Gathering Provider Perspectives to Evaluate the Use of the PLAY Project with Traditionally Underserved Populations

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Presentation Outline

- Background
  - Terminology
  - Autism
  - PLAY Project
- Research Questions
- Theories
- Proposed Study
- Methods
- Analysis
- Anticipated Timeline

Background

Terminology

Autism/Autism Spectrum Disorder (ASD)

- Professionals prefer person-first language (e.g. “child with autism”)
- Advocates prefer identity-first language (e.g. “autistic child”)
- Autistic advocates’ preference: “autism” vs “autism spectrum disorder” (ASD)

Parent-implemented models

- Interventions in which professionals involve parents in implementing strategies to address outcomes with their child with autism.
- Additional terms
  - Parent-implemented intervention (PII)
  - Parent-mediated intervention (PMI)
  - Caregiver-mediated model (CMM).

Autism

- The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V)
  1) Deficits in social communication and interaction throughout multiple settings
     a) Social-emotional reciprocity
     b) Nonverbal communication
     c) Ability to understand relationships and develop and maintain them
  2) Restricted, repetitive behavior patterns, interests, or activities
     a) Repetitive movements
     b) Attachment to sameness and routines
     c) Intense focus on particular, restricted interests
     d) Hyper- or hypo-reactivity to sensory input

  - Must be present in the child's early development, even if noted retrospectively
  - Must cause significant impairment in the child's daily functioning

Autism (cont.)

- 1 in 54 children
  - 4 males: 1 female
- Economic cost in the United States in 2011
  - $17,081 per year per child
  - Total costs ≈ $11.5 billion
- High costs often due to interventions that rely heavily on professionals rather than caregivers
- Insurance mandates for autism intervention for those on state-regulated health plans
  - Require insurance coverage for Applied Behavioral Analysis (ABA)
    - Operant conditioning, not originally created as a PIM

Terminology – Traditionally Underserved Families (TUF)

Low-resourced	Culturally Diverse	Rural-dwelling
• < high school diploma • Unemployed • Government assistance (i.e., Medicaid)	• Race, ethnicity, or nationality (REN) other than white • Language	• Zip code

Barriers and Facilitators to Using Autism Interventions with TUF

Barriers

- Language barriers
- Stigma
- Stress
- Therapy strategies overwhelming
- Limited training of providers
- Limited support for services

Facilitators

- Flexibility in service delivery
- Using preferred language of family
- Involvement of extended family
- Intervention part of daily routines and family interactions
- Considering cultural values in interventions

Literature Review - adaptations made to evidence-based, parent-mediated autism interventions in the US

- Using parent-mediated autism interventions with families who have limited resources
  - Carr, T., & Lord, C. (2016). A pilot study promoting participation of families with limited resources in early autism intervention. Research in Autism Spectrum Disorders, 25, 87–96. https://doi.org/10.1016/j.rasd.2016.02.003
  - Kasari, C., Lawton, K., Shih, W., Barker, T. V., Landa, R., Lord, C., Orlich, F., King, B., Wetherby, A., & Senturk, D. (2014). Caregiver-Mediated Intervention for Low-Resourced Preschoolers With Autism: An RCT. Pediatrics, 134(1), e72–e79. https://doi.org/10.1542/peds.2013-3229
- Barriers to using evidence-based PIMs for autism with low-resourced families
  - Pickard, K. E., Kilgore, A. N., & Ingersoll, B. R. (2016). Using Community Partnerships to Better Understand the Barriers to Using an Evidence-Based, Parent-Mediated Intervention for Autism Spectrum Disorder in a Medicaid System. American Journal of Community Psychology, 57(3/4), 391–403. https://doi.org/10.1002/ajcp.12050
- Caregiver input about the cultural appropriateness of parent-mediated interventions
  - DuBay, M., Watson, L. R., & Zhang, W. (2018). In Search of Culturally Appropriate Autism Interventions: Perspectives of Latino Caregivers. Journal of Autism and Developmental Disorders, 48, 1623–1639. https://doi.org/10.1007/s10803-017-3394-8

Literature Review (cont.) - adaptations made to evidence-based, non-parent-mediated autism interventions

- Adaptations to non-parent-mediated evidence-based autism interventions
  - Kim, S. (2016). Use of video modeling to teach developmentally appropriate play with Korean American children with autism. Research and Practice for Persons with Severe Disabilities, 41(3), 158–172. https://doi.org/10.1177/1540796916658015
- Parents' and providers' perspectives about needed cultural adaptations regarding the diagnosis and management of autism
  - Sakai, C., Mulé, C., Leclair, A., Chang, F., Sliwinski, S., Yau, Y., & Freund, K. M. (2019). Parent and provider perspectives on the diagnosis and management of autism in a Chinese immigrant population. Journal of Developmental and Behavioral Pediatrics, 40(4), 257–265. https://doi.org/10.1097/DBP.0000000000000660
- Providers' perspectives of barriers and facilitators to using a parent training with families within the Medicaid system
  - Straiton, D., Groom, B., & Ingersoll, B. (2021). A mixed methods exploration of community providers' perceived barriers and facilitators to the use of parent training with Medicaid-enrolled clients with autism. Autism. https://doi.org/10.1177/1362361321989911

Barriers and Facilitators to Using Autism Interventions with TUF

Barriers/needs	Facilitators
Access/design/logistics (Carr & Lord, 2016; C. Kasari et al., 2014; Straiton et al., 2021)	Home/local sessions (Carr & Lord, 2016; C. Kasari et al., 2014) Travel expense compensation (Carr & Lord, 2016) Work with family schedules (C. Kasari et al., 2014) Decrease complexity of written materials (Pickard, Kilgore, et al., 2016) Improve care coordination (Sakai et al., 2019)
• **Language barrier (DuBay et al., 2018)**	Use CG's preferred language (C. Kasari et al., 2014) Improve interpretation/translation (Sakai et al., 2019)
Attrition (Carr & Lord, 2016)	Flexible service delivery (Carr & Lord, 2016; Pickard, Kilgore, et al., 2016) Liberal cancellation policy (Carr & Lord, 2016) Monetary incentives (Carr & Lord, 2016)

Barriers and Facilitators to Using Autism Interventions with TUF (cont.)

Barriers (cont.)	Facilitators (cont.)
Promote change (Carr & Lord, 2016)	Assist with/strengthen community resources (Carr & Lord, 2016; Sakai et al., 2019)
Family • **Stigma (DuBay et al., 2018)** • **Stressors/structure (Straiton et al., 2021)**	More extended family involvement (DuBay et al., 2018) Less extended family involvement (DuBay et al., 2018)
Therapy strategies • **Overwhelming when mixed and matched (DuBay et al., 2018)**	Must be seen as effective (DuBay et al., 2018) Incorporate physical connection (DuBay et al., 2018) Use daily routines (C. Kasari et al., 2014; Pickard, Kilgore, et al., 2016)

Barriers and Facilitators to Using Autism Interventions with TUF (cont.)

Barriers (cont.)	Facilitators (cont.)
Service providers • **Language barrier (DuBay et al., 2018)** • **Lack of professionalism (DuBay et al., 2018)** • **Limited training (DuBay et al., 2018)**	More involvement & support (DuBay et al., 2018) Open communication (DuBay et al., 2018) Increase professionalism (DuBay et al., 2018) Increase trainings (DuBay et al., 2018)
Other barriers: • **Limited family engagement/interest (Straiton et al., 2021)** • **Limited agency support (Straiton et al., 2021)**	Other facilitators: • Include all family members present (Carr & Lord, 2016; Pickard, Kilgore, et al., 2016) • Strong parent-therapist alliance (Pickard, Kilgore, et al., 2016) • Group therapy (DuBay et al., 2018) • Consider cultural values (DuBay et al., 2018; Kim, 2016; Sakai et al., 2019)

- Interventions mediated mostly by parents rather than professionals (PIMs)
  - Cost less
  - Easier to implement

- PLAY Project Consultants (PPCs)
  - Master's level pediatric professional and child development expert
  - Two-day intensive PLAY Project workshop
  - Six-week online course
  - 12-18 months of supervision

- PLAY Project
  - Evidence-based parent-implemented autism intervention

- PLAY Project randomized controlled trial (RCT)
  - Increased interaction skills
  - Increased functional development
  - Improved autism symptoms

PLAY RCT Limitations

Generalizability limited

- Parents
  - Higher than average education level: 53.1% of the parents had bachelors or higher degrees
  - Higher than average socio-economic status (SES) levels
- Families in the treatment group
  - 30% children of color
  - 91% of children from 2-parent households
- PLAY research and evaluation efforts to date - largely with urban dwelling and non-diverse populations

Knowledge gap

- Clear need for determining whether PLAY is effective with traditionally underserved populations, including children from culturally diverse, rural-dwelling, and low-resourced families
- Identify ways in which adaptations have been made by PPCs when implementing the PLAY Project intervention to meet the needs of traditionally underserved populations

Proposed Research Questions

Quantitative

1) How effective do PPCs consider the PLAY Project to be when used with TUF as compared to well-resourced families?

- Hypothesis: PPCs consider the PLAY Project to be less effective when used with TUF as compared with well-resourced families.

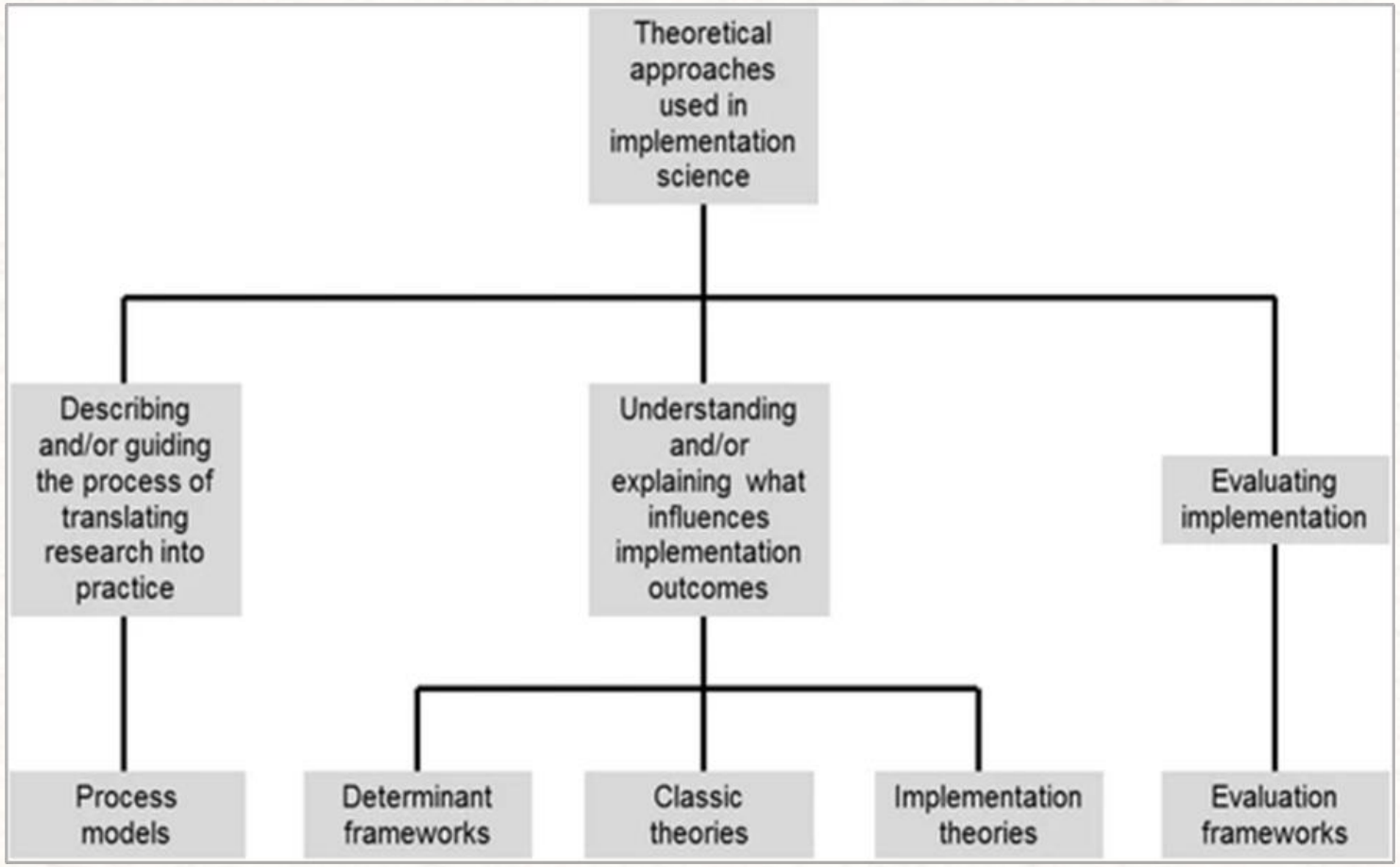
Qualitative

2) According to PPCs, what adaptations could be made when using the PLAY Project to facilitate its implementation and increase its effectiveness for rural, culturally diverse, and/or low-resourced families while maintaining its fidelity?

Theories

Implementation Science

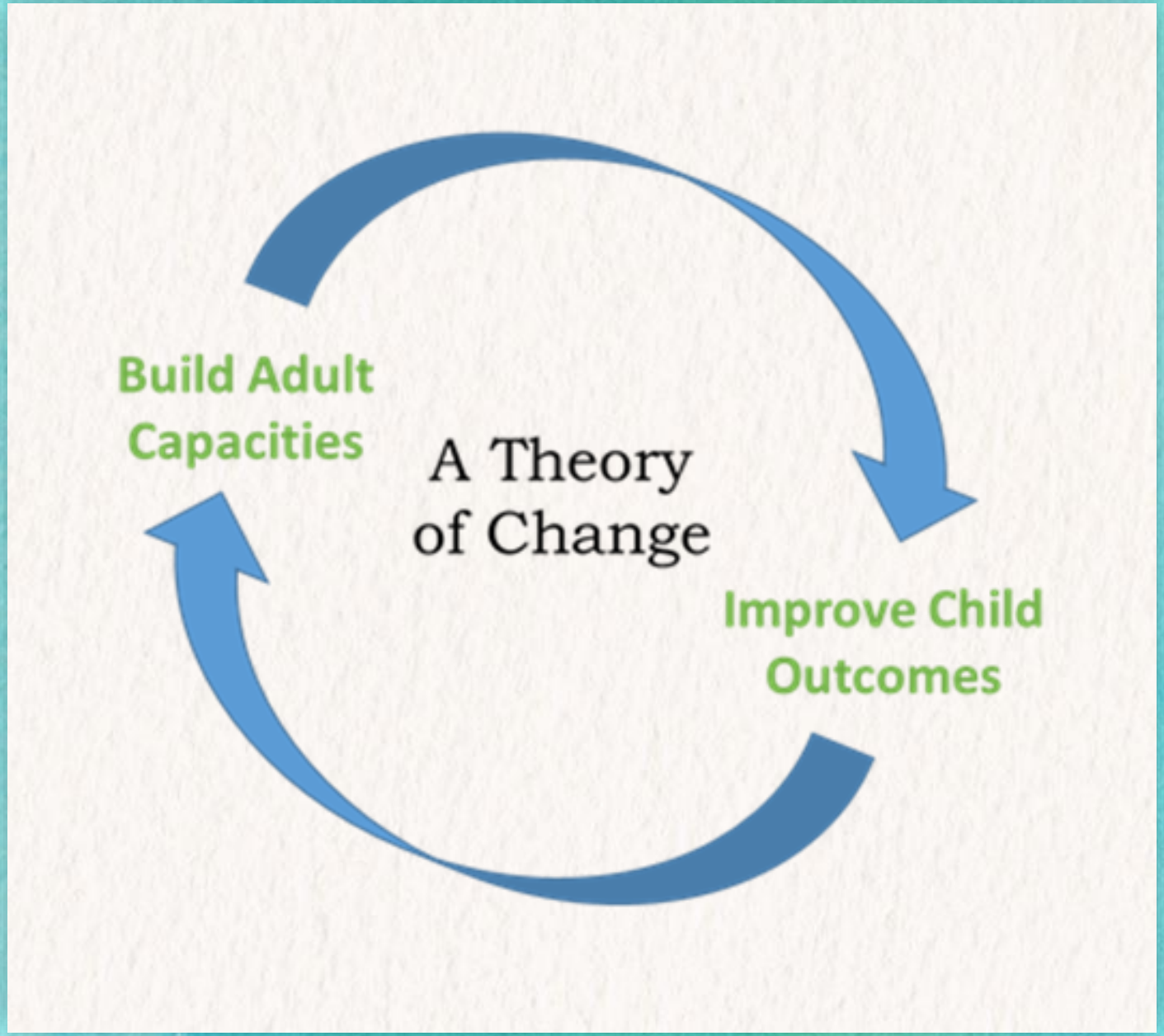
Use of theoretical approaches to help understand and explain how and why implementation of evidence-based programs in practice either succeeds or fails based on the need for strategies to facilitate implementation in real world settings



Nilsen, 2015

Theory of Change

Classic Theory



Ecological Validity Model (EVM)

Determinant Framework

8 Key Dimensions

1. Language
2. Persons
3. Metaphors
4. Content
5. Concept
6. Goals
7. Methods
8. Context

Methods

- Sequential mixed-methods analysis
  - Quantitative survey
  - Qualitative interview

Participants

Fully Certified PLAY Project Consultants (PPCs)

400 entities/emails registered with the PLAY Project organization

Survey

Overview

- Qualtrics
- Guided by EVM & Theory of Change
- Pilot survey
  - 3 PLAY Supervisors
  - $50 gift card incentive
  - Complete survey
  - Feedback via Zoom
- E-mailed to all 400 PLAY entities/emails
- Full support from PLAY Project organization

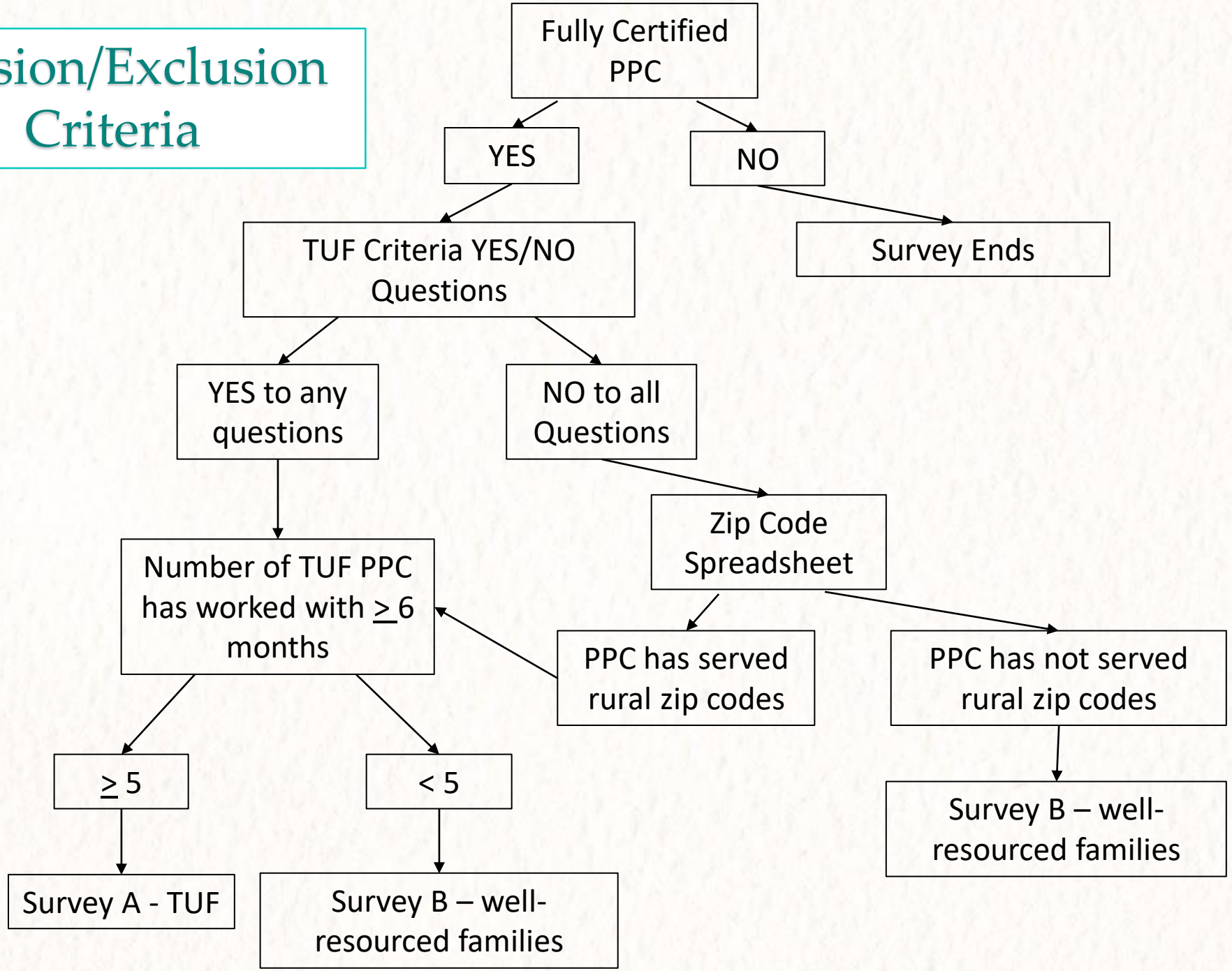
Survey

Online Survey Consent

PPC demographics

- Gender
- Age
- Race/ethnicity/nationality
- Education/degree(s)
- Discipline
- Professional role
- Professional certifications
- Employment setting
- PLAY delivery setting(s)
- Current PLAY caseload
- Length of time as a fully certified PPC

Inclusion/Exclusion Criteria



Survey – Format

- Definition
  - Survey A – TUF
  - Survey B – well-resourced families
- 5-point Likert-type Scale

1	2	3	4	5
Never	Sometimes	About half the time	Most of the time	Always

Survey (cont.)

Questions

3 Broad Statements

1) I feel successful/helpful when I use the PLAY Project with TUF.
2) I encounter barriers to using PLAY with TUF.
3) When using the PLAY Project, I adapt the way I implement the model with TUF.

Statements based on 8 key dimensions of EVM

3) When using PLAY with families who are non-English speaking, the family's primary **language** makes it easier (no impact, more difficult) to implement the PLAY Project than with English speaking families.
4) A family's diversity in **REN** makes it easier (no impact, more difficult) to implement the PLAY Project than with non-diverse families.
5) When working with TUF, families tend to understand the **vocabulary** and **concepts** used in PLAY better (the same as, more difficult) than well-resourced or English-speaking families.
6) When working with TUF, the family's **cultural identity** makes it easy (no impact, more difficult) to implement PLAY.
7) When working with TUF, the structural aspects (**constructs**) of PLAY, such as the time commitment, activities, techniques, and methods, coincide (conflict) with the culture of families, making them easier (no impact, difficult) to implement.
8) The **goals** of the PLAY Project coincide (conflict) with the goals of TUF, making them easier (no impact, more difficult) to implement than with well-resourced families.
9) When working with TUF, I adapt the way I implement the PLAY Project based on **culture**.
10) When using PLAY with TUF, I consider and support the degree to which that particular family has **acculturated** (as defined above) into mainstream American culture.

Survey

Questions (cont.)

- Degree to which PPCs agree/disagree that each of the following family/caregiver characteristics facilitates or creates a barrier to using PLAY with families (2 scales per characteristic)
  - Geographic location of family's home
  - Characteristics of home
  - Family's socio-economic status
  - Family's technological access/capabilities
  - Caregivers' education level

Survey

Questions (cont.)

- Degree to which PPCs agree/disagree that each of the following modalities through which they may deliver PLAY sessions facilitates or creates a barrier to using PLAY with TUF (2 scales per modality)
  - In-person
  - Video conference
  - Telephone

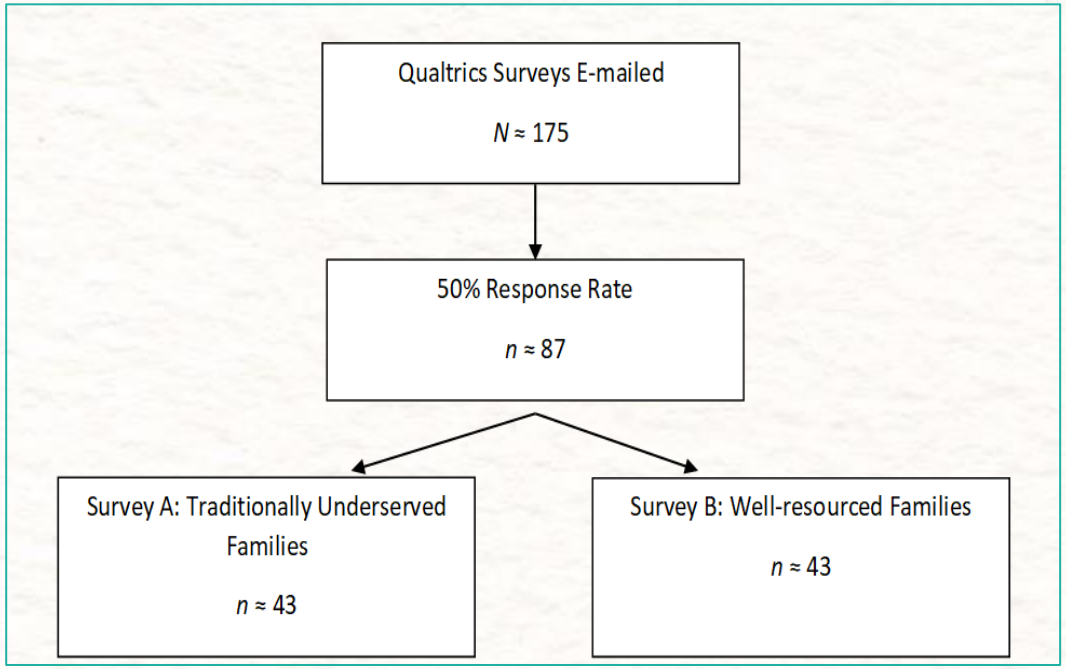
Survey

Questions (cont.)

- Theory of Change
  - Stressors
    - Low-resourced
    - Culturally diverse
    - Rural-dwelling
  - Familial/community supports
    - Low-resourced
    - Culturally diverse
    - Rural-dwelling
- COVID
- Comments

Survey – Response Rate

Conservative Prediction



To Maximize

1) Elicit aid of PLAY Project organization
2) Target PPCs
3) $10 gift card incentive
4) Short and concise
5) Inform approximate time
6) No open-ended questions (except comments at the end)
7) Confidentiality
8) Data collection, storage, and disposal
9) Personalized professional invitations
10) Reminder
11) (Time of year)

Survey Analysis

- Descriptive statistics
  - PPC Demographics
- Independent groups *t*-tests
  - Survey A – TUF
  - Survey B – well-resourced families

Interviews

Overview

Survey A participants	Semi-structured; iterative	Guided by 8 key dimensions of EVM & Theory of Change
Pilot tested and finalized by 3 PLAY Project supervisors • $50 gift card incentive	Purposive sampling	$20 gift card incentive
Zoom • Audio and video recorded	Saturation (n ≈ 13-16)	Reflexivity

Interviews

Questions

1) Broad, open-ended questions
   a) How has it been helpful to use PLAY with families who are rural, culturally diverse, and/or low-resourced?
   b) What barriers have you encountered while using PLAY with TUF?
2) 8 key dimensions of EVM
3) Family/caregiver characteristics
4) Modality
5) Theory of Change
6) COVID
7) Follow-up questions
   a) What have I missed?
   b) Given your years of experience, what I should I know to help me understand how to best use PLAY with TUF?

Interviews

Questions (cont.)

8 key dimensions of the Ecological Validity Model – Sample draft questions

1) Language
   a) What do you do when a family speaks a different language than you?
   b) Can you give me an example of that?

2) Persons
   a) What do you do when a family's race/ethnicity/nationality (REN) is different you're your own?
   b) Can you give me an example of that?

Interviews

Analysis

- Transcription
- Thematic analysis
  - Researcher + 1 additional coder
- Adaptations/strategies
- EVM/Theory of Change
- Member checking

Ethical Considerations

- NAU's Institutional Review Board
- Informed consent
- Potential risks/benefits
- Confidentiality
- Data storage

Considerations

Limitations

- Provider perspectives
  - Incomplete
  - Bias
- Researcher bias

Strengths

- First analysis of PLAY use with TUF
- Replicability – EVM
- Validity – member checking
- Knowledge/familiarity

Anticipated Timeline – 2022 – 2023

January – March

- Survey creation
- IRB approval

April – June

- Distribute survey
- Collect & analyze results
- Create interview guide

July – September

- Conduct interviews
- Transcribe, code, analyze interviews
- Write article 1 (Literature Review)

October – May

- Write article 2 (Results)
- Write article 3 (Clinical application)
- Defend dissertation

Conclusion

Desired Outcome

- To identify potential strategies that could help PLAY Project Consultants deliver the PLAY Project autism intervention in a way that may be more effective for rural, culturally diverse, and/or low-resourced families.

Thank You