) and female (93%)
- Large range of experience (min=1 year, max=46 years)
- Most worked in school setting (56%), followed by early intervention or private practice (29%)
- Most SLPs had 1-15 children with ASD on caseload
- Half of the SLPs (51%) reported no training in working with families

Measures: The Measures of Processes of Care (MPOC)

MPOC
MEASURE OF PROCESSES OF CARE

SP

27 items across 4 domains

•The scales are both self-administered, Likert-scale, questionnaires that ask parents (MPOC-20) and service providers (MPOC-SP) to rate their perceptions of the family-centered services received or provided.

•Both measures have been shown to have strong psychometric properties (King et al., 1996; King et al., 2004)

MPOC
MEASURE OF PROCESSES OF CARE

20

20 items across 5 domains



Measures: The Measures of Processes of Care (MPOC)

MPOC
MEASURE OF PROCESSES OF CARE

SP

Example Question

"In the past year, to what extent did you suggest treatment/management activities that fit with each family's needs and life style?"

Example Question

"In the past year, to what extent did your child's SLP provide opportunities for you to make decisions about treatment?"

MPOC
MEASURE OF PROCESSES OF CARE

20

To a very great extent	To a great extent	To a fairly great extent	To a moderate extent	To a small extent	To a very small extent	Not at all	Not applicable
7	6	5	4	3	2	1	0

Comparable Domains Across the MPOC-20 and MPOC-SP

MPOC-20 Domains	Comparable MPOC-SP Domains
Enabling and partnership	Showing interpersonal sensitivity
Providing general information	Providing general information
Providing specific information	Communicating specific information
Respectful and supportive care	Treating people respectfully

Comparable Domains Across the MPOC-20 and MPOC-SP

MPOC-20 Domains	Comparable MPOC-SP Domains
Enabling and partnership	Showing interpersonal sensitivity
Providing general information	Providing general information
Providing specific information	Communicating specific information
Respectful and supportive care	Treating people respectfully

Are the parents actively involved in their child's care, particularly in decision-making?

Do the SLPs support and enable families?

Comparable Domains Across the MPOC-20 and MPOC-SP

MPOC-20 Domains	Comparable MPOC-SP Domains
Enabling and partnership	Showing interpersonal sensitivity
Providing general information	Providing general information
Providing specific information	Communicating specific information
Respectful and supportive care	Treating people respectfully



Do parents receive general information about the condition, supports and resources?

Do SLPs provide general information about condition, services, and resources?



Comparable Domains Across the MPOC-20 and MPOC-SP

MPOC-20 Domains	Comparable MPOC-SP Domains
Enabling and partnership	Showing interpersonal sensitivity
Providing general information	Providing general information
Providing specific information	Communicating specific information
Respectful and supportive care	Treating people respectfully



Do parents receive information specific to their child?

Do SLPs provide specific information particular to the child's status, treatment, and progress?



Comparable Domains Across the MPOC-20 and MPOC-SP

MPOC-20 Domains	Comparable MPOC-SP Domains
Enabling and partnership	Showing interpersonal sensitivity
Providing general information	Providing general information
Providing specific information	Communicating specific information
Respectful and supportive care	Treating people respectfully

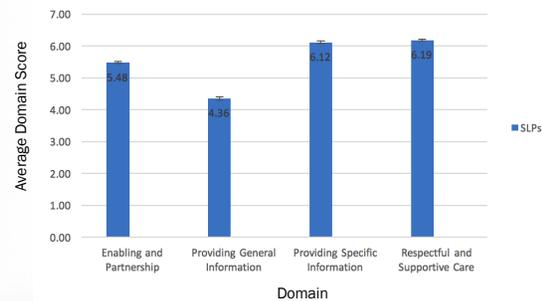


Are parents treated respectfully and viewed as individuals, equals, and experts on their child?

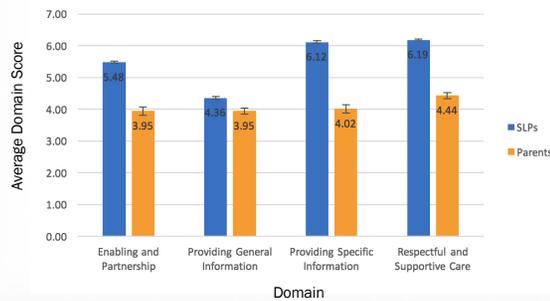
Do SLPs treat children and their families as individuals and equals with valuable insights?



MPOC Domain Scores: SLPs & Parents



MPOC Domain Scores: SLPs & Parents



Item-by-Item Comparisons

- Planned item-by-item comparisons were made. The individual items on each scale were analyzed to identify the distribution of participant responses (i.e., the number of respondents that reported each rating for each item).
- In order to improve service delivery, The MPOC developers suggested to focus on items where an appreciable amount (at least 33%) of respondents reported "never" to "sometimes" (points 1 to 4 on the seven-point scale).

MPOC-SP Items that 33% or More of SLPs Identified as Occurring to a Moderate Extent (i.e. "Sometimes") or Less

Domain	Item	%
Showing interpersonal sensitivity	Discuss/explore each family's feelings about having a child with special needs (e.g., their worries about their child's health or function)?	35.1
Providing general information	Promote family-to-family "connections" for social, informational or shared experiences?	49.0
	Provide opportunities for the entire family, including siblings, to obtain information?	4.6
	Have general information available about different concerns (e.g., financial costs or assistance, genetic counselling, respite care, dating and sexuality)?	5.7
	Provide opportunities for the entire family, including siblings, to obtain information?	57.1
	Have general information available about different concerns (e.g., financial costs or assistance, genetic counselling, respite care, dating and sexuality)?	54.5

22% of the MPOC-SP items fit this criterion with more than one-third of SLPs rating 6 items with 4 points or less.

Item-by-Item Comparisons

MPOC-20 Items that 33% or More of Parents Identified as Occurring to a Moderate Extent (i.e. "Sometimes") or Less

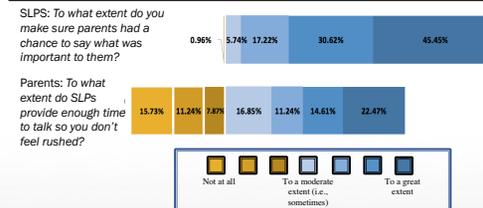
Domain	Item	%
Enabling and partnership	Let you choose when to receive information and the type of information you want?	61.1
	Fully explain treatment choices to you?	56.8
	Provide opportunities for you to make decisions about treatment?	51.6
Providing general information	Give you information about the types of services offered at the organization or in your community?	55.2
	Have information available about your child's disability (e.g., its causes, how it progresses, future outlook)?	71.9
	Provide opportunities for the entire family to obtain information?	66.7
Providing specific information	Provide information about your child's physical needs?	73.4
	Provide information about your child's educational needs?	64.6
	Provide information about your child's social needs?	65.7
	Provide information about your child's emotional needs?	56.7
Coordinated and comprehensive care	Plan together so they are all working in the same direction?	48.9
	Give you information about your child that is consistent from person to person?	45.4
Respectful and supportive care	Help you to feel competent as a parent?	54.3
	Provide a caring atmosphere rather than just give you information?	46.3
	Provide enough time to talk so you don't feel rushed?	42.3
	Treat you as an equal rather than just as the parent of a patient (e.g., by not referring to you as "Mom" or "Dad")?	57.0
	Treat you as an individual rather than as a "typical" parent of a child with a disability?	39.6
	Treat you as an individual rather than as a "typical" parent of a child with a disability?	51.7
	Treat you as an individual rather than as a "typical" parent of a child with a disability?	49.5
	Treat you as an individual rather than as a "typical" parent of a child with a disability?	43.8

100% of the MPOC-20 items fit this criterion with more than one-third of parents rating all 20 items 4 points or less.

Looking Deeper at One Domain

- Even though the comparison of means provided evidence that the SLPs perceived their services as more family-centered than parents, the distribution of scores further revealed the extent of this incongruity.
- As an example, let's look at the "Respectful and supportive care" domain, which was ranked as the highest domain from both the parent and SLP perspectives.

Example score distribution comparison for a set of comparable items



Examples of "Respectful and Supportive Care" Items

To what extent does your child's SLP...

...help you feel competent as a parent?

...treat you as an individual rather than as a "typical" parent of a child with ASD?

...treat you as an equal rather than just as a parent of a child on his or her caseload?

...provide enough time to talk so you don't feel rushed?

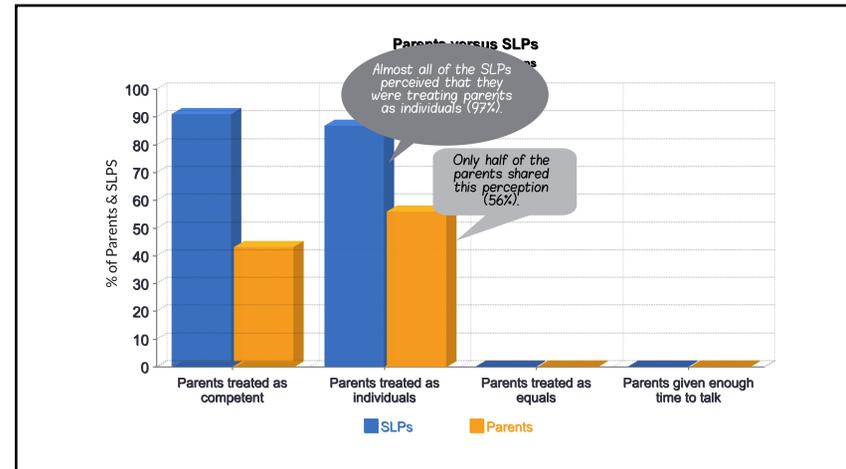
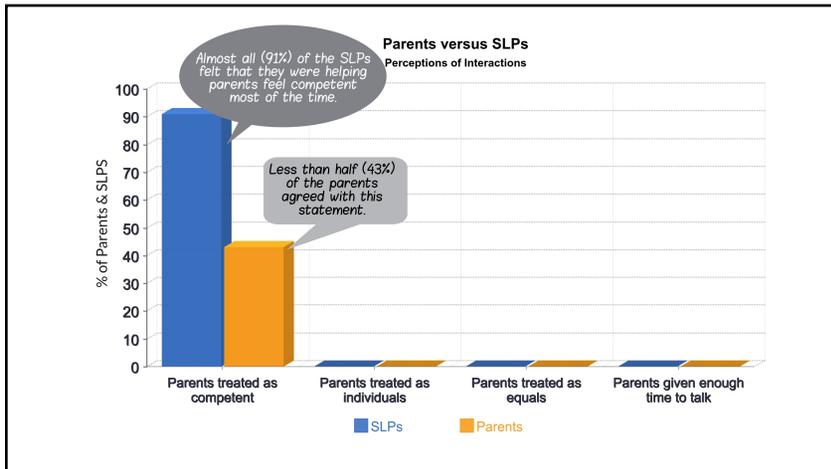
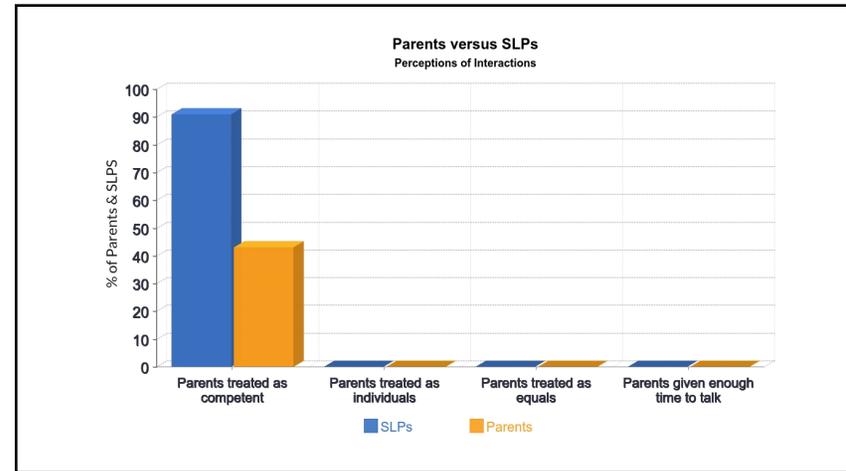
To what extent do you...

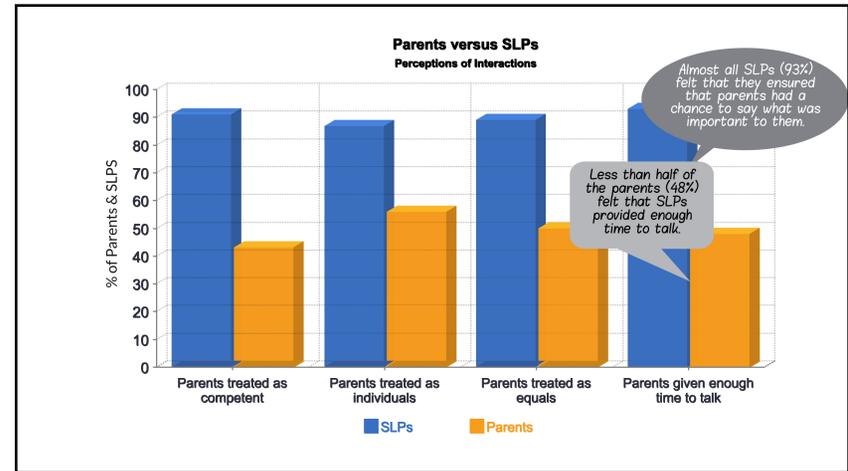
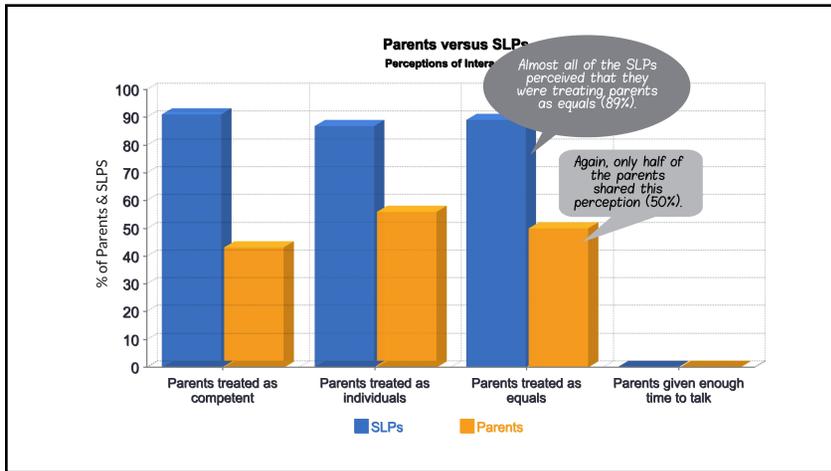
...help parents feel competent in their roles as parents?

...treat each parent as an individual rather than as a "typical" parent of a child on your caseload?

...treat parents as equals rather than just as the parent of a child on your caseload?

...make sure parents had a chance to say what was important to them?





Key Domains and Clinical Suggestions

Family-centered Area	Clinical Suggestions
Respectful and supportive care (i.e., relational practices)	<ul style="list-style-type: none"> Address parents by their names (i.e., not "Mom" or "Dad") Write down personal details about families and refer to your notes before you speak with families Ask families for their permission before sharing information with others Acknowledge the good things that parents do for their child Do not make promises that you cannot keep (i.e., do what you say you will do) Provide enough time for parents to speak (e.g., do not interrupt; wait a few seconds before responding) Actively listen to families (i.e., see the LAFF strategy)
Enabling and partnership (i.e., participatory practices)	
Provision of Information	

Key Domains and Clinical Suggestions

Family-centered Area	Clinical Suggestions
Respectful and supportive care (i.e., relational practices)	<ul style="list-style-type: none"> Write down personal details about families and refer to your notes before you speak with families Ask families for their permission before sharing information with others Acknowledge the good things that parents do for their child Do not make promises that you cannot keep (i.e., do what you say you will do) Provide enough time for parents to speak (e.g., do not interrupt; wait a few seconds before responding) Actively listen to families (i.e., see the LAFF strategy)
Enabling and partnership (i.e., participatory practices)	
Provision of Information	

The relational practices of this domain (i.e., empathy, compassion, active listening, etc.) are directly related to a family's satisfaction with services and family well-being

Key Domains and Clinical Suggestions

Family-centered Area	Clinical Suggestions
Respectful and supportive care (i.e., relational practices)	<ul style="list-style-type: none"> Address parents by their names (i.e., not "Mom" or "Dad") Write down personal details about families and refer to your notes before you speak with families Ask families for their permission before sharing information with others Acknowledge the good things that parents do for their child Do not make promises that you cannot keep (i.e., do what you say you will do) Provide enough time for parents to speak (e.g., do not interrupt; wait a few seconds before responding) Actively listen to families (i.e., see the LAFF strategy)
Enabling and partnership (i.e., participatory practices)	<ul style="list-style-type: none"> Ensure that the family has the final say about treatment decisions (i.e., end conversations ensuring that families have nothing to add) Offer encouragement and support when families make decisions Ask families if there is any information that they are missing or would like to have Respond to all and any requests for advice or assistance Demonstrate flexibility when families' situations change
Provision of Information	

Key Domains and Clinical Suggestions

Family-centered Area	Clinical Suggestions
Respectful and supportive care (i.e., relational practices)	<ul style="list-style-type: none"> Address parents by their names (i.e., not "Mom" or "Dad") Write down personal details about families and refer to your notes before you speak with families Ask families for their permission before sharing information with others Acknowledge the good things that parents do for their child Do not make promises that you cannot keep (i.e., do what you say you will do) Provide enough time for parents to speak (e.g., do not interrupt; wait a few seconds before responding) Actively listen to families (i.e., see the LAFF strategy)
Enabling and partnership (i.e., participatory practices)	<ul style="list-style-type: none"> Ensure that the family has the final say about treatment decisions (i.e., end conversations ensuring that families have nothing to add) Offer encouragement and support when families make decisions Ask families if there is any information that they are missing or would like to have Respond to all and any requests for advice or assistance Demonstrate flexibility when families' situations change
Provision of Information	

Participatory practices are strongly related to parents' positive judgements of professional supports and services; parenting competence, confidence, and enjoyment; and child functioning (i.e., parents' judgement of child's learning, development, and competence).

Key Domains and Clinical Suggestions

Family-centered Area	Clinical Suggestions
Respectful and supportive care (i.e., relational practices)	<ul style="list-style-type: none"> Address parents by their names (i.e., not "Mom" or "Dad") Write down personal details about families and refer to your notes before you speak with families Ask families for their permission before sharing information with others Acknowledge the good things that parents do for their child Do not make promises that you cannot keep (i.e., do what you say you will do) Provide enough time for parents to speak (e.g., do not interrupt; wait a few seconds before responding) Actively listen to families (i.e., see the LAFF strategy)
Enabling and partnership (i.e., participatory practices)	<ul style="list-style-type: none"> Ensure that the family has the final say about treatment decisions (i.e., end conversations ensuring that families have nothing to add) Offer encouragement and support when families make decisions Ask families if there is any information that they are missing or would like to have Respond to all and any requests for advice or assistance Demonstrate flexibility when families' situations change
Provision of Information	<ul style="list-style-type: none"> Develop a master list of "general information" including (but not limited to): a) community-resources; b) parent-to-parent groups; and c) information about the child's disability. Collaborate with other professionals inside and outside of your discipline to develop resources for families

Key Domains and Clinical Suggestions

Family-centered Area	Clinical Suggestions
Respectful and supportive care (i.e., relational practices)	<ul style="list-style-type: none"> Address parents by their names (i.e., not "Mom" or "Dad") Write down personal details about families and refer to your notes before you speak with families Ask families for their permission before sharing information with others Acknowledge the good things that parents do for their child Do not make promises that you cannot keep (i.e., do what you say you will do) Provide enough time for parents to speak (e.g., do not interrupt; wait a few seconds before responding) Actively listen to families (i.e., see the LAFF strategy)
Enabling and partnership (i.e., participatory practices)	<ul style="list-style-type: none"> Ensure that the family has the final say about treatment decisions (i.e., end conversations ensuring that families have nothing to add) Offer encouragement and support when families make decisions Ask families if there is any information that they are missing or would like to have Respond to all and any requests for advice or assistance Demonstrate flexibility when families' situations change
Provision of Information	<ul style="list-style-type: none"> Develop a master list of "general information" including (but not limited to): a) community-resources; b) parent-to-parent groups; and c) information about the child's disability. Collaborate with other professionals inside and outside of your discipline to develop resources for families

Sharing information can empower families to make decisions about their children and alleviate the stress or burden associated with seeking information or uncertainty.

Future research

- **Relationship between the delivery of family centered services and family satisfaction.**
 - Although parents experienced less family-centered services, it is unknown how satisfied the parents were with their child's services and how the services impacted their child and family.



- **Relationship between the delivery of family centered services and child and family outcomes for children with ASD and limited speech.**
 - Future investigations must identify how these families are specifically affected by their child's services.

Future research

- **Pre-service Training:** How to train future SLPs in family-centered practices in most EFFICIENT and EFFECTIVE way

Relational skills
How to best train SLPs to truly communicate respect and develop a supportive environment for families.

- Active listening
- SLPs' beliefs and attitudes (helping students form dispositions that will allow them to work effectively with families)



Participatory skills

- Empowerment perspective of parents/families
- How to increase family exposure in pre-service training



Conclusion

- This study revealed that parents and SLPs differed in their views on the degree to which family-centered services were being implemented.
- Based on this discrepancy of perspectives, there are many areas that require improvement:
 - enabling families
 - sharing general and specific information
 - communicating respect
 - providing a supportive environment
- These domains can provide guidance for in-service and pre-service SLP in terms of strategies and skills to improve family-centered services.
- Improvements must be made in order to families and professionals to reap the benefits associated with family-centeredness, including increased parent satisfaction, decreased parent stress, and most importantly, improved child outcomes.



References

American Speech-Language-Hearing Association. (2013). *SLP Health Care Survey report: Caseload characteristics trends, 2005–2013*. Available from www.asha.org.

American Speech-Language-Hearing Association. (2014). *2014 Schools Survey report: SLP caseload characteristics*. Available from www.asha.org.

American Speech-Language-Hearing Association (n.d.a). *Family-Centered Practice* (Practice Portal). Retrieved November 12, 2016, from http://www.asha.org

Arango, P. (2011). Family-centered care. *Academic Pediatrics, 11*, 97–99. doi:10.1016/j.acap.2010.12.004

Dunst, C. (2002). Family-centered practices: Birth through high school. *Journal of Special Education, 36*, 139–147. doi:10.1177/00224669020360030401

Dunst, C. J., Boyd, K., Trivette, C. M., & Hamby, D. W. (2002). Family-oriented program models and professional helpgiving practices. *Family Relations, 51*, 221–229. doi:10.1111/j.1741-3729.2002.00221.x

Dunst, C. J., Trivette, C. M., & Hamby, D. W. (2007). Meta-analysis of family-centered helpgiving practices research. *Mental Retardation and Developmental Disabilities Research Reviews, 13*, 370–378. doi:10.1002/mrdd.20176

Dunst, C. J. & Trivette, C. M. (1996). Empowerment, effective helpgiving practices and family-centered care. *Pediatric Nursing, 22*, 334–337. doi:10.1002/mrdd.20176

King, S., Rosenbaum, P., & King, G. (1996). Parents' perceptions of caregiving: Development and validation of a measure of processes. *Developmental Medicine and Child Neurology, 38*, 757–772. doi:10.1111/j.1469-8749.1996.tb15110.x

King, S., King, G., & Rosenbaum, P. (2004). Evaluating health service delivery to children with chronic conditions and their families: Development of a refined Measure of Process of Care (MPoC – 20). *Children's Health Care, 33*, 35–57. doi:10.1207/s15326888chc3303_3

Kogan, M., Strickland, B., Blumberg, S., Singh, G., Perrin, J., & van Dyck, P. (2008). A national profile of the health care experiences and family impact of autism spectrum disorder among children in the United States, 2005–2006. *Pediatrics, 122*, 1149–1158. doi:10.1542/peds.2008.1057

Mandak, K., O'Neill, T., Light, J., & Fosco, G. M. (2017). Bridging the gap from values to actions: a family systems framework for family-centered AAC services. *Augmentative and Alternative Communication*. doi:10.1080/07434618.2016.1271453

Mannion, A., & Leister, G. (2013). Comorbidity in autism spectrum disorder: A literature review. *Research in Autism Spectrum Disorders, 7*, 1595–1616. doi:10.1016/j.rasd.2013.09.006

Marshall, J., & Goldbart, J. (2008). "Communication is everything I think." Parenting a child who needs augmentative and alternative communication (AAC). *International Journal of Language & Communication Disorders, 43*, 77–98. doi:10.1080/13682820701267444

Mason, J., Kozlowski, A., & Matson, M. (2012). Speech deficits in persons with autism: Etiology and symptom presentation. *Research in Autism Spectrum Disorders, 6*, 573–577. doi:10.1016/j.rasd.2011.10.009

Neely-Barnes S., Hall H., Roberts R., et al. (2011) Parenting a child with an autism spectrum disorder: public perceptions and parental conceptualizations. *Journal of Family Social Work, 14*, 208–225. doi:10.1207/s15566935jfs1404_9

Reichman, N. E., Cornum, H., & Noonan, K. (2008). Impact of child disability on the family. *Maternal and Child Health Journal, 12*, 679–683. doi:10.1007/s10995-007-0307-z

Volkmar, F., & Pauls, D. (2003). Autism. *Lancet, 362*, 1133–1141.

Woodside, J., Rosenbaum, P., King, S., & King, G. (2001). Family-centered services: developing and validating a self-assessment tool for pediatric service providers. *Children's Health Care, 30*, 237–252. doi:10.1207/s15326888chc3003_5

THANK YOU!
Email: KCH5029@GMAIL.COM
For handouts, go to aac.psu.edu
(they will be posted in the coming days!)

