

# DEVELOPING AND TESTING STRENGTHS-BASED INTERVENTIONS FOR PARENTS OF CHILDREN WITH DISABILITIES

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# **PARENTS TAKING ACTION: SUPPORTING LATINO FAMILIES RAISING CHILDREN WITH AUTISM SPECTRUM DISORDER**

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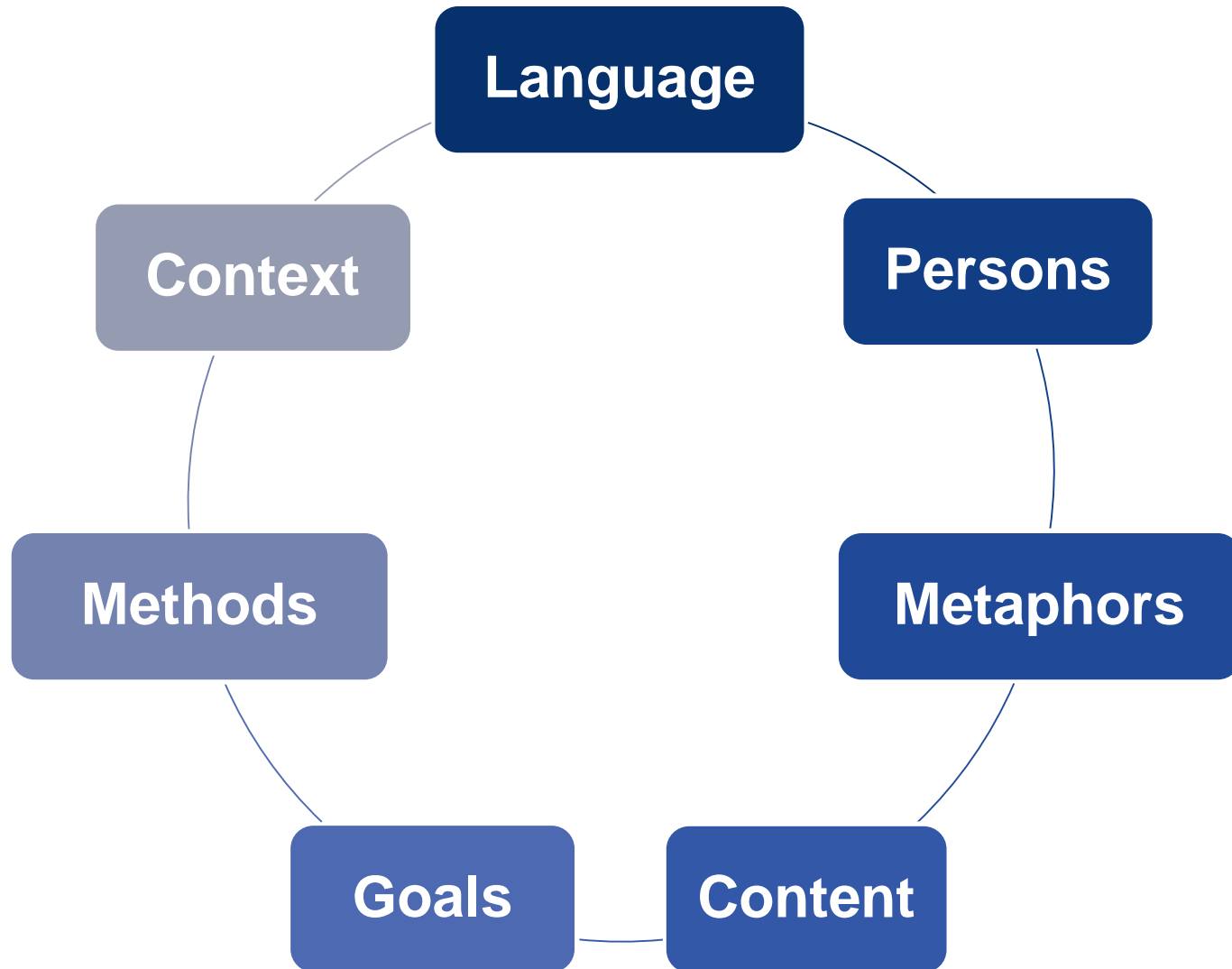
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# *Padres en Acción/Parents* **Taking Action**

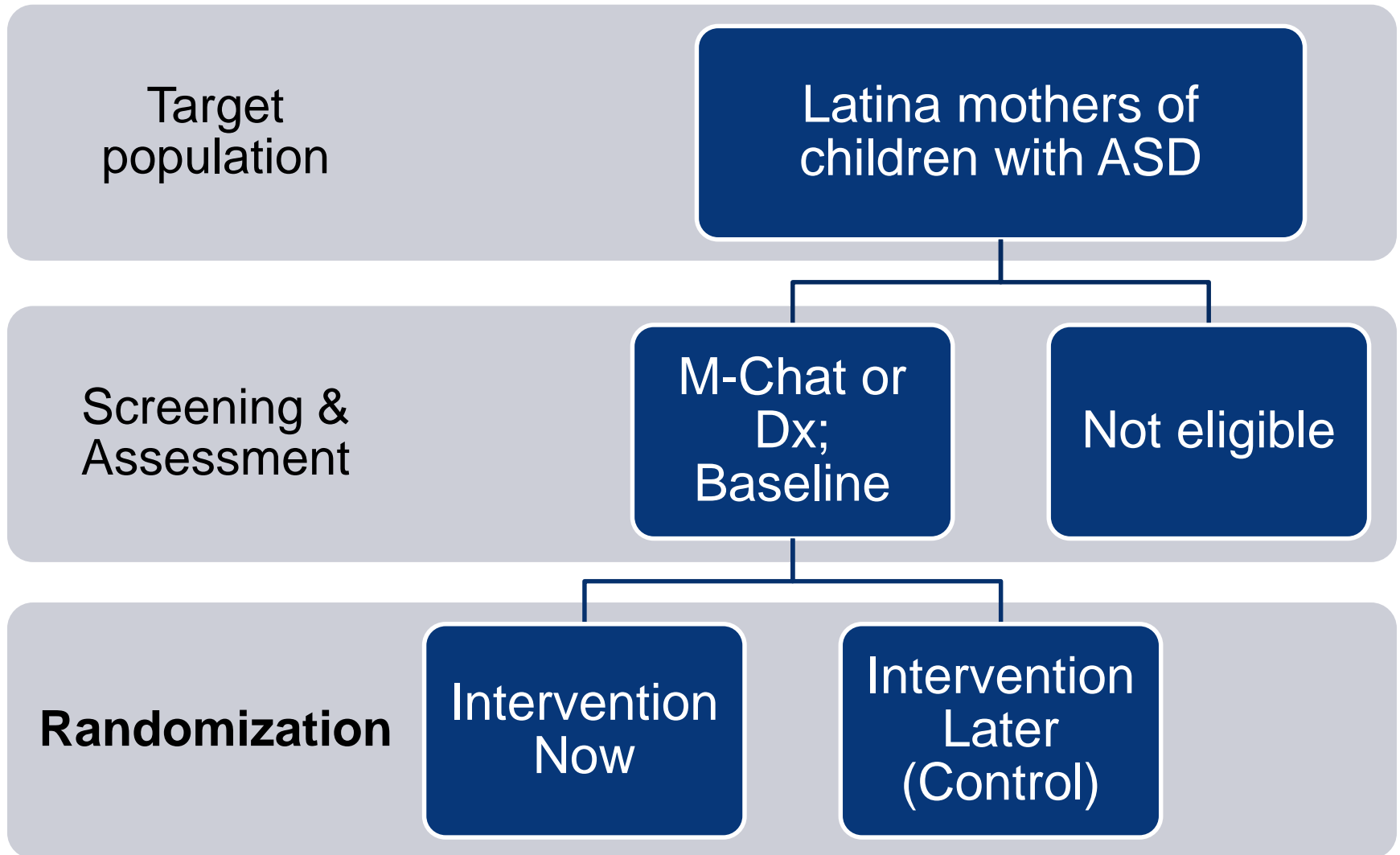
- Rooted in previous studies identifying disparities and the informational needs of Latino families (Lopez, 2014; Magaña, Lopez, Aguinaga, & Morton, 2013).
- Parent participation in early intervention is critical to enhancing outcomes for children with ASD (Magaña, Lopez, & Machalicek, 2014) and reducing parent stress (Estes et al., 2014).
- Culturally informed outreach and psychoeducation intervention for Latino parents are critical components of reaching Latino children and families.

# Ecological Validity Framework



Bernal et al., 1995

# Procedure



All received follow-up assessments at 4 and 8 months

# Table 1. Demographics

## Intervention (n=40)

- *Child age*: 5.5, SD=1.8
- 34% male
- *Total DD & EB services*: 2.5, SD=1.7
- Maternal age: 37.9, SD=5.3
- Maternal edu\*: 25% < than HS, 37.5% HS, 37.5% HS+
- 77.5% married or living together
- 90% foreign born

## Control (n=49)

- *Child age*: 5.2, SD=1.8
- 46% male
- *Total DD & EB services*: 3.0, SD=2.1
- Maternal age: 36.2, SD=6.6
- Maternal edu\*: 44% < than HS, 34% HS, 20.4% HS+
- 67.3% married or living together
- 91.8% foreign born

# Table 2: EB Strategies and Services

		Intervention Group (n = 40)				Control group (n = 49)			
		M	SD	M diff.	T-test	M	SD	M diff.	T-test
Efficacy in using strategies	T 1	33.9	5.5	-4.6	-4.9***	34.8	5.5	-0.4	-0.5
	T 2	38.5	4.5			35.2	5.3		
Frequency of using strategies	T 1	40.7	7.1	-5.1	-4.9***	40.9	7.7	-2.3	-2.8**
	T 2	45.9	6.5			43.2	7.9		
Total typical DD & EB services	T 1	2.5	1.7	-1.7	-4.7***	3.0	2.1	-0.9	-3.3**
	T 2	4.2	2.0			3.0	2.5		

**+ < 0.10 \* < 0.05 \*\* < 0.01 \*\*\* < 0.001**

# Table 2a: Parent Outcomes

		Intervention (n = 40)			Control (n = 49)		
		M	SD	T-test	M	SD	T-test
Understanding child's strengths and needs	T1	11.6	3.0	-3.7**	11.4	3.4	-2.4*
	T2	13.5	2.3		12.5	3.3	
Knowing your rights	T1	10.6	5.2	-2.3*	9.8	4.7	-2.1*
	T2	12.7	3.9		10.7	5.8	
Helping your child develop and learn	T1	11.7	3.7	-2.5*	11.6	3.2	-1.7
	T2	13.2	3.0		12.3	3.3	

**\* $p < 0.05$ , \*\* $p < 0.01$ , \*\*\* $p < 0.001$**



# Table 2b: Parent Outcomes

		Intervention (n =40)			Control (n = 49)		
		M	SD	T-test	M	SD	T-test
Having support systems	T1	12.2	5.0	-1.5	11.3	5.0	-3.1**
	T2	13.5	4.7		13.1	5.1	
Accessing the community	T1	17.3	4.8	-3.9***	17.4	4.6	-2.4*
	T2	19.6	3.8		18.8	4.1	
Total Score Family Outcomes	T1	63.3	18.0	-3.4**	61.5	15.2	-4.2***
	T2	72.5	14.1		67.4	16.8	

\* $p < 0.05$ , \*\* $p < 0.01$ , \*\*\* $p < 0.001$

# DISCUSSION

- More equipped to be self and child advocates
- Increased caregiver efficacy suggests that mothers may also be able to exhibit more effective parenting (Jones & Prinz, 2005).
- Parents can be more involved in developing their child's skills and managing their child's behaviors (Hastings & Brown, 2002).
- PTA is a promising culturally informed intervention that can be delivered in a cost effective manner.

# Dissemination

- Universidad Nacional de Bogotá Colombia
- Easter Seals Arc, Indiana
- Washington Autism Alliance and Advocacy, WA
- FIRST Resource Center, North Carolina
- Family Connections, South Carolina
- UCSD and the San Diego Regional Center:  
January 2018
- ASU/Southwest Autism Research and Resource  
Center: January 2018

# State Policy Implications

- Mental Health Services Act, Family Empowerment Centers, and regional centers
- Arizona Rural Network Development Planning Grant Program
- Medicaid Managed Care Organizations (MCOs) for internal investments in CHWs.

# Federal Policy Implications

- American Public Health Association (APHA) Community Health Care Worker Policies
- Early intervention services and Title V/Maternal and Child Health
- Interagency Autism Coordinating Committee (IACC) Strategic Plan for Autism Spectrum Disorder Research.
- Title II of the DD Act , titled Families of Children With Disabilities Support Act of 2000, addresses issues of family support, developed by the Administration on Developmental Disabilities.

# Acknowledgements

- Co PI's
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Austin
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# THE VOLUNTEER ADVOCACY PROJECT

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# What is it?



- A special education advocacy training
  - Modeled after two existing trainings (SEAT and PLSP)
- Consists of 36 hours of instruction
  - In-person or webcast
  - Facilitated by experts
  - Content relates to: federal law, state regulations, advocacy skills, policy
  - Includes a resource binder and assigned readings
- Each graduate expected to volunteer to support four other families



# Why is it needed?

Originally created to fill the void of special education advocates in TN

But, for many reasons, it is challenging for parents to advocate for their children

Since the passage of federal law in 1975, parents must be included and act as an accountability mechanism for public schools

# The VAP has five main goals:

1. To provide instrumental support
2. To provide affective support
3. To help at least four families per graduate
4. To grow and improve the VAP training model
5. To research advocacy training and special education advocacy



# What do we know about the effectiveness of the intervention?

**Research Question:** After completing the VAP, do participants improve their special education knowledge and advocacy skills?

- 90 participants from six training cohorts

## Findings:

	Pre-test mean (SD)	Post-test mean (SD)	<i>t</i>	<i>p</i>	ES
Knowledge	14.90 (3.59)	23.32 (3.58)	16.90	<.001	1.70
Advocacy	32.82 (6.91)	40.97 (5.42)	9.74	<.001	1.03

(Burke, Goldman, Hart, & Hodapp, 2016)

But we need to learn more about how advocates support families and capitalize on their strengths...

**Research Question:** What is the advocacy process that special education advocates use when working with families?

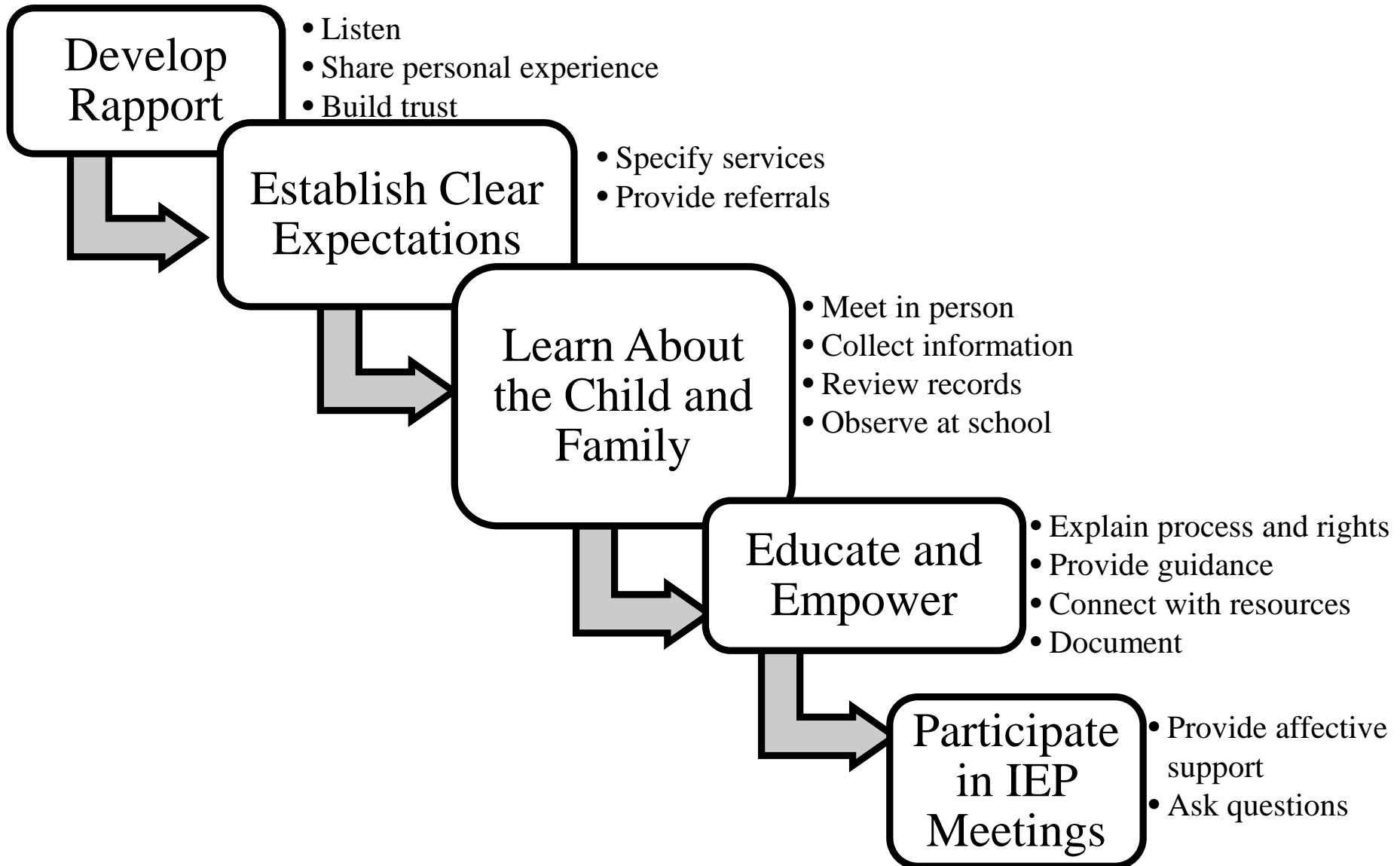
- Individual interviews with 33 VAP graduates from TN and IL

Participants:

- Range of ages, race/ethnicity, level of education
- Advocated for 1-105 families

(Burke & Goldman, 2017)

# Findings: Advocacy Process



# How does the VAP capitalize on parent strengths?

- ✓ Parents use their own experiences to advocate for others
- ✓ Historical role of parents in advocating for civil rights of children with disabilities
- ✓ Ongoing adaptation of the VAP training based on parent feedback and need

# How can we use these findings to inform policy?

1. Federally funded organizations (e.g., PTIs and P&As) should encourage families to connect with special education advocates who can provide them with instrumental and affective support
2. Need to develop and regulate special education advocacy at the national level
3. Focus on further engaging families in advocating for special education policy



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Volunteer Advocacy Project TN  
Website:

[http://vkc.mc.vanderbilt.edu/vkc/  
services/project/volunteer-  
advocacy/](http://vkc.mc.vanderbilt.edu/vkc/services/project/volunteer-advocacy/)

VAP Kentucky Website:

[www.buildinclusion.org/engage/v  
ap](http://www.buildinclusion.org/engage/vap)



# SUPPORTING FAMILIES IN THE TRANSITION TO EMPLOYMENT

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# FAMILY EMPLOYMENT AWARENESS TRAINING (FEAT)

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# Family Employment Awareness Training

## What is FEAT?

Two-part family-focused training designed to:

- Increase expectations regarding integrated and competitive employment
- Teach how to access local, state, and federal employment resources
- Develop self-advocacy and problem-solving skills
- Build state capacity through “train-the-trainer” model

# Working with Partners

- Kansas Health Policy Authority
- National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR)
- Beach Center on Disability, University of Kansas
- Families Together, Inc. (Kansas' Parent Training and Information Center)
- Kansas Workforce Services
- Kansas Public Schools



# F E A T

Family  
Employment  
Awareness  
Training



Expectations



Knowledge



Support/TA

# FAMILY ATTENDEE RESEARCH

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# Research Methods

- Survey

- Pre
- Short-term (1-2 months post)
- Long-term (1-year)

- Interviews

- 6-months
- 12-months
- 20-months

# Knowledge and Expectations

## Expectations

1-Month – Significantly higher

1-Year – Higher, but not significant

## Knowledge

1-Month – Significantly higher

1-Year – Significantly higher

**Key Takeaway:** While FEAT family attendees' expectations were significantly higher than non-attendees in the short-term, the impact of FEAT on expectations was not maintained over time like knowledge was.



# Short-term Perceptions of FEAT

FEAT positively influenced /improved . . .	Agreed	Strongly agreed
... my expectations for the employment of individuals with disabilities	46.1%	34.3%
... my accessing more resources	38.2%	16.7%
... my knowledge about employment resources	40.2%	52%
... the way I seek out and use employment resources	54.4%	24.3%
...my feeling that I can overcome barriers	50%	21.4%
... the way I address barriers to employment for individuals with disabilities	59.6%	27.3%

**Key Takeaway:** FEAT participants generally agreed or strongly agreed that attending FEAT was beneficial.

# Technical Assistance at 1-Year

- Forty percent of 1-year survey family respondents reported using technical assistance
- All found TA helpful or very helpful

**Key Takeaway:** FEAT participants benefited from receiving technical assistance throughout the year.

# Use of FEAT Resources

- 68% of respondents reported using FEAT resources in the year since the training
- 54% of respondents reported that they used FEAT resources at least once a month or more frequently

**Key Takeaway:** Participants continued to use FEAT information and resources throughout the year that followed training.

# Policy Implications

- Information
- Family engagement
- Training overlap

- Data for the professionals attending FEAT mimics families' data
  - ✓ Both increased expectations and knowledge
- Though both stakeholders report low expectations on the part of the other as a barrier
- Lack of knowledge of available resources
- Need to “be on the same page” – hearing the same info and speaking the same language

# THANK YOU!!

FAMILY EMPLOYMENT AWARENESS TRAINING (FEAT)

[HTTPS://BEACH.DRUPAL.KU.EDU/FAMILY-EMPLOYMENT-AWARENESS-TRAINING-FEAT](https://beach.drupal.ku.edu/family-employment-awareness-training-feat)

OR JUST GOOGLE “FAMILY EMPLOYMENT AWARENESS TRAINING”

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# SUMMARY AND QUESTIONS

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# History:

## Situating this Symposium in Context

- Previous research about families of individuals with disabilities was negative
  - Grieving process of having a child with a disability
- Current research about families of individuals with disabilities
  - Positive psychology framework
  - Caregiving burden, rewards, and self-efficacy

# Moving the field forward: Common Trends

- Capitalizing on Parent Strengths
  - History of parent advocacy (VAP)
  - Cultural values and beliefs (PTA)
  - Knowledge of child (FEAT)
- Building capacity
  - Train-The-Trainer (TTT) model
  - Parents (vs. professionals) in various roles
- Emphasizing family engagement
  - Need for families to have an outlet to be involved
  - Recognition of the importance of the family perspective



# History:

## Impact of the Family Perspective on Policy

- Namely, the Individuals with Disabilities Education Act (IDEA)
  - Parents filed lawsuits to enable their children with disabilities to attend school
  - Parents contacted legislators to request inclusive education
  - Parents collectively advocated for public education

# Moving the Field Forward: Multiple Policies Are Impacted by Family Perspectives

- Impacting multiple polices
  - Early Intervention, Maternal and Child Health Bureau, Developmental Disabilities Act, Parent Training and Information Centers, Medicaid, Vocational Rehabilitative Services, Social Security, Workforce Innovation Opportunity Act
- Building capacity for knowledge and advocacy
- Using parent voices to inform policy

Questions?

# THANK YOU!!

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