

Family Outcomes of Newborn Screening: Project Background and Overview



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Administration, through a cooperative agreement with
the Association of Public Health Laboratories*

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Summary points

- Although newborn screening (NBS) focuses mostly on benefits to the child, families benefit as well
- Very little work has been done to assess family outcomes of NBS, and there is no agreement on what those outcomes should be
- We have prior experiences in developing an assessment tool to document family outcomes of early intervention
- We are building on these experiences to develop a tool and process to assess family outcomes of NBS
- Such an instrument could be an important component to assess long-term outcomes of NBS

Some definitions

- ***Family-centered approach***: The essential assumption is that young children cannot be viewed apart from their families, nor can services be provided without a consideration of the family context.
- Families are not viewed as clients receiving services but are partners in making decisions about goals and activities.
- Core principles
 - focus on family strengths
 - respect family diversity and values
 - encourage family decision making and empowerment
 - communicate with families in an open and collaborative fashion
 - adopt a flexible approach to service provision
 - recognize the value of informal support systems

Some definitions (continued)

- ***Family satisfaction***: The extent to which families are satisfied with various aspects of a program (e.g., amount of services, quality of services).
- ***Family outcome***: A benefit that families receive as a result of services. An outcome is not the receipt of services, but what happens as a consequence of services or supports.
- ***Example differentiation***:
 - Satisfaction: How a family feels about the quality of the information provided about their child's health condition
 - Outcome: How well a family understands the nature and consequences of their child's health condition

Rationale for assessing family outcomes

- Heritable disorders are family disorders
- Child well-being cannot be fully understood without considering family context
- Families play critical roles in their child's health and development. They spend more time with their child than any professional ever will. Supporting family adaptation and confidence in parenting has direct benefits for children
- Documenting whether and how NBS and subsequent follow-up services affect family outcomes is essential for understanding the long-term consequences of NBS

The National Early Intervention Longitudinal Study (NEILS) 1996-2005

PEDIATRICS

First Experiences With Early Intervention: A National Perspective

Donald B. Bailey, Jr, PhD*; Kathleen Hebbeler, PhD‡; Anita Scarborough, PhD*; Donna Spiker, PhD‡; and Sangeeta Mallik, PhD‡

Thirty-Six-Month Outcomes for Families of Children Who Have Disabilities and Participated in Early Intervention

Donald B. Bailey, Jr, Kathleen Hebbeler, Donna Spiker, Anita Scarborough, Sangeeta Mallik and Lauren Nelson
Pediatrics 2005;116;1346-1352
DOI: 10.1542/peds.2004-1239

Modeling the Impact of Formal and Informal Supports for Young Children With Disabilities and Their Families

Donald B. Bailey, Jr, Lauren Nelson, Kathy Hebbeler and Donna Spiker
Pediatrics 2007;120:e992-e1001; originally published online Sep 24, 2007;
DOI: 10.1542/peds.2006-2775

Exceptional Children

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Measuring Family Outcomes in Early Intervention: Findings From a Large-Scale Assessment

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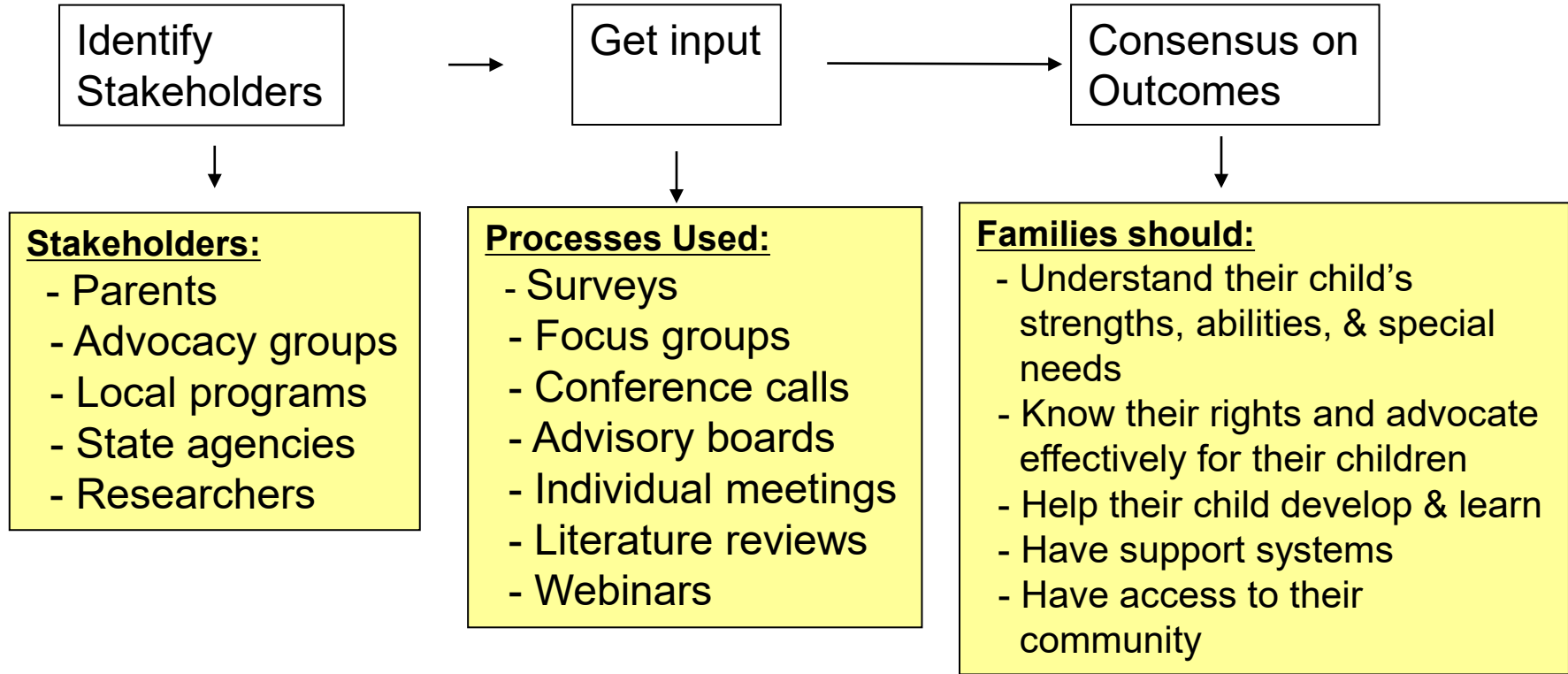
Near the completion of NEILS, the Early Childhood Outcomes (ECO) Center was funded

Goal: Promote the development and implementation of child and family outcome measures that can be used in local, state, and national accountability systems

Activities:

- Consensus building
- Collaboration
- Technical assistance
- Research
- Recommendations

The first task was to identify a broad set of family outcomes



Example: Can help their child develop and learn

- Know and use styles of effective parenting
- Provide a nurturing and stimulating environment
- Help child participate in family routines and activities
- Use special techniques to enhance learning or manage behavior
- Modify the home environment or routines
- Help their child use special adaptive equipment

Outcomes published and became the foundation for instrument development and measurement

Journal of Early Intervention, 2006
Vol. 28, No. 4, 227-251
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REGULAR ARTICLES

Recommended Outcomes for Families of Young Children with Disabilities

DONALD B. BAILEY, JR.
RTI International

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University of Connecticut

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SRI International¹

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JOY MARKOWITZ
Westat

DONNA SPIKER¹, DALE WALKER², LAUREN BARTON¹

We developed, tested, and revised the Family Outcomes Scale

- Based on the 5 family outcomes
- A self-report instrument completed by families
- Items developed through extensive lit review and feedback from parents and professionals
- 2 iterations with modifications based on data and feedback
- Initial version published in 2006
- Revised version (FOS-R) published in 2011
- Posted on website
- Now freely available in 16 languages:

<https://ectacenter.org/eco/pages/familysurveys.asp>

Outcomes Reported by Spanish-Speaking Families in Early Intervention

Topics in Early Childhood
Special Education
30(1) 46-55
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DOI: 10.1177/0271121409360827
<http://tccse.sagepub.com>
SAGE

Murrey G. Olmsted¹, Donald B. Bailey, Jr.¹, Melissa Raspa¹, Robin E. Nelson², Nyle D. Robinson³, Mary Ellen Simpson⁴, and Chelsea Guillen⁵

English: Your child is growing and learning. How much does your family understand about your child's development?

1	2	3	4	5	6	7
We are just beginning to understand our child's development		We understand some about our child's development		We understand a good amount about our child's development		We understand a great deal about our child's development

Spanish: Su hijo está creciendo y aprendiendo. ¿Qué tan bien entienden el desarrollo de su hijo?

1	2	3	4	5	6	7
Apenas estamos empezando a entender el desarrollo de nuestro hijo		Tenemos un entendimiento básico del desarrollo de nuestro hijo, pero todavía hay mucho por aprender		Tenemos un buen entendimiento del desarrollo de nuestro hijo		Entendemos muy bien el desarrollo de nuestro hijo

Version 2: FOS-R (2011)

- Create a new format that would be easier for parents to use
- Revise and expand survey items to provide more information for states to use in planning for program improvement
- Test psychometric properties and finalize accordingly

Articles

Development and Psychometric Validation of the Family Outcomes Survey–Revised

Journal of Early Intervention

Volume 33 Number 1

March 2011 6-23

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FAMILY OUTCOMES SURVEY
Revised Version
Section A: Family Outcomes

Instructions: Section A of the Family Outcomes Survey focuses on the ways in which you support your child's needs. For each statement below, please select which option best describes your family right now: not at all, a little, somewhat, almost, or completely.

	Not at all	A little	Somewhat	Almost	Completely
Outcome 1: Understanding your child's strengths, needs, and abilities					
1. We know the next steps for our child's growth and learning.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. We understand our child's strengths and abilities.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. We understand our child's delays and/or needs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. We are able to tell when our child is making progress.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Outcome 2: Knowing your rights and advocating for your child					
5. We are able to find and use the services and programs available to us.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. We know our rights related to our child's special needs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. We know who to contact and what to do when we have questions or concerns.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. We know what options are available when our child leaves the program.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. We are comfortable asking for services & supports that our child and family need.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Outcome 3: Helping your child develop and learn					
10. We are able to help our child get along with others.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. We are able to help our child learn new skills.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. We are able to help our child take care of his/her needs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. We are able to work on our child's goals during everyday routines.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Outcome 4: Having support systems					
14. We are comfortable talking to family and friends about our child's needs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. We have friends or family members who listen and care.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. We are able to talk with other families who have a child with similar needs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. We have friends or family members we can rely on when we need help.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. I am able to take care of my own needs and do things I enjoy.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Outcome 5: Accessing the community					
19. Our child participates in social, recreational, or religious activities that we want.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. We are able to do things we enjoy together as a family.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21. Our medical and dental needs are met.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22. Our child care needs are met.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23. Our transportation needs are met.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
24. Our food, clothing, and housing needs are met.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

FAMILY OUTCOMES SURVEY
Revised Version
Section B: Helpfulness of Early Intervention



Instructions: Section B of the Family Outcomes Survey focuses on the helpfulness of early intervention. For each question below, please select how helpful early intervention has been to you and your family over the past year: Not at all helpful, a little helpful, somewhat helpful, very helpful, or extremely helpful.

	Not at all helpful	A little helpful	Somewhat helpful	Very helpful	Extremely helpful
Knowing your rights					
How helpful has early intervention been in...					
1. giving you useful information about services and supports for you and your child?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. giving you useful information about your rights related to your child's special needs?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. giving you useful information about who to contact when you have questions or concerns?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. giving you useful information about available options when your child leaves the program?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. explaining your rights in ways that are easy for you to understand?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Communicating your child's needs					
How helpful has early intervention been in...					
6. giving you useful information about your child's delays or needs?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. listening to you and respecting your choices?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. connecting you with other services or people who can help your child and family?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. talking with you about your child and family's strengths and needs?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. talking with you about what you think is important for your child and family?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. developing a good relationship with you and your family?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Helping your child develop and learn					
How helpful has early intervention been in...					
12. giving you useful information about how to help your child get along with others?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. giving you useful information about how to help your child learn new skills?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. giving you useful information about how to help your child take care of his/her needs?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. identifying things you do that help your child learn and grow?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. sharing ideas on how to include your child in daily activities?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. working with you to know when your child is making progress?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



What have we learned from research using the FOS and FOS-R?

- Many factors need to be considered when developing an assessment tool
- FOS-R has robust psychometric properties
- Wide acceptance among states
- Families generally reported positive outcomes
- Family-centered practices are associated with outcomes
- Race/ethnicity and language continue to be associated with outcomes
- International interest

Infants & Young Children

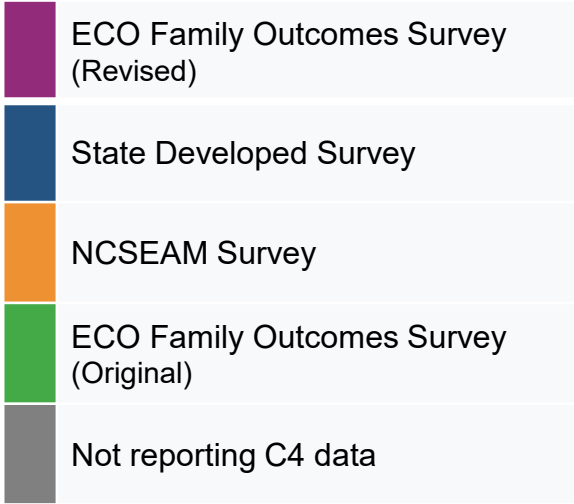
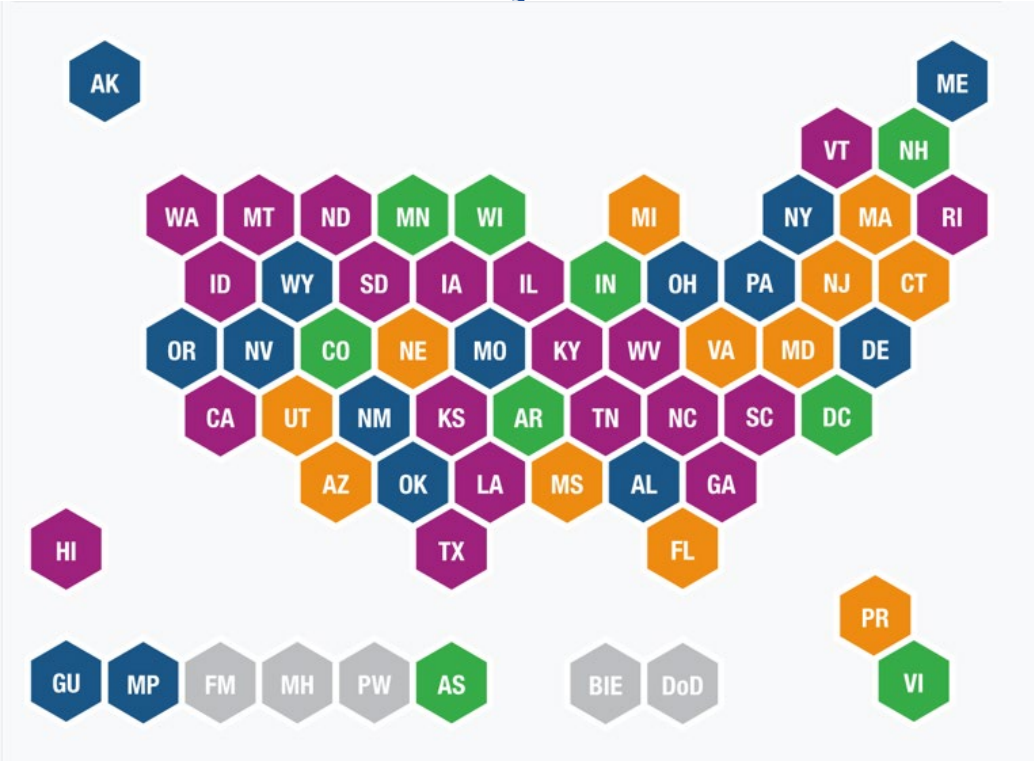
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Measuring Family Outcomes Considerations for Large-Scale Data Collection in Early Intervention

*Donald B. Bailey, Jr, PhD; Kathleen Hebbeler, PhD;
Murrey G. Olmsted, PhD; Melissa Raspa, PhD;
Mary Beth Bruder, PhD*

FFY 2020 FOS used by states for annual reporting purposes



<https://ectacenter.org/eco/pages/familyoutcomes.asp>

Source: Early Childhood Technical Assistance Center, University of North Carolina at Chapel Hill

International Research

Contents lists available at [ScienceDirect](#)

Research in Developmental Disabilities

ELSEVIER

Psychometric validation of the Family Outcome Survey-Revised in Singapore

Kenneth K. Poon^{a,*}, Nona Ooi^a, Rebecca Bull^a, Donald B. Bailey Jr.^b



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SAGE

Exploring the Predictors of Family Outcomes of Early Intervention for Children on the Autism Spectrum: An Australian Cohort Study

Rachelle Wicks^{1,2} , Jessica Paynter^{1,2}, and Dawn Adams^{1,2} 

- We are working on a paper based on a longitudinal study of outcomes experienced by families who have a child with Congenital Zika Syndrome in Brazil



Primary goal of the current project: Develop a framework and identify domains for assessing family outcomes of NBS

- Use multiple sources of input and engagement to identify an initial set of family outcomes
 - Literature review
 - Stakeholder engagement (including community partnerships and focus groups)
 - Advisory board
- Widely distribute draft outcomes for input
 - Survey with opportunities for quantitative and qualitative feedback
 - Direct outreach to parent and professional organizations
 - Ongoing advisory board feedback
- Finalize a set of outcomes generally endorsed by diverse stakeholders
- Write and submit an article for publication detailing the rationale, process and recommendations
- Begin work to determine next steps in instrument development and use



Thank you

Contact: Don Bailey d Bailey@rti.org