Meeting of the Interagency Autism Coordinating Committee

Friday, January 13, 2017

Neuroscience Center (NSC) Building
6001 Executive Boulevard
Conference Rooms C and D
Rockville, MD 20892

Conference Call Access:
Phone: 888-989-9784
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Meeting of the IACC

Morning Agenda

9:00 AM **Welcome, Introductions, Roll Call, and Approval of Minutes**

Joshua Gordon, M.D., Ph.D.
Director, NIMH and Chair, IACC

Susan Daniels, Ph.D.
Director, OARC, NIMH and Executive Secretary, IACC

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Meeting of the IACC

Morning Agenda – continued

9:15 **Update from the HHS Office of the National Autism Coordinator**

Thomas Novotny, M.D.
Deputy Assistant Secretary for Health and National Autism Coordinator
Department of Health and Human Services

9:25 **Update from Autism Speaks**

Angela Geiger
Chief Executive Officer of Autism Speaks

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Autism Speaks

Angela Geiger,

Chief Executive Officer

Meeting of the IACC

Morning Agenda - continued

10:10 **Translating Science into Practices: Autism Focused Intervention Resources and Modules**

Sam Odom, Ph.D
Director
Frank Porter Graham Child Development Institute
University of North Carolina-Chapel Hill

10:55 **Morning Break**

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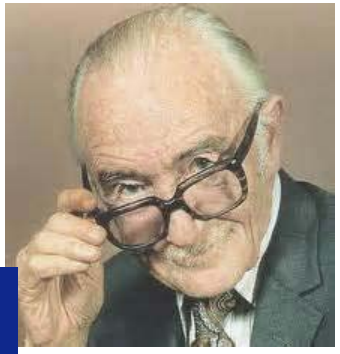
Translating Science into Practices: Autism Focused Intervention Resources and Modules

Samuel L. Odom, Ann Sam, and Ann Cox
Frank Porter Graham Child Development Institute
University of North Carolina at Chapel Hill

The Research-Practice Gap

- Evidence-based medicine movement dates back to the 1960s (Cochrane's work)
  - Followed by Sackett's work in Canada
- Clinical psychology identification of "empirically supported treatments"
- No Child Left Behind: "Scientifically based practices"
- Every Student Succeeds Act (ESSA): "Evidence-based Practices"

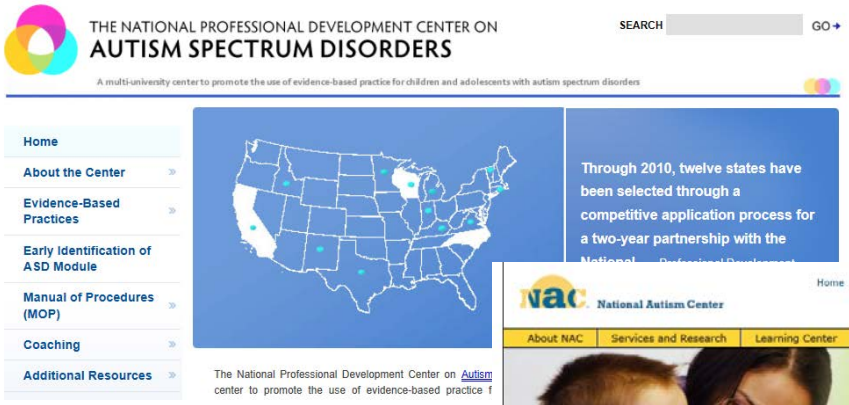


The Cochrane Collaboration

Autism and Evidence-Based Focused Intervention Practices: Early Sources of Information

- Books
- Book chapters
- Narrative reviews

Systematic and Critical Reviews of Intervention Literature: NPDC & NAC



Odom, Collet-Klingenberg, Rogers, & Hatton (2010)

National Autism Center (2009)

National Standards Project

- About NSP
- Phase 1 (2009)
- Phase 2 (2015)

Home › National Standards Project

National Standards Project

Families, educators, and service providers are constantly bombarded by a massive amount of confusing and often conflicting information about the myriad treatments available. The National Standards Project is helping to reduce the resulting turmoil and uncertainty by addressing the need for evidence-based practice standards and providing guidelines for how to make choices about interventions.

> *"The National Standards Report may be the most important document that parents and practitioners ever read and the most important weapon in their arsenal to fight autism."*
>
> *Marjorie H. Charlop, Ph.D. / Professor of Psychology, Claremont McKenna College / Director, The Claremont Autism Center*

Overview

The National Standards Project – Phase 1 and Phase 2 – answers one of the most pressing public health questions of our time — how do we effectively treat individuals with autism spectrum disorder (ASD)? The project's primary goal is to provide critical information about which interventions have been shown to be effective for individuals with ASD.

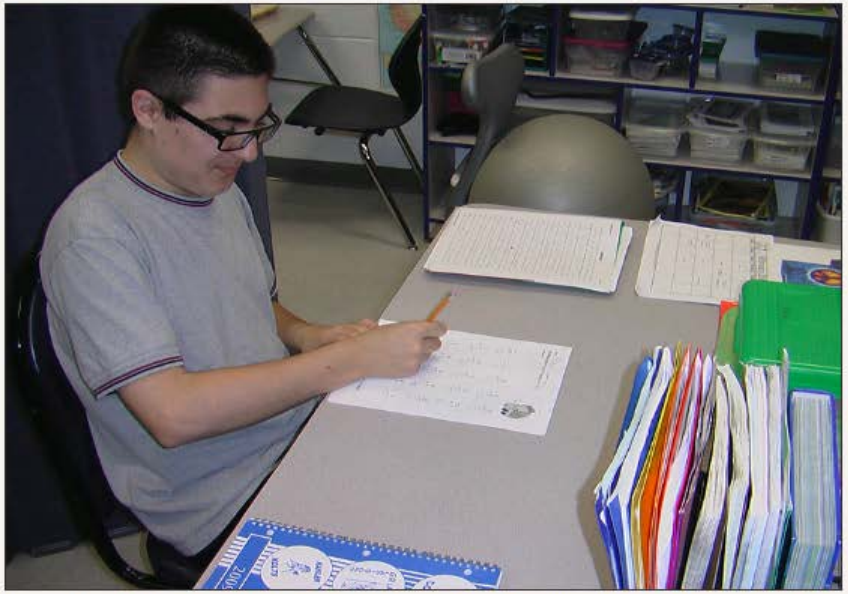
Phase 1 (released in 2009) examined and quantified the level of research supporting interventions that target the core characteristics of ASD in children, adolescents, and young adults (below 22 years of age) on the autism spectrum.

Phase 2 (released in 2015) provides an update to the literature for interventions for those under age 22, and also included studies evaluating interventions for adults (22+), which have never been systematically evaluated before now.

The National Standards Report serves as a single, authoritative source of guidance for parents, caregivers, educators, and service providers as they make informed intervention decisions. We are confident that these findings and recommendations will change lives and give hope and direction to people whose lives are touched by autism.

The National Professional Development Center
on Autism Spectrum Disorder

HOME | ABOUT NPDC | NEWS | EVIDENCE-BASED PRACTICES | NPDC MODEL | RESOURCES | TESELA



Since 2007, the National Professional Development Center on Autism Spectrum Disorder (NPDC) has worked to develop free professional resources for teachers, therapists, and technical assistance providers who work with individuals with ASD. Resources include detailed information on how to plan, implement, and monitor specific evidence-based practices.

IDEAs that Work
Office of Special Education Programs
U.S. Department of Education

NPDC NEWS & UPDATES

New AFIRM Module Available
Access your account now or create a free account to see the Self-management module

READ MORE

More

AFIRM

AFIRM Autism Focused Intervention Resources and Modules

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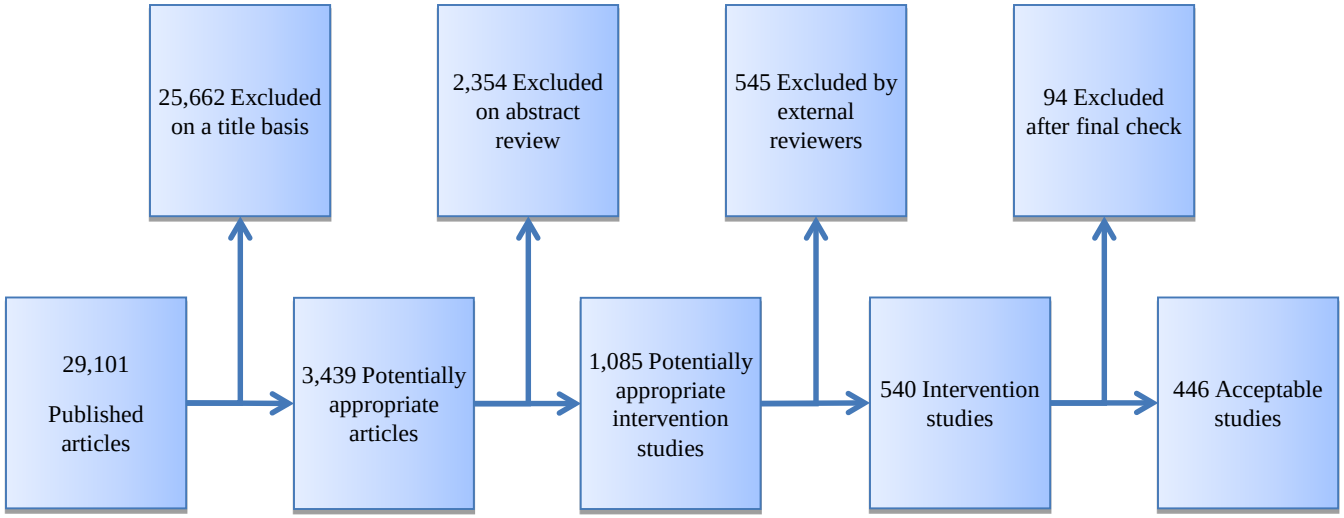
BRIEF NPDC OVERVIEW VIDEO

A coach talks about the NPDC model and the impact of using evidence-based practices.

Literature Results

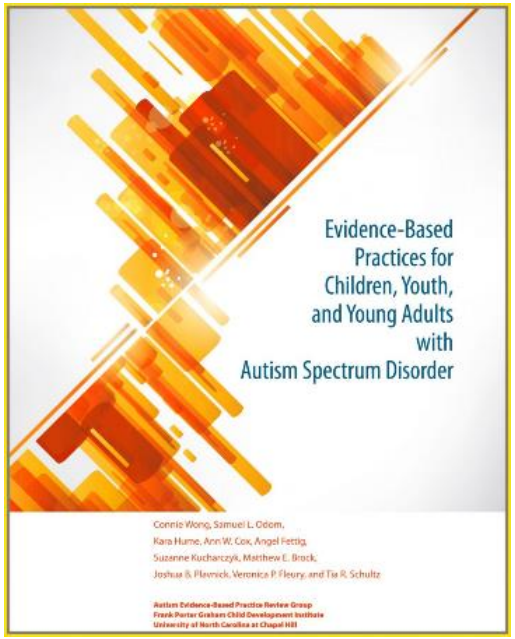


25,662 excluded on a title basis
2,354 excluded on abstract review
545 excluded by external reviewers
94 excluded after final check
29,101 published articles
3,439 potentially appropriate articles
1,085 potentially appropriate intervention studies
540 intervention studies
446 acceptable studies

Content Analysis

National Professional Development Center on ASD

- Wong et al. 2014 recently updated Odom et al. (2010) EBP review
  - http://autismpdc.fpg.unc.edu/how-do-i-find-out-more-about-ebps
- Began with pool of 29,150+ articles and reduced to 456 articles
- 27 EBPs identified



EBP Criteria

- Criteria for Qualification as an Evidence-Based Practice
  - At least two high quality experimental group or quasi-experimental design articles
    - Conducted by at least two different researchers or research groups

OR

  - At least five high quality single case design articles
    - Conducted by at least three different researchers or research groups
    - Having a total of at least 20 participants across studies

OR

  - A combination of at least one high quality group experimental or quasi-experimental design article and at least three high quality single case design articles
    - Conducted by at least two different research groups

Evidence-Based Focused Intervention Practices

Fundamental Applied Behavior Analysis Practices

- Reinforcement*
- Prompts*
- Time delay*
- Modeling*
- Task analysis*

*ABA Techniques

Positive Behavior Intervention and Support

- Functional assessment*
- Antecedent-based* intervention
- Extinction*
- Response interruption/redirection*
- Differential reinforcement of alternative/other behavior*
- Functional communication training*

Evidence-Based Focused Intervention Practices

Social Communication Interventions

- Social skills training
- Peer-mediated interventions and instruction*
- Social narratives
- Structured play groups
- Picture Exchange Communication System (PECS®)*

Broad Teaching Strategies

- Visual supports
- Discrete trial training*
- Naturalistic interventions*
- Pivotal response training*
- Parent implemented interventions
- Scripting*
- Exercise

*ABA Techniques

Evidence-Based Focused Intervention Practices

Cognitive Behavior

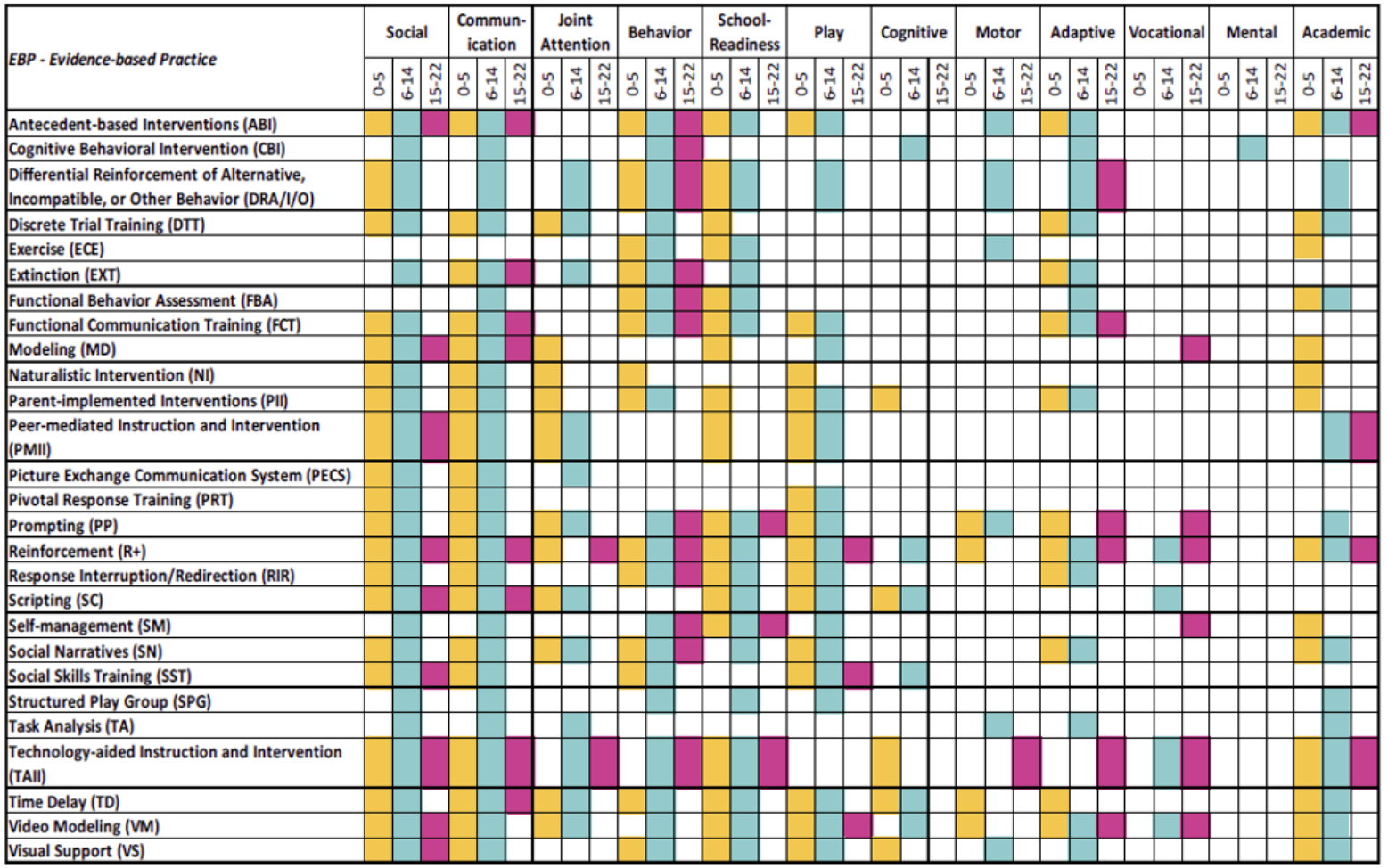
- Self management*
- Cognitive behavior interventions*

Technology Oriented

- Technology-assisted instruction and intervention
- Video modeling*

*ABA Techniques

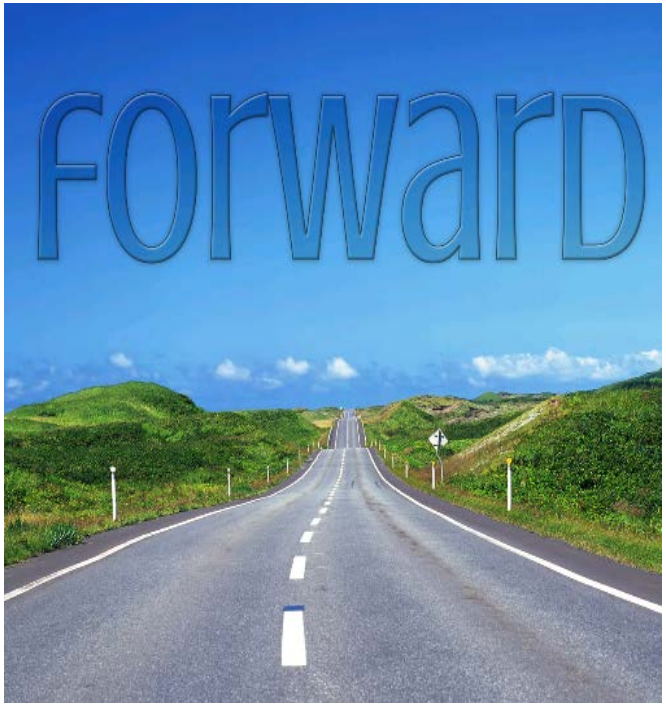
Matrix of Evidence-based Practices by Outcome and Age

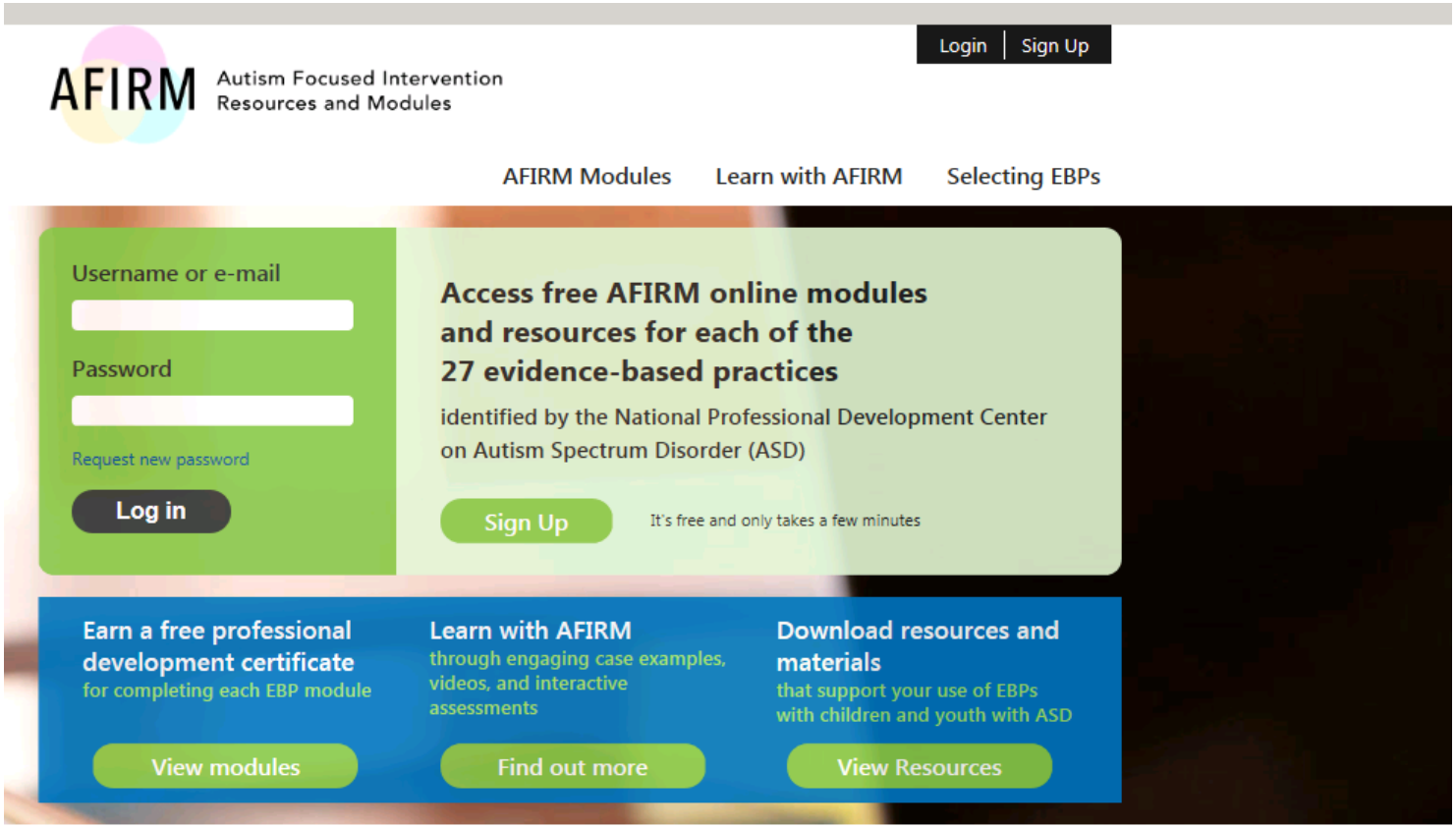


Evidence-Based Practices Identified by the National Professional Development Center (NPDC) on ASD	Established Treatments Identified by the National Standards Project (NSP)													
	Behavioral Interventions	Cognitive Behavioral Interventions	Language Training	Modeling	Natural Teaching Strategies	Parent Training	Peer Training Package	Pivotal Response Training	Schedules	Scripting	Self-management	Social Skills Package	Story-based Intervention	Comprehensive Behavioral Treatment for Young Children
Antecedent-Based Intervention	X													The NPDC on ASD did not review comprehensive treatment models. Components of The Comprehensive Behavioral Treatment of young Children overlap with many NPDC identified practices.
Differential reinforcement	X													
Discrete trial training	X													
Extinction	X													
Modeling	X			X										
Prompting	X													
Reinforcement	X													
Response Interruption/Redirection	X													
Scripting	X									X				
Task Analysis	X													
Video Modeling	X			X										
Time Delay	X													
Cognitive Behavioral Intervention		X												
Naturalistic Intervention					X									
Parent Implemented Intervention						X								
Peer-mediated Intervention							X							
Pivotal Response Training								X						
Self-management											X			
Social Narratives													X	
Social Skills Training												X		
Visual Supports									X					
Exercise	Exercise was identified as an emerging practice by the NSP.													
Functional Behavior Assessment	The NSP did not consider Functional Behavior Assessment as a category of evidence-based practice.													
Functional Communication Training	Functional communication training was identified as an emerging practice by the NSP.													
Picture Exchange Communication	Picture Exchange Communication System was identified as an emerging practice by the NSP.													
Structured Play Groups	The NSP Did not consider Structured Play Groups as a category of evidence-based practice.													
Technology-aided intervention	Technology-aided intervention was identified as an emerging practice by the NSP.													

Next Step in This Work: National Clearinghouse for Autism Practice Evidence (NCAPE)

- Launching this new center in January, 2017
- Incorporate last five-six years of focused intervention practices research (2011-2017)
- Develop process for continuous update Conduct a review of comprehensive treatment models
- Conduct a review of psychopharm and behavioral/psycho-pharma interventions
- Operating on initial seed funding for first year





Contact Us

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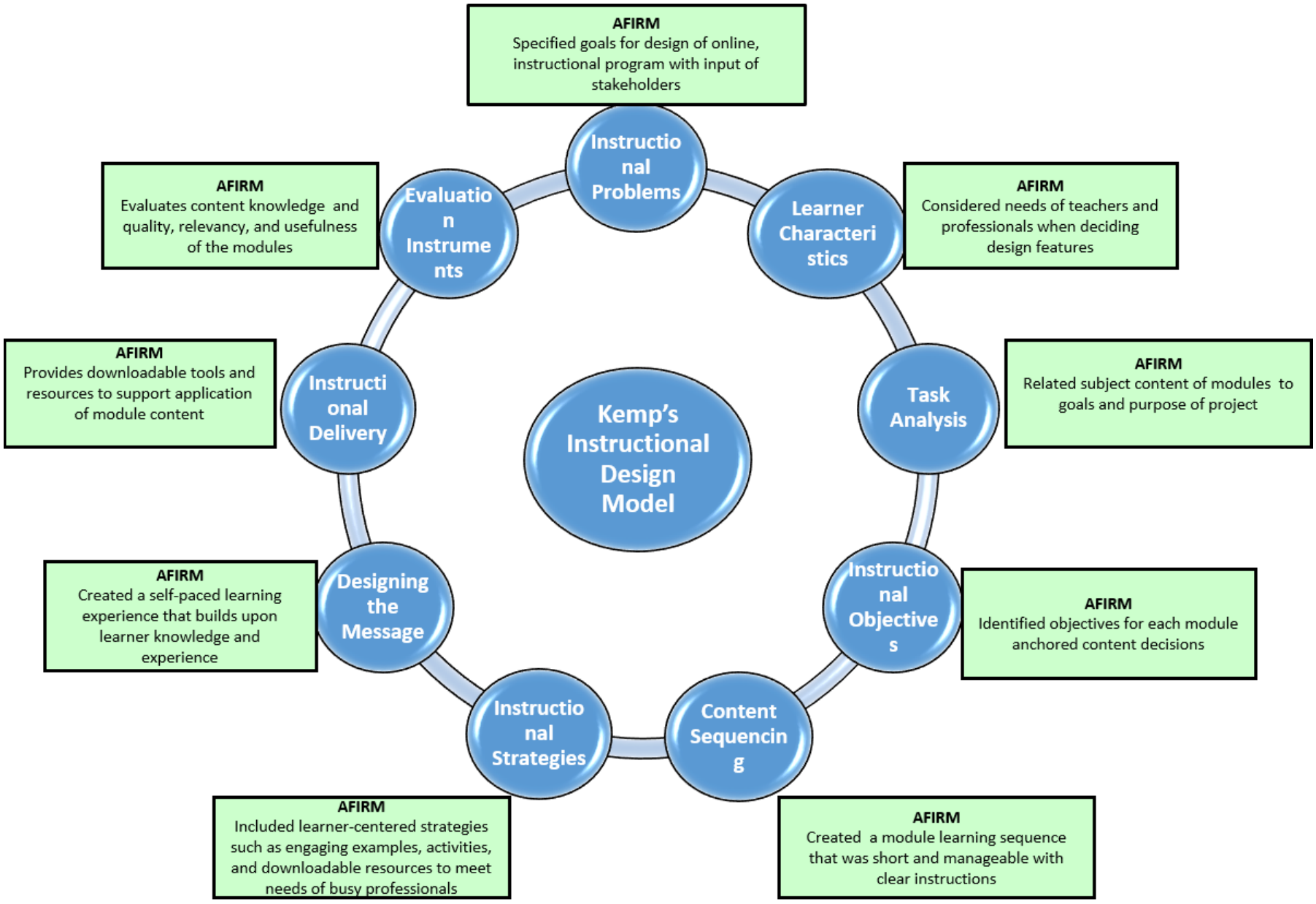
Autism Focused Intervention Resources & Modules (AFIRM) is an extension of the National Professional Development Center (NPDC) on ASD. Visit the NPDC website for more information.

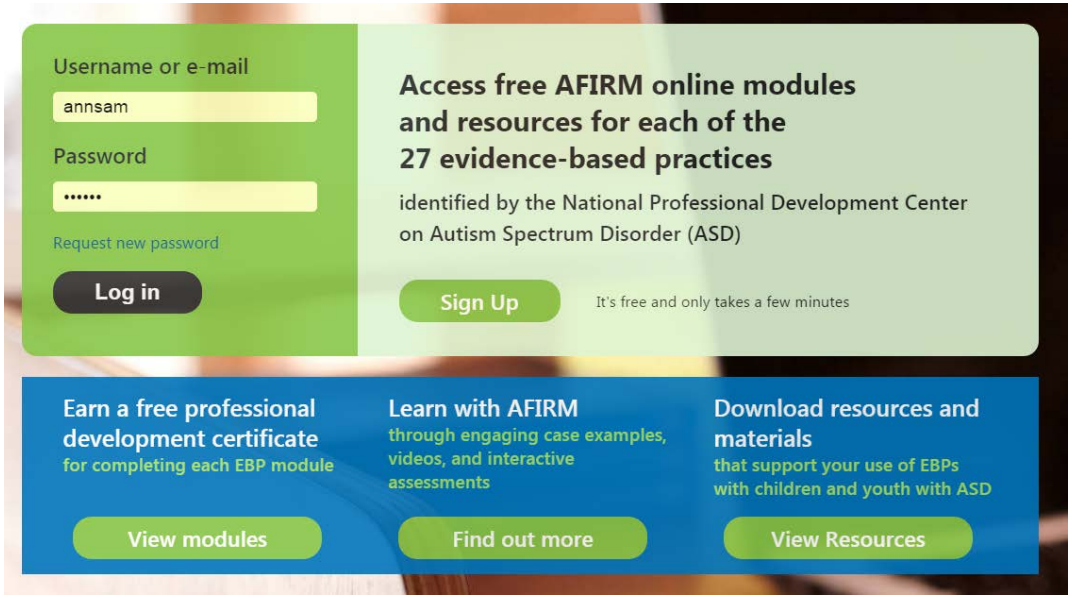
IDEAs that Work
Office of Special Education Programs
U.S. Department of Education

UNC
FRANK PORTER GRAHAM CHILD DEVELOPMENT INSTITUTE


Kemp's Instructional Design Model
Instructional Problems
AFIRM
Specified goals for design of online, instructional program with input of stakeholders
Learner Characteristics
AFIRM
Considered needs of teachers and professionals when deciding design features
Task Analysis
AFIRM
Related subject content of modules to goals and purpose of project
Instructional Objectives
AFIRM
Identified objectives for each module anchored content decisions
Content Sequencing
AFIRM
Created a module learning sequence that was short and manageable with clear instructions
Instructional Strategies
AFIRM
Included learner-centered strategies such as engaging examples, activities, and downloadable resources to meet needs of busy professionals
Designing the Message
AFIRM
Created a self-paced learning experience that builds upon learner knowledge and experience
Instructional Delivery
AFIRM
Provides downloadable tools and resources to support application of module content
Evaluation Instruments
AFIRM
Evaluates content knowledge and quality, relevancy, and usefulness of the modules

AFIRM

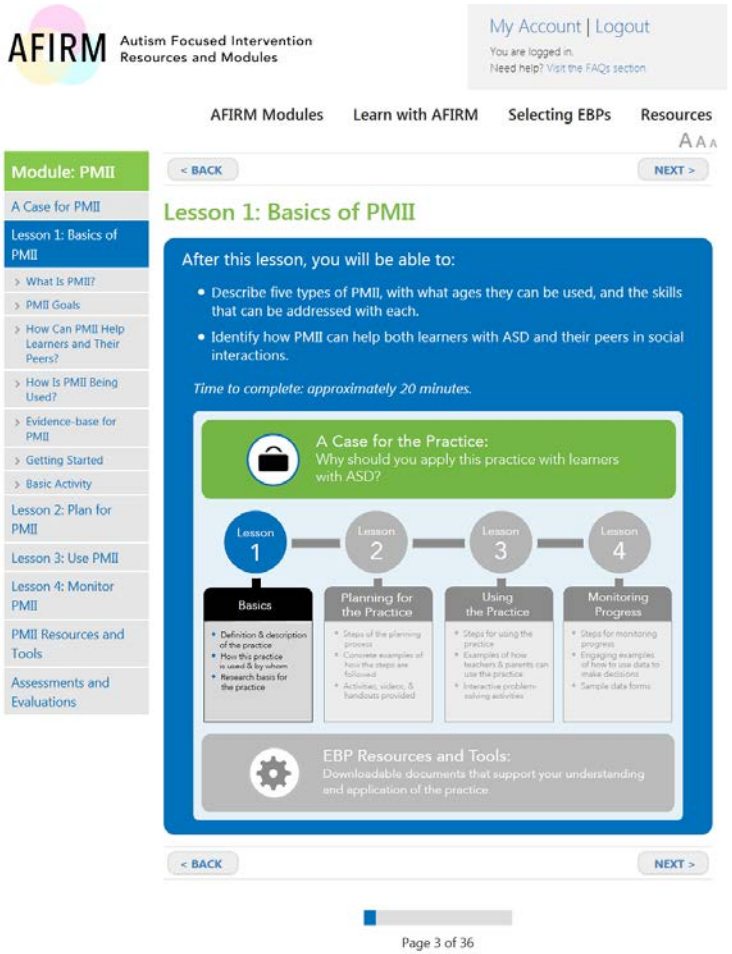
- E-learning modules for 27 EBPs
  - http://afirm.fpg.unc.edu/
- Target audience
  - Special educators
  - General education teachers
  - Related service personnel
  - Early interventionism
- Planning, using, monitoring EBPs



AFIRM Autism Focused Intervention Resources & Modules

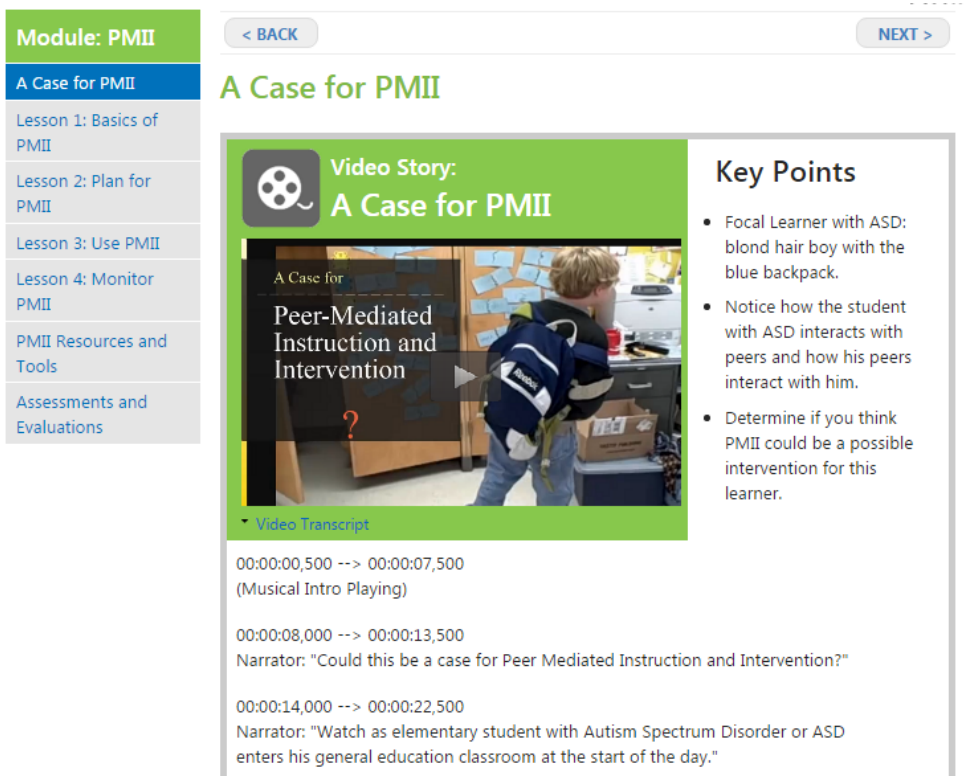
AFIRM Structure

- 4 lessons
  - Basics of EBP
  - Plan for EBP
  - Use EBP
  - Monitor EBP
- Key components of EBPs
- Step-by-step process for applying practice



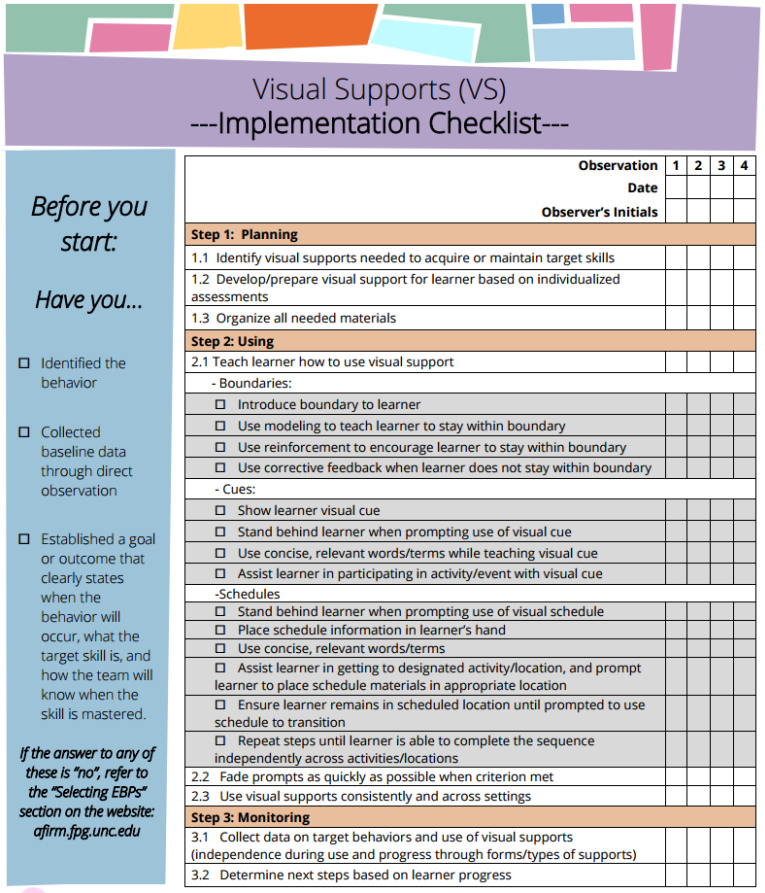
AFIRM Content

- Engaging case examples
- Multimedia presentation of content
- Interactive assessments
- Free professional



AFIRM Supplemental Materials

- ❖Implementation checklist
- ❖Step-by-step practice guide
- ❖Parent's guide
- ❖Tip sheet for professionals
- ❖Data sheets
- ❖Evidence-base



Visual Supports (VS)
---Implementation Checklist---

Before you start:

Have you...

- ☐ Identified the behavior
- ☐ Collected baseline data through direct observation
- ☐ Established a goal or outcome that clearly states when the behavior will occur, what the target skill is, and how the team will know when the skill is mastered.

If the answer to any of these is "no", refer to the "Selecting EBPs" section on the website: afirm.fpg.unc.edu

Observation	1	2	3	4
Date				
Observer's Initials				
Step 1: Planning				
1.1 Identify visual supports needed to acquire or maintain target skills				
1.2 Develop/prepare visual support for learner based on individualized assessments				
1.3 Organize all needed materials				
Step 2: Using				
2.1 Teach learner how to use visual support				
- Boundaries:				
☐ Introduce boundary to learner				
☐ Use modeling to teach learner to stay within boundary				
☐ Use reinforcement to encourage learner to stay within boundary				
☐ Use corrective feedback when learner does not stay within boundary				
- Cues:				
☐ Show learner visual cue				
☐ Stand behind learner when prompting use of visual cue				
☐ Use concise, relevant words/terms while teaching visual cue				
☐ Assist learner in participating in activity/event with visual cue				
-Schedules				
☐ Stand behind learner when prompting use of visual schedule				
☐ Place schedule information in learner's hand				
☐ Use concise, relevant words/terms				
☐ Assist learner in getting to designated activity/location, and prompt learner to place schedule materials in appropriate location				
☐ Ensure learner remains in scheduled location until prompted to use schedule to transition				
☐ Repeat steps until learner is able to complete the sequence independently across activities/locations				
2.2 Fade prompts as quickly as possible when criterion met				
2.3 Use visual supports consistently and across settings				
Step 3: Monitoring				
3.1 Collect data on target behaviors and use of visual supports (independence during use and progress through forms/types of supports)				
3.2 Determine next steps based on learner progress				

AFIRM Certificates

The National Professional Development Center on ASD

Awards this
Certificate of Completion to

Jane Smith

For completing the AFIRM Module

Time Delay

January 8, 2016

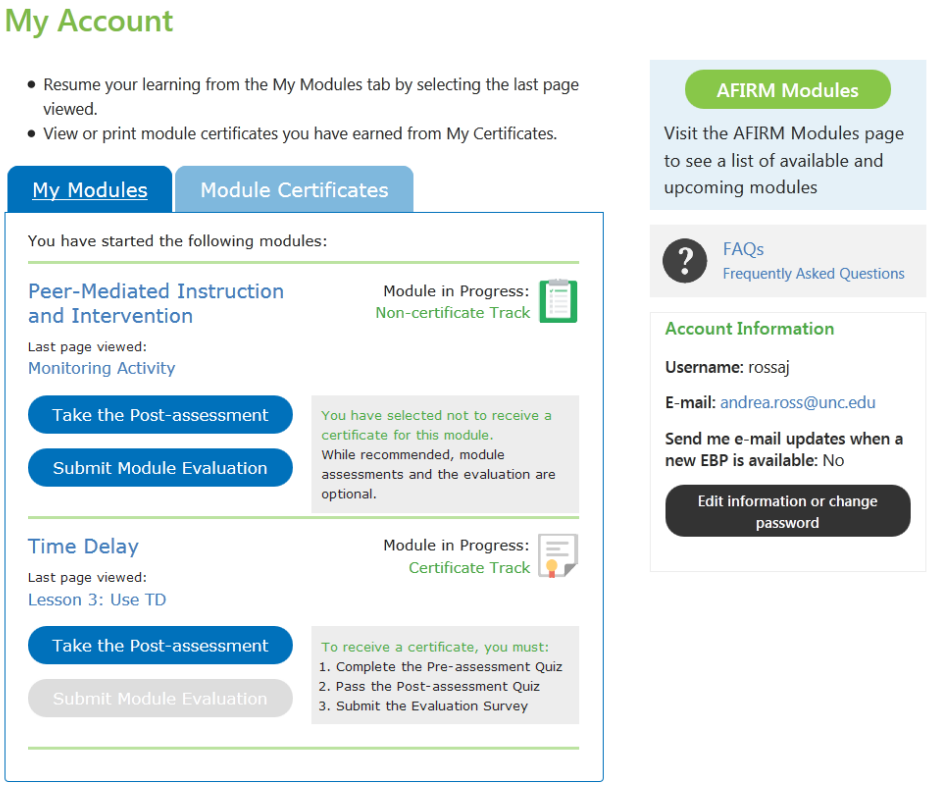
Time to complete: 2 hours

Samuel L. Odom, Ph.D.
Director, FPG Child Development Institute

Ann W. Cox, Ph.D.
Director, NPDC and AFIRM Module Projects

UNC FRANK PORTER GRAHAM CHILD DEVELOPMENT INSTITUTE

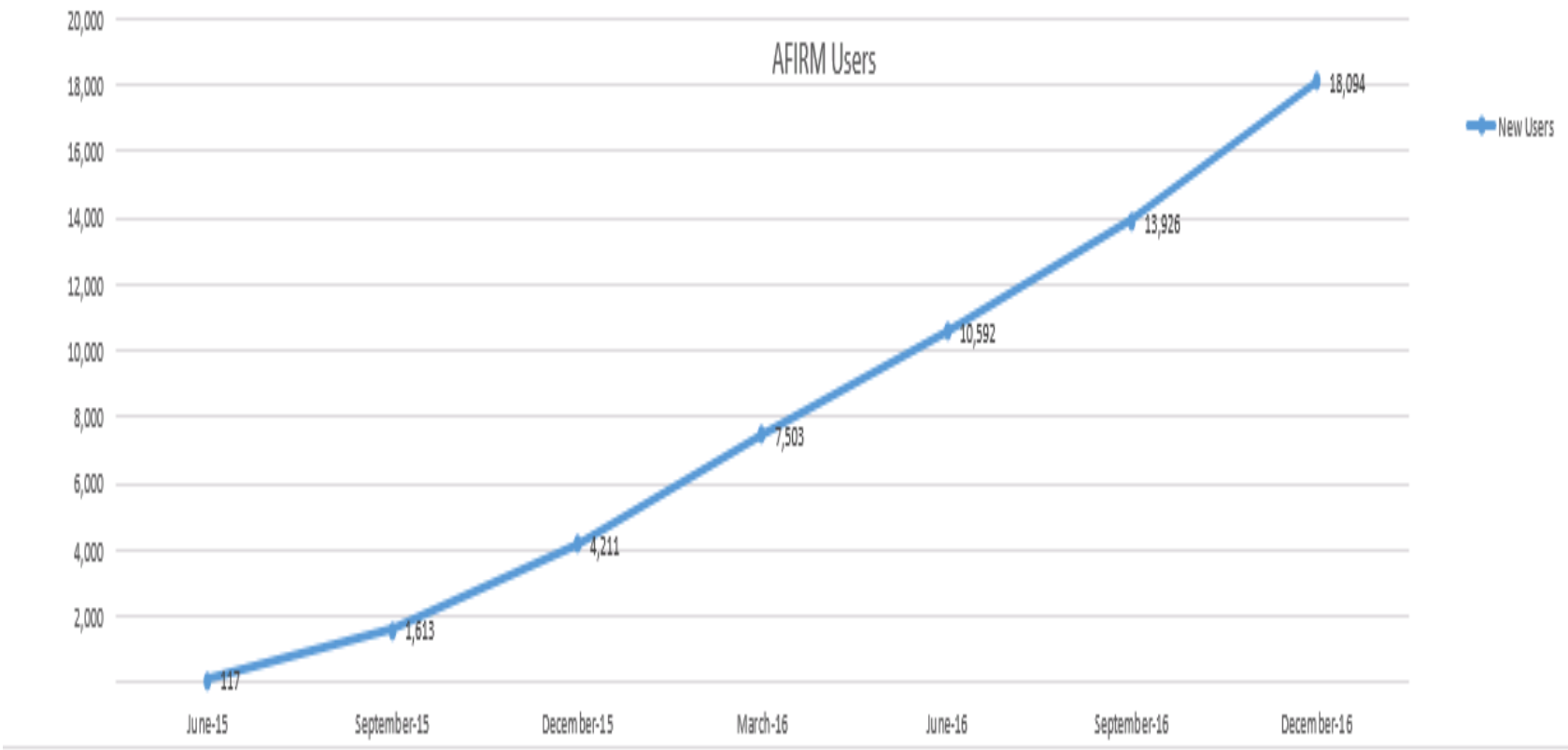
AFIRM Autism Focused Intervention Resources and Modules



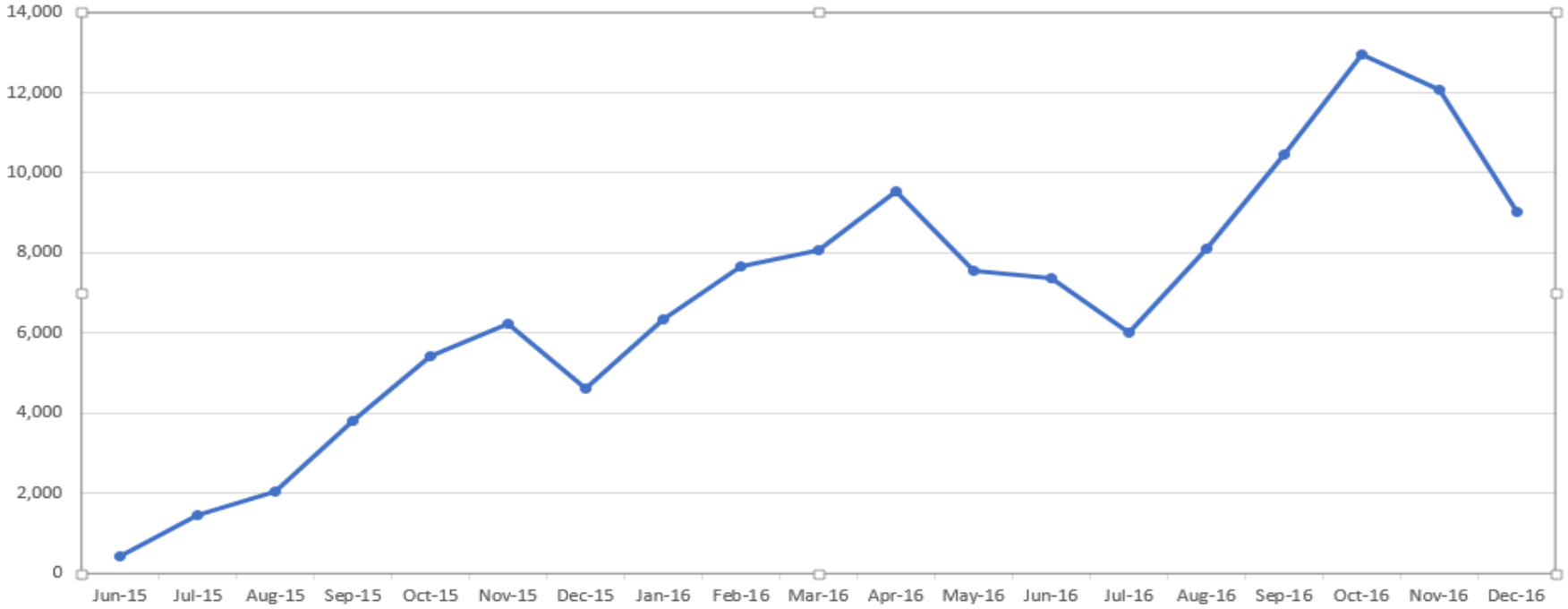
AFIRM

http://afirm.fpg.unc.edu/

Cumulative Growth of New Users



Sessions Viewed

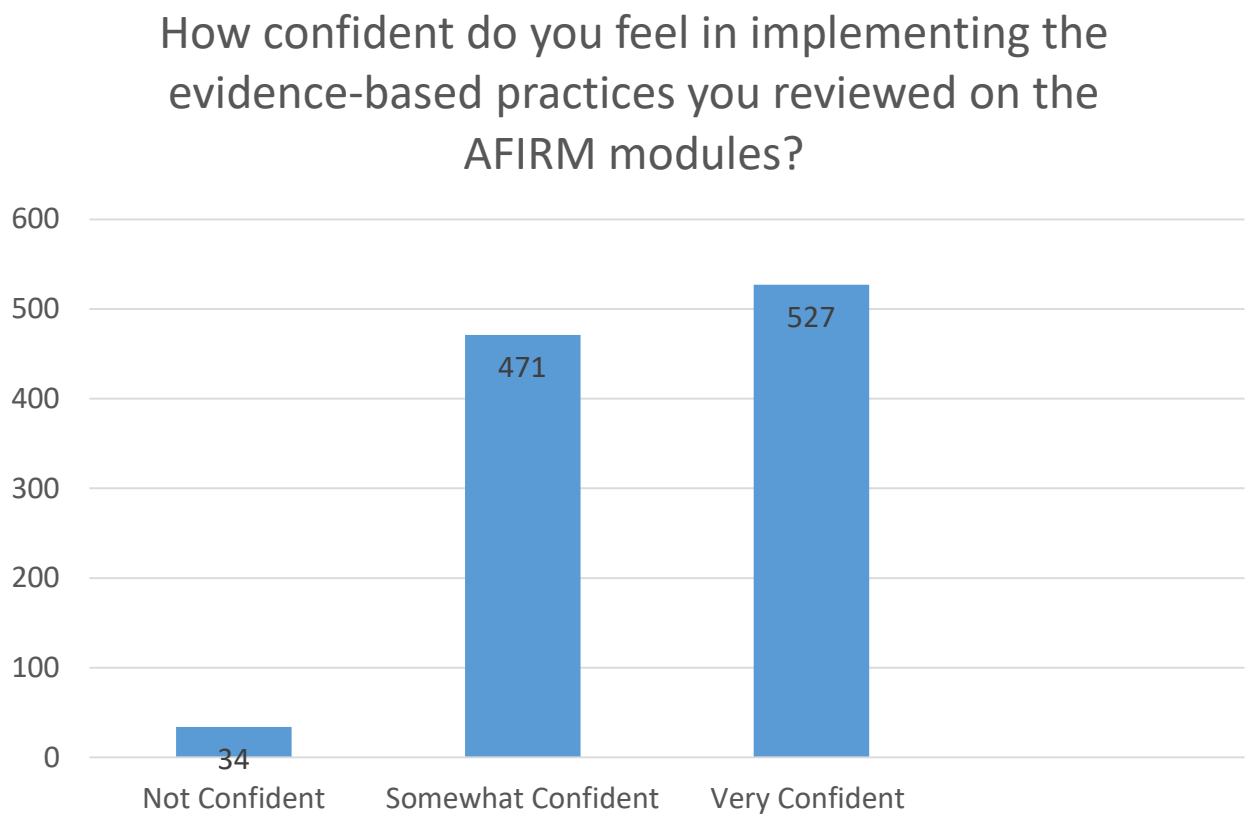


Total Sessions: 129,251
Total Page Views: 1,523,853
Total Downloads: 138,670

Who Are Our Users?

Occupation	n
Administrator	1,025
Early Interventionist	1,005
General Education Teacher	869
Special Education Teacher	4,985
Technical Assistant Provider	424
Paraeducator	1,974
Related Service Provider	1,749
Health Care Provider	609
Family Member	387
University Faculty	625
University Student	2,549
Other	2,149
	18,350

Confidence in Using EBPs



Conclusions

- AFIRM Modules translate research into focused intervention practice resources that practitioners can use to implement EBPs in their programs for students with ASD
- It is one tool, but it alone may not be sufficient in some circumstances
  - Training and support on site may be an important feature
- Modules appear to be important for preservice training—universities are using them in preservice training.
- Research does not stand still—ongoing updating and translation is critical

AFIRM

http://afirm.fpg.unc.edu/

Meeting of the IACC

Break

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Meeting of the IACC

Morning Agenda - continued

11:10 **Committee Business**

Susan Daniels, Ph.D.
Director, Office of Autism Research Coordination, NIMH and Executive Secretary, IACC

IACC Strategic Plan Update

- Discussion of chapters and objectives
- Discussion of duplication of effort statement
- Discussion of budgetary requirements

12:00 PM **Lunch**

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Meeting of the IACC

Committee Business

- **IACC Strategic Plan Update**
  - Discussion of chapters and objectives
  - Discussion of duplication of effort statement

Susan Daniels, Ph.D.
Director, Office of Autism Research Coordination, NIMH and
Executive Secretary, IACC

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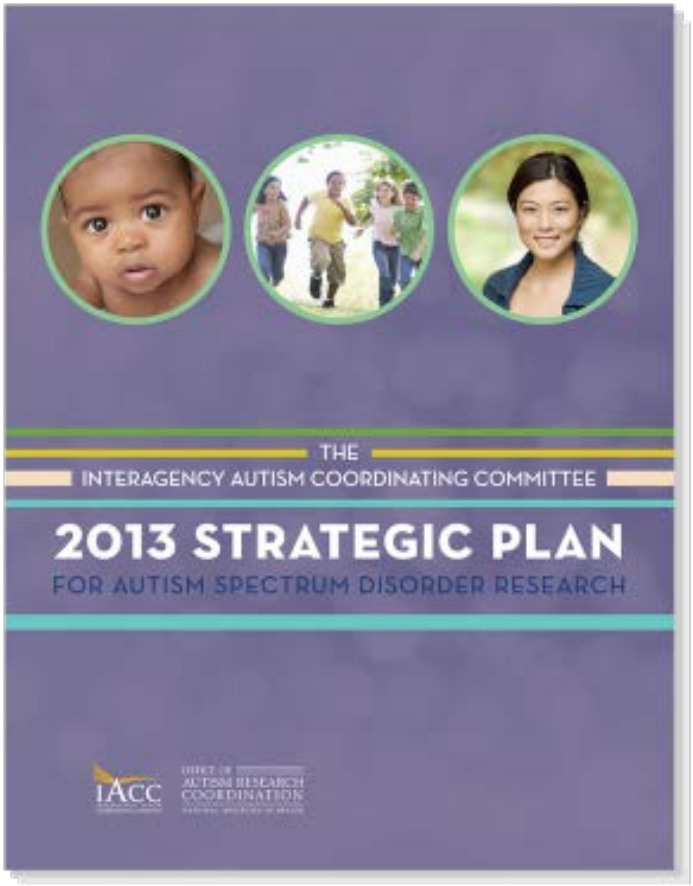
IACC Committee Business

Susan A. Daniels, Ph.D.
Director, Office of Autism Research Coordination
Executive Secretary, IACC
National Institute of Mental Health

IACC Full Committee Meeting
January 13, 2017

IACC Strategic Plan Update



- **The IACC Strategic Plan provides a blueprint to guide autism-related efforts across federal agencies and partner private organizations.**
- **The first IACC Strategic Plan was launched in 2009 and its focus was research efforts.**
- **Under the Autism CARES Act, the IACC Strategic Plan is being expanded to address both research and services activities.**
- **The IACC Strategic Plan is organized around 7 consumer-based questions.**

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Working Group Activities

- **The Committee formed 7 working groups to address the 7 questions of the Strategic Plan.**
- **Each of the 7 working groups completed a series of 3 conference calls and have developed the following for each of the 7 Question areas:**

  - **Draft chapter outline that describes progress in the field, gaps/needs, barriers, and opportunities**
  - **Proposed revisions to Chapter Titles and Aspirational Goals**
  - **Three broad draft objectives for each Question; examples of responsive research projects and services or policy activities may be included under each objective**
  - ***Today: Review and discuss draft Strategic Plan materials***

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Structure of Strategic Plan Chapters

For each Question:

- **Title**
- **Aspirational Goal**
- **Introduction that describes content of question area**
- **Overview of progress toward meeting previous plan's objectives (OARC will provide)**
- **For each of the key topics identified:**
  - **Overview of recent progress in the field**
  - **Gaps, opportunities, and needs in research, services, and policy**
- **3 New Broad-based Objectives that can address research, services, and policy**

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Question 1

Question 1 Key Topics

- Improve implementation of diagnostic and screening tools, especially in community settings
- Address disparities through improved early access to diagnostic and screening tools and culturally appropriate instruments
- Develop a culturally competent workforce through increased workforce training and funding
- Improve collaboration among different sectors of the service system

Question 1

Question 1 Title

Previous:

When Should I Be Concerned?

Proposed:

What Are the Signs of ASD and Why Is Early Detection So Important?

Question 1

Question 1 Aspirational Goal

Previous:

Children at risk for ASD will be identified through reliable methods before ASD behavioral characteristics fully manifest.

Proposed:

Provide the earliest possible diagnosis for children and adults on the autism spectrum, so they can be linked to appropriate interventions, services, and supports in as timely a manner as possible to maximize positive outcomes.

Question 1

Question 1 Objectives

1. Strengthen the evidence base for the benefits of early detection of ASD.

2. Reduce disparities in early detection by removing barriers to access and enhance culturally appropriate outreach efforts.

3. Improve/validate existing, or develop new tools, methods, and service delivery models for detecting ASD that will facilitate timely linkage of individuals with ASD to early, targeted interventions and supports.

Question 2

Question 2 Key Topics

- Understand the molecular mechanisms by which genetic mutations or common variants lead to ASD, brain structure and function in individuals with ASD, and brain circuit abnormalities implicated in validated animal models
- Understand the underlying biology of co-occurring conditions, as well as phenotypes and subtypes of ASD
- Need for more longitudinal data to understand brain development and developmental trajectories
- Establish standardized data elements and data acquisition parameters, and improve replicability
- Assemble larger research teams, including the participation of individuals on the autism spectrum, and grow a more diverse workforce

Question 2

Question 2 Title

Previous:

How Can I Understand What Is Happening?

Proposed:

What Is the Biology Underlying ASD?

Question 2

Question 2 Aspirational Goal

Previous:

Discover how ASD affects development, which will lead to targeted and personalized interventions.

Proposed:

Discover how alterations in brain development and nervous system function lead to ASD in order to enable the development of effective, targeted interventions and societal accommodations that improve quality of life for people on the autism spectrum.

Question 2

Question 2 Objectives

1. Foster research to better understand the genetic and non-genetic components that contribute to the structural and functional basis of ASD.

2. Support research to understand the underlying biology of co-occurring conditions in ASD and to understand the relationship of these conditions to ASD.

3. Support large scale longitudinal studies that can answer questions about the development of ASD from pregnancy through adulthood and the natural history of ASD across the lifespan.

Question 3

Question 3 Key Topics

- Identify genetic risk factors in the context of diverse populations and sex differences
- Understand how multiple risk factors combine to result in phenotype
- Understand the effects of environmental exposures during early development in diverse populations
- Understand interactions between genes and environment and the biological mechanisms underlying risk factors
- Improve data access and data sharing
- Foster a multidisciplinary workforce

Question 3

Question 3 Title

Previous:

What Caused This To Happen and Can It Be Prevented?

Proposed:

What Causes ASD, and Can Disabling Aspects of ASD Be Prevented or Preempted?

Question 3

Question 3 Aspirational Goal

Previous:

Causes of ASD will be discovered that inform prognosis and treatments and lead to prevention/preemption of the challenges and disabilities of ASD.

Proposed:

Causes of ASD will be discovered that inform diagnosis, prognosis, and interventions and lead to prevention/preemption of the challenges and disabilities of ASD.

Question 3

Question 3 Objectives

1. Strengthen understanding of genetic risk factors for ASD across a large population representing the full diversity and heterogeneity of those with ASD, enabling development of strategies for reducing disability and comorbidities in ASD.

2. Understand the effects on ASD risk of individual and multiple exposures in early development, enabling development of strategies for reducing disability and comorbidities in ASD.

3. Expand knowledge about how multiple environmental and genetic risk factors interact through specific biological mechanisms to manifest in ASD phenotypes.

Question 4

Question 4 Key Topics

- Develop a range of different intervention types, including technology-based and parent- and caregiver-mediated interventions, among others
- Improve evidence-based approaches, community-based approaches, and treatments for co-occurring conditions, minimally verbal individuals, and different age groups
- Improve outcome measures and metrics for measuring treatment response, including in the context of sex differences, subgroups, and personalized medicine
- Recommend strategies for accelerating research translation, providing incentives for industry involvement, and increasing access to treatments and interventions
- Prepare a workforce skilled in implementation and dissemination of evidence based practices

Question 4

Question 4 Title

Keep current:
Which Treatments and Interventions Will Help?

Question 4

Question 4 Aspirational Goal

Previous:

Interventions will be developed that are effective for reducing both core and associated symptoms, for building adaptive skills, and for maximizing quality of life and health for people with ASD.

Proposed:

Develop a range of interventions that optimize function and abilities across the lifespan to achieve meaningful outcomes and maximize quality of life for people on the autism spectrum.

Question 4

Question 4 Objectives

1. Develop and improve pharmacological and medical interventions to address both core symptoms and comorbidities in ASD.

2. Develop and improve cognitive, behavioral, social, developmental, and naturalistic interventions for ASD.

3. Maximize the potential for technologies and development of technology-based interventions to improve the lives of people on the autism spectrum.

Question 4

Cross-cutting themes
(applicable to all three Question 4 objectives)

1. Enhance understanding of the brain basis and mechanisms underlying these therapeutic approaches.
2. Maximize effectiveness for individuals by taking advantage of combination therapies.
3. Develop more robust standardized outcome measures, including adaptive measures, predictive measures, measures that address heterogeneity, and measures of practical outcomes that will help better target therapies to individual needs.
4. Ensure support for the entire intervention research and development pipeline.
5. Support translation of research to community-based practice and use of effective dissemination strategies to maximize uptake of evidence-based practice.

Question 5

Question 5 Key Topics

- Improve the quality of the education and healthcare systems through increased portability, better access, and valid outcome measures
- Ensure lifelong supports, including services for co-occurring conditions, person-centered planning and choice, and housing and communication supports
- Foster a larger, appropriately trained, diverse workforce, including providers and practitioners, who can meet service needs across a variety of community contexts
- Address existing policy barriers to coordination of services/providers and personalized services

Question 5

Question 5 Title

Previous:

Where Can I Turn for Services?

Proposed:

What Kinds of Services and Supports Are Needed to Maximize Quality of Life for People on the Autism Spectrum?

Question 5

Question 5 Aspirational Goal

Previous:

Communities will access and implement necessary high-quality, evidence-based services and supports that maximize quality of life and health across the lifespan for all people with ASD.

Proposed:

Communities will develop, access, and implement high-quality, evidence-based services and supports that maximize quality of life and health across the lifespan for all people with ASD and their families.

Question 5

Question 5 Objectives

1. Fully and successfully scale up evidence-based interventions in community settings.

2. Reduce disparities in access and in outcomes for underserved populations.

3. Improve service models to ensure consistency of care across many domains with the goal of maximizing outcomes and improving the value that individuals get from services.

Question 6

Question 6 Key Topics

- Support individuals with ASD as they transition to adulthood, including aspects of health, employment, education, and social and community participation
- Improve the full range of health and healthcare for adults on the spectrum, including preventative care, mental health, physical health, co-occurring conditions, and aging
- Address issues of safety, including wandering, self-harm, criminal justice issues, and victimization
- Provide adults with employment and financial planning supports, social and recreational opportunities, housing, and long-term supports
- Increase research on effective caregiver supports across the lifespan

Question 6

Question 6 Title

Previous:

What Does the Future Hold, Particularly for Adults?

Proposed:

How Can We Meet the Needs of People With ASD [As They Progress Into and Through Adulthood] [Or Across the Lifespan]?

Question 6

Question 6 Aspirational Goal

Previous:

All people with ASD will have the opportunity to lead self-determined lives in the community of their choice through school, work, community participation, meaningful relationships, and access to necessary and individualized services and supports.

Proposed:

All people with ASD will have the opportunity to lead self-determined lives in the community of their choice through school, work, community participation, satisfying relationships, and meaningful access to services and supports.

Question 6

Question 6 Objectives

1. Support development and coordination of integrated services to help youth make a successful transition to adulthood and continue to provide additional supports throughout the lifespan.

2. Improve health, safety, and well-being of individuals on the autism spectrum across the lifespan.

3. Increase acceptance, accommodation, inclusion, independence, and integration of people on the autism spectrum.

Question 7

Question 7 Key Topics

- Support brain banking, tissue collection, and efforts to encourage donation and participation in research
- Continue ongoing surveillance efforts, and consider methods for understanding prevalence in adults
- Provide resources to support and expand data networks for the purpose of improved data sharing and data accessibility
- Build virtual cohorts, and use technology and surveys to collect data
- Support workforce training that fosters skills in collaboration, dissemination of science, and communication with the public
- Engage in global efforts, sharing strategies and best practices to support people on the autism spectrum and their families

Question 7

Question 7 Title

Previous:

What Other Infrastructure and Surveillance Needs Must Be Met?

Proposed:

How Do We Continue to Build, Expand, and Enhance the Infrastructure System to Meet the Needs of the ASD Community?

Question 7

Question 7 Aspirational Goal

Previous:

Develop and support infrastructure and surveillance systems that advance the speed, efficacy and dissemination of ASD research.

Proposed:

Develop, enhance, and support infrastructure and surveillance systems that advance the speed, efficacy, and dissemination of ASD research and services.

Question 7

Question 7 Objectives

1. Promote growth and integration of the biorepository infrastructure.

2. Develop, enhance, and link the data infrastructure.

3. Develop the human infrastructure to disseminate research, support community-based service delivery, and communicate science.

Strategic Plan Update Requirements: Duplication

- **The Autism CARES Act requires the IACC in its Strategic Plan to provide:**

  "Recommendations to ensure that autism spectrum disorder research, and services and support activities to the extent practicable, of the Department of Health and Human Services and of other Federal departments and agencies are not unnecessarily duplicative."

- **This requirement was based on a 2013 report by the GAO that stated concerns about potential for duplication in the research portfolio**
- **At the October 2016, the committee shared input on this topic; Alison Singer volunteered to draft a statement to meet the Autism CARES Act requirement**
- **The draft statement has been circulated**

Comments?

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Meeting of the IACC

Lunch

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Meeting of the IACC

Afternoon Agenda

1:00 **Oral Public Comment Session**

1:10 **Summary of Written Public Comments**
Karen Mowrer, Ph.D.
Health Science Policy Analyst
OARC, NIMH

1:20 **IACC Committee Member Discussion of Public Comments**

1:40 **Committee Business**
Susan Daniels, Ph.D.
Director, OARC and Executive Secretary, IACC

- IACC Strategic Plan Update (continued)
- IACC Summary of Advances

3:20 **Afternoon Break**

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Meeting of the IACC

Oral Comments Session

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Meeting of the IACC

Summary of Written Public Comments

Karen Mowrer, Ph.D.
Health Science Policy Analyst
Office of Autism Research Coordination, NIMH

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IACC Committee Member Discussion of Public Comments

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Meeting of the IACC

Committee Business

- **IACC Strategic Plan Update (continued)**
  - Discussion of budgetary requirements
- **IACC Summary of Advances**

Susan Daniels, Ph.D.
Director, Office of Autism Research Coordination, NIMH and
Executive Secretary, IACC

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Strategic Plan Update: Budgetary Requirements

- **The Autism CARES Act requires the IACC Strategic Plan to include "proposed budgetary requirements."**
- **The previous Strategic Plan provided estimated budgetary requirements for each objective**
- **Does the committee want to develop budgetary requirements based on the objectives, the questions, or the overall plan, keeping in mind that the new objectives will be broad and inclusive of both research and services activities?**
- **Does the committee want to try to estimate actual budgets or project percentage increases, decreases, etc.? Growth over time?**

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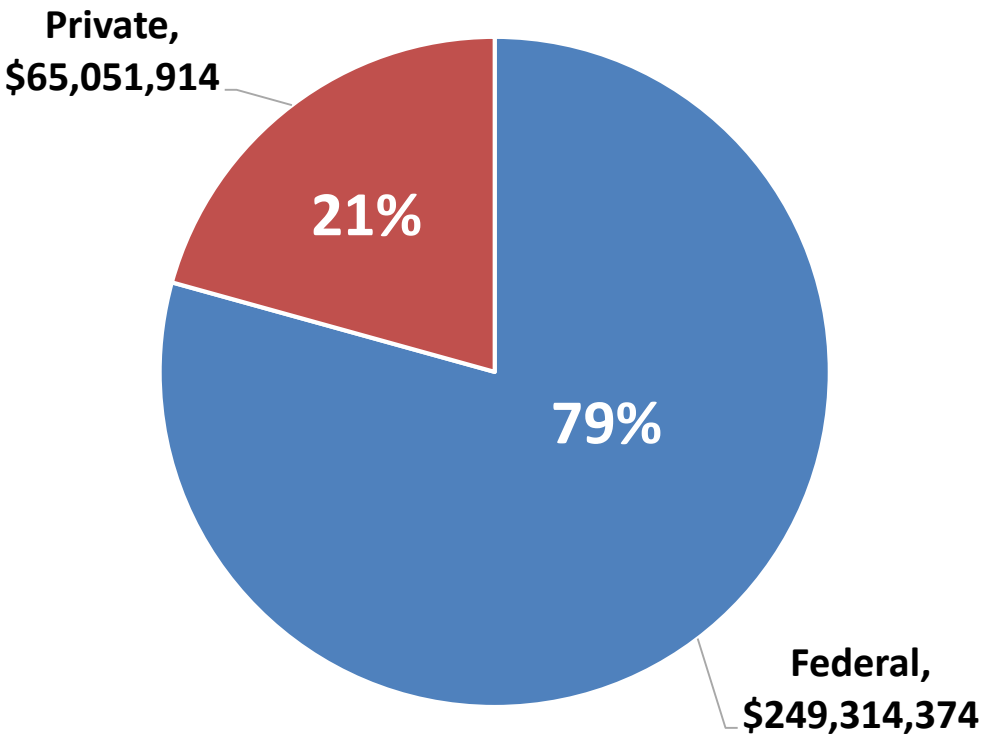
Preliminary Data: 2015 IACC Portfolio Analysis Report

- **2015 ASD research portfolio data have been collected from 18 funders, and preliminary analysis is available for use by the IACC for the IACC Strategic Plan Update**
- **The analysis provides detailed information about the ASD research portfolio across both Federal agencies and private organizations**
- **Informs the IACC and stakeholders about the research funding landscape and trends**
- **Helps the IACC monitor progress in fulfilling the objectives of the IACC Strategic Plan**

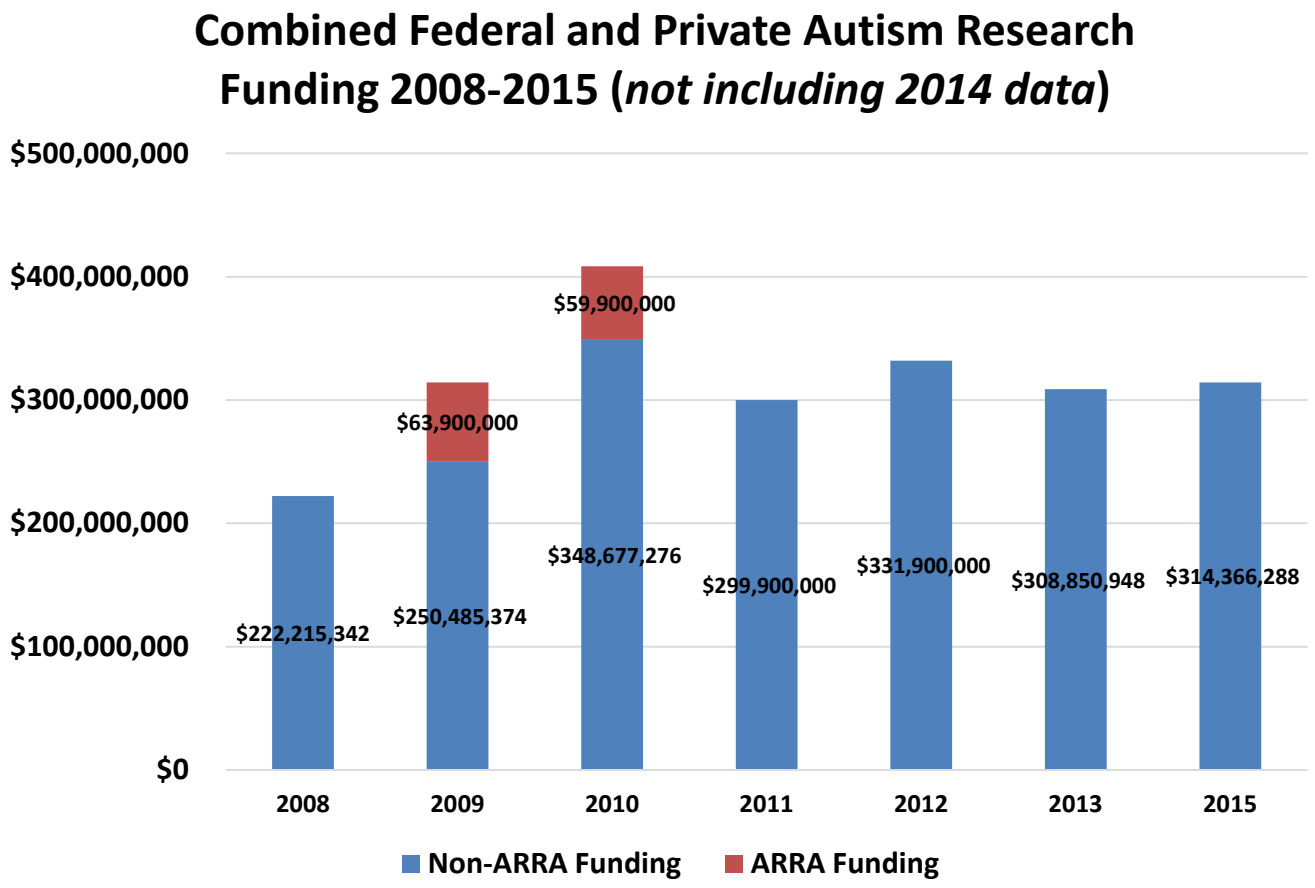
Proportion of Federal and Private Funds Supporting ASD Research - 2015

2015 Total Funding: $314,366,288
Number of Projects: 1,311



Overall funding has decreased since 2012 from $331.9 m; federal was 78% $260 m; private was 22% $71m

2015 ASD Research Portfolio Analysis: Preliminary Data



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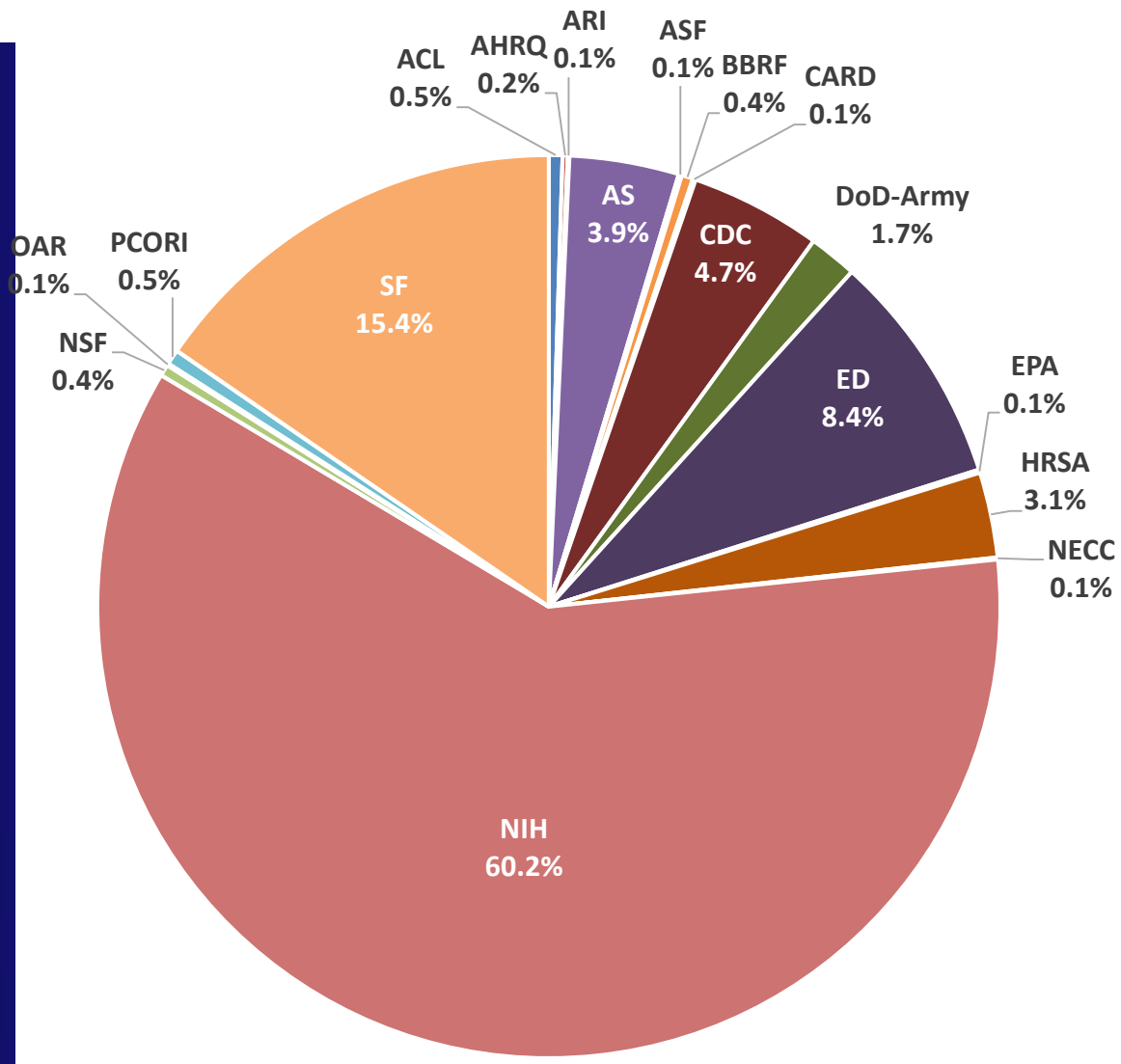
Draft data - subject to change

2015 ASD Research Portfolio Analysis: Preliminary Data



Federal or Private Funder	2015 Funding	Percentage of 2015 Funding
ACL	$ 1,528,535	0.5%
AHRQ	$ 576,949	0.2%
ARI	$ 179,456	0.1%
AS	$ 12,324,957	3.9%
ASF	$ 355,000	0.1%
BBRF	$ 1,290,484	0.4%
CARD	$ 314,060	0.1%
CDC	$ 14,789,418	4.7%
DoD-Army	$ 5,440,886	1.7%
ED	$ 26,362,194	8.4%
EPA	$ 343,850	0.1%
HRSA	$ 9,618,017	3.1%
NECC	$ 219,416	0.1%
NIH	$ 189,362,799	60.2%
NSF	$ 1,291,726	0.4%
OAR	$ 229,755	0.1%
PCORI	$ 1,695,006	0.5%
SF	$ 48,443,781	15.4%
TOTAL	**$ 314,366, 288**	**100%**

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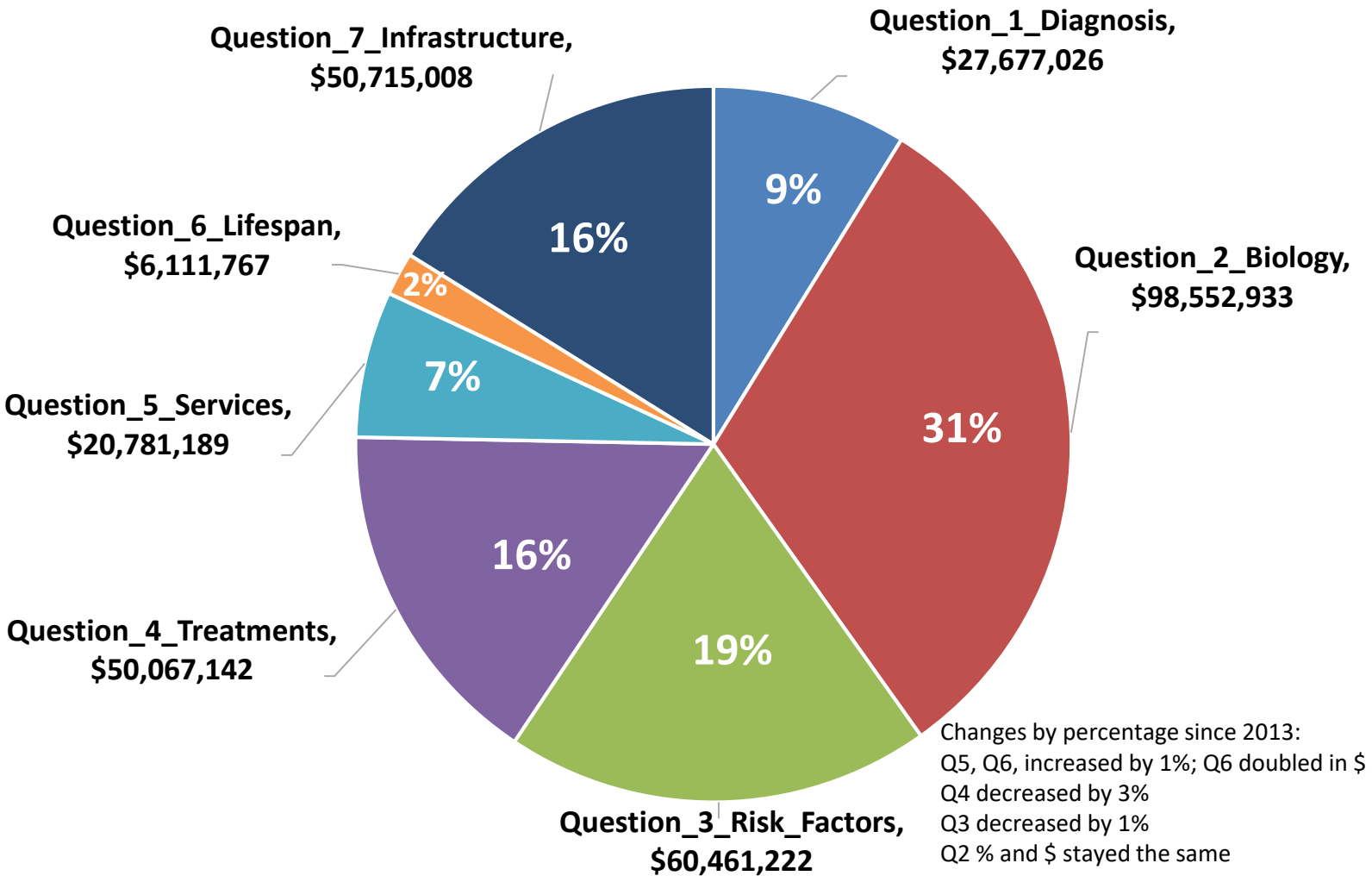
Draft data - subject to change

2015 ASD Research Portfolio Analysis: Preliminary Data

Percentage of 2015 Funding by *IACC Strategic Plan* Question



Changes by percentage since 2013:
Q5, Q6, increased by 1%; Q6 doubled in $
Q4 decreased by 3%
Q3 decreased by 1%
Q2 % and $ stayed the same

Proposed Budgetary Requirements for Research

Possible Options:

- **Base proposed budgetary requirements on Questions?**
- **Base proposed budgetary requirements on objectives?**
- **Base proposed budgetary requirements on the entire research budget or on the federal research budget?**
- **Could set a target amount of funding to reach by a certain year; percentage increase to reach by a certain year.**

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Services Budget Estimate

How can the IACC get a baseline on services expenditures that it can use as a basis for recommendations?

Proposal:

Number of people served and budget for key categories:

- **Medicaid (CMS)**
- **Private insurance (NIH, others?)**
- **Public education (Dept. of Ed.)**
- **Vocational rehabilitation (ACL/NIDILRR)**

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Services Budget Estimate

Alternative or Additional Services Data Collection:

Identify gaps on a qualitative basis by requesting data from federal agencies about autism-specific service programs?

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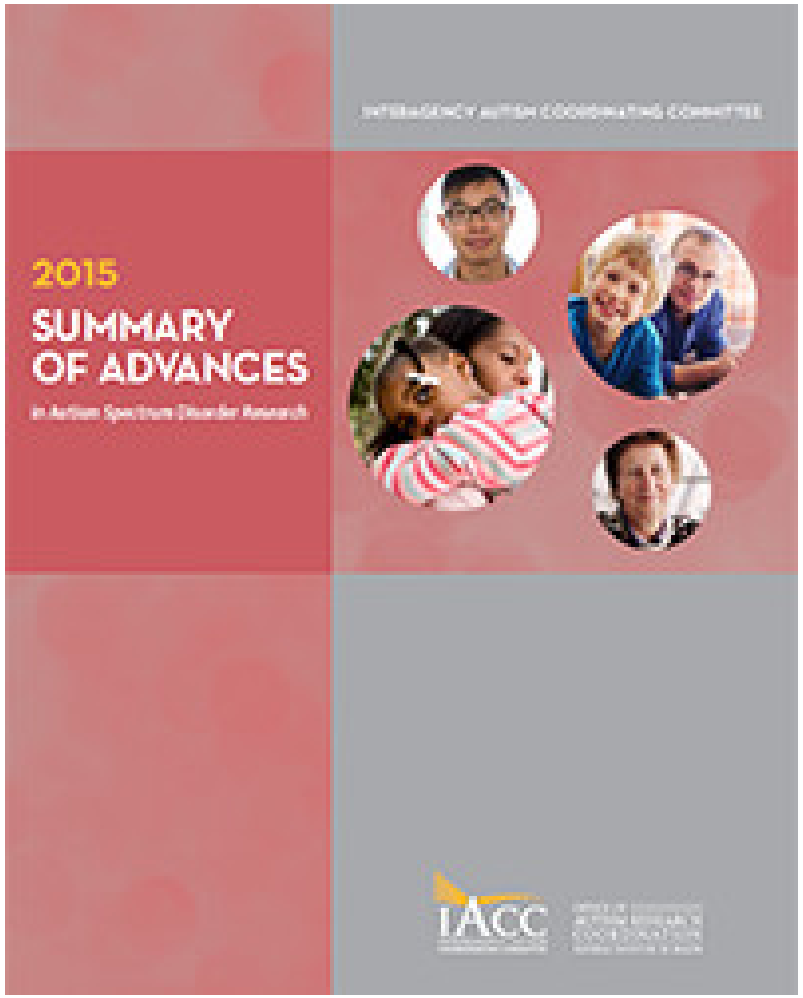
IACC Summary of Advances



- Annual publication – required by CARES Act
- Lay-friendly summaries of the 20 most significant advances in ASD biomedical and services research selected by the IACC
- Covers:
  - Prevalence
  - Diagnosis
  - Biology
  - Risk factors
  - Interventions
  - Lifespan issues

www.iacc.hhs.gov

Summary of Advances Process

- **Monthly solicitation from OARC to collect nominated advances from IACC members**
- **Advances compiled quarterly and discussed at IACC meetings**
- **At January IACC meeting, discussion of top articles among those nominated**
- **Decide on remainder of process – additional nominations or vote based on revised list from today's discussion?**
- **Does the Committee want to accept other organizations' lists as "en bloc" nomination submissions?**

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Summary of Advances Nominations Stats

- **15 IACC members submitted a total of 59 nominations:**
  - **Question 1 (Diagnosis & Screening): 5**
  - **Question 2 (Biology): 14**
  - **Question 3 (Risk Factors): 7**
  - **Question 4 (Treatments & Interventions): 19**
  - **Question 5 (Services): 4**
  - **Question 6 (Lifespan Issues): 8**
  - **Question 7 (Infrastructure & Surveillance): 2**

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Summary of Advances Process

- After today – solicit more nominations or vote from current list?
- Do we still want to select a top 20/21?

Process following final selections:

- Selected articles are summarized
- Nominated articles not selected are listed in the appendix
- Draft publication is prepared and sent out to committee for very brief review
- Final publication is prepared for release
- Target date – April 26

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IACC
INTERAGENCY AUTISM COORDINATING COMMITTEE

OFFICE OF AUTISM RESEARCH COORDINATION
NATIONAL INSTITUTES OF HEALTH

Susan Daniels, Ph.D., Director

Oni Celestin, Ph.D., Science Policy Analyst

Ben Feldman, Ph.D., Science Policy Analyst

Rebecca Martin, M.P.H., Public Health Analyst

Angelice Mitrakas, **B.A.**, Management Analyst

Karen Mowrer, Ph.D., Science Policy Analyst

Julianna Rava, M.P.H., Science Policy Analyst

Jeff Wiegand, **B.S.**, Web Development Manager

Meeting of the IACC

Break

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Meeting of the IACC

Afternoon Agenda - continued

3:30 Update on National Database for Autism Research (NDAR)
Greg Farber, Ph.D.
Director, Office of Technology Development and Coordination
NIMH

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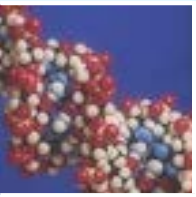
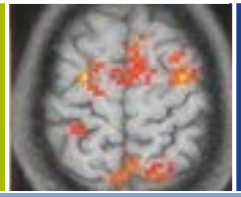
Data Integration and Data Management

The NIMH Data Archive

Greg Farber

Office of Technology Development and Coordination
National Institute of Mental Health





The National Database for Autism Research has Transformed and Expanded into the NIMH Data Archives (NDA)

National Institute of Mental Health

Why Bother Aggregating Data?

1) Understanding complex conditions requires data from large numbers of subjects.
   - Genetic studies have shown that tens of thousands of subjects are required for a partial understanding of the genes associated with neurological diseases.
   - When environmental influences are also important in understanding a disorder, the numbers of subjects needed are likely to be much larger.
   - In addition to requiring large numbers of subjects, understanding complex conditions also requires aggregating many different types of data in a meaningful way.
2) Aggregating data from different laboratories allows the research community to understand how similar (or not) the data being collected really are. This leads to agreement on the best way to perform certain experiments. (common data elements)
3) Depositing data to a repository on a regular basis during data collection allows the laboratory to improve the rigor and reproducibility of their experiments.
4) Aggregating data allows the research community to evaluate the costs and outcomes from different ways of collecting data.

Who Contributes Data to the NDA?

- NIMH awardees who are doing experiments using human subjects
  - National Database for Autism Research
  - Legacy clinical trials funded by NIMH
  - Data from all applications submitted to NIMH after May 1, 2015
  - Pediatric MRI Study
  - A total of 550 awardees are currently expected to share data
- Data from the Adolescent Brain Cognitive Development Study
- Data from the Human Connectome Project (coming soon)
- Awards made by other funding agencies
  - Stanley Foundation
  - Autism Science Foundation
- NDA is federated with
  - Autism Tissue Program
  - Autism Genetic Research Exchange
  - Interactive Autism Network
  - Simons Foundation Autism Research Initiative
  - Ontario Brain Institute (in progress)

NDA Overview

- NDA is a federal data repository that accepts data from the research community.
- The NDA only contains data from human subjects. We have some capability to deal with data that has different types of consent, but NIMH funded data is broadly consented for use by the research community.
- NIMH data are available to the research community through a not too difficult application process that involves a data access committee. (Currently support 4 independent DACs.)
- Summary data are available to everyone with a browser at https://data-archive.nimh.nih.gov/

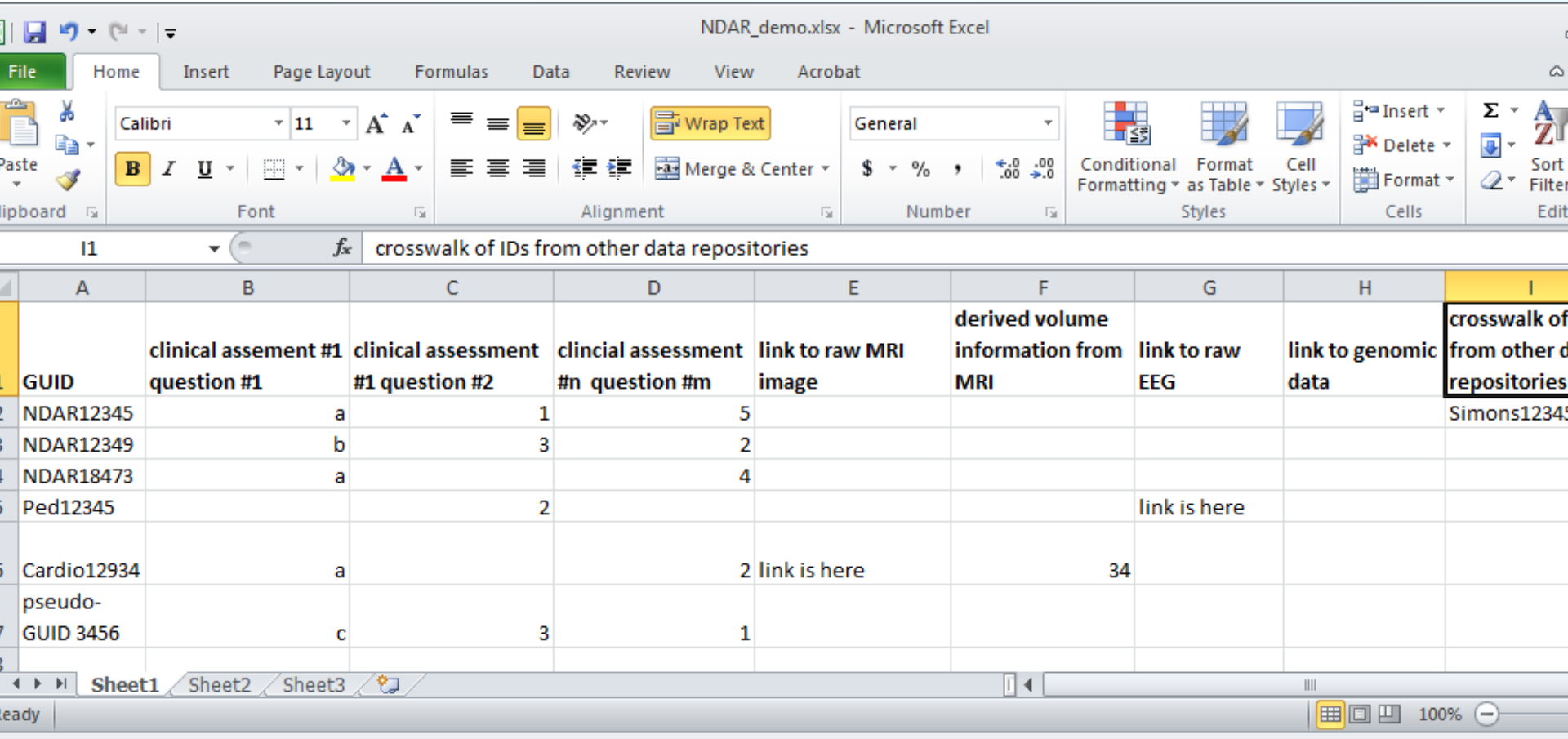
NDA – Types of Data (January 2017)

Type of Data	Participants Submitted	Participants Shared
Any	146,274	131,314
MRI	7,154	4,824
Eye Tracking	1,309	723
Genomics	34,903	32,119
EEG	4,292	803

- ~800 terabytes of imaging, –omic, and other complex experimental data is secured in the Amazon cloud. We expect this go grow to 4-5 petabyte in the next 5 years.
- (kilobyte < megabyte < gigabyte < terabyte < petabyte)
- (document file < PowerPoint presentation < movie < Library of Congress < 13 year long movie)

NDA Basic Structure

- NDA can be thought of as a large two dimensional matrix.
- Dimension 1: The data dictionaries which provide definitions for clinical assessments, imaging experiments, or any other experimental data are the other dimension of the matrix.
- Dimension 2: Global Unique Identifiers (GUID) which are generated using personally identifiable information at the research site are one dimension of the matrix. The GUIDs allow data from the same subject who was seen in different laboratories to be aggregated without requiring that the NDA have any personally identifiable information.
- A variety of queries have been implemented to allow researchers to find the data they are interested in. The queries cross all of the parts of the NDA and also reach into other federated data repositories outside of NIMH.



	A	B	C	D	E	F	G	H	I
1	GUID	clinical assement #1 question #1	clinical assessment #1 question #2	clincial assessment #n question #m	link to raw MRI image	derived volume information from MRI	link to raw EEG	link to genomic data	crosswalk of from other d repositories
2	NDAR12345	a	1	5					Simons12345
3	NDAR12349	b	3	2					
4	NDAR18473	a		4					
5	Ped12345		2				link is here		
6	Cardio12934	a		2	link is here	34			
7	pseudo-GUID 3456	c	3	1					
8									

National Institute of Mental Health

Data Dictionary – The First Building Block

- The NDA data dictionary is one of the key building blocks for this repository. It provides a flexible framework that allows us to work with the research community to define the data they are collecting.
- 1500+ data collection instruments (measures, forms) which are freely available to anyone
  - 130,000+ unique data elements (“questions”) and growing
  - A research community platform for defining the complex language characterizing mental health research
    - Clinical
    - Genomics/Proteomics
    - MRI Modalities
    - Other complex data (EEG, Eye Tracking)
- Accommodates any data type and data structure
- Curated by NDA Staff
- Allows investigators to quickly perform quality control tests of their data without submitting data anywhere by validating that the answer to each data element is within an expected range.

Data Dictionary List (1500+ Measures)

Home | Query | Harmonization Tools | Cloud | Contribute | Request Access | Policy | Tutorials | About | FAQ | Tools | login

Query Data | Data from Labs | Data from Papers | Query by Data Dictionary | Query by Concept | Query by GUID | Query Instructions

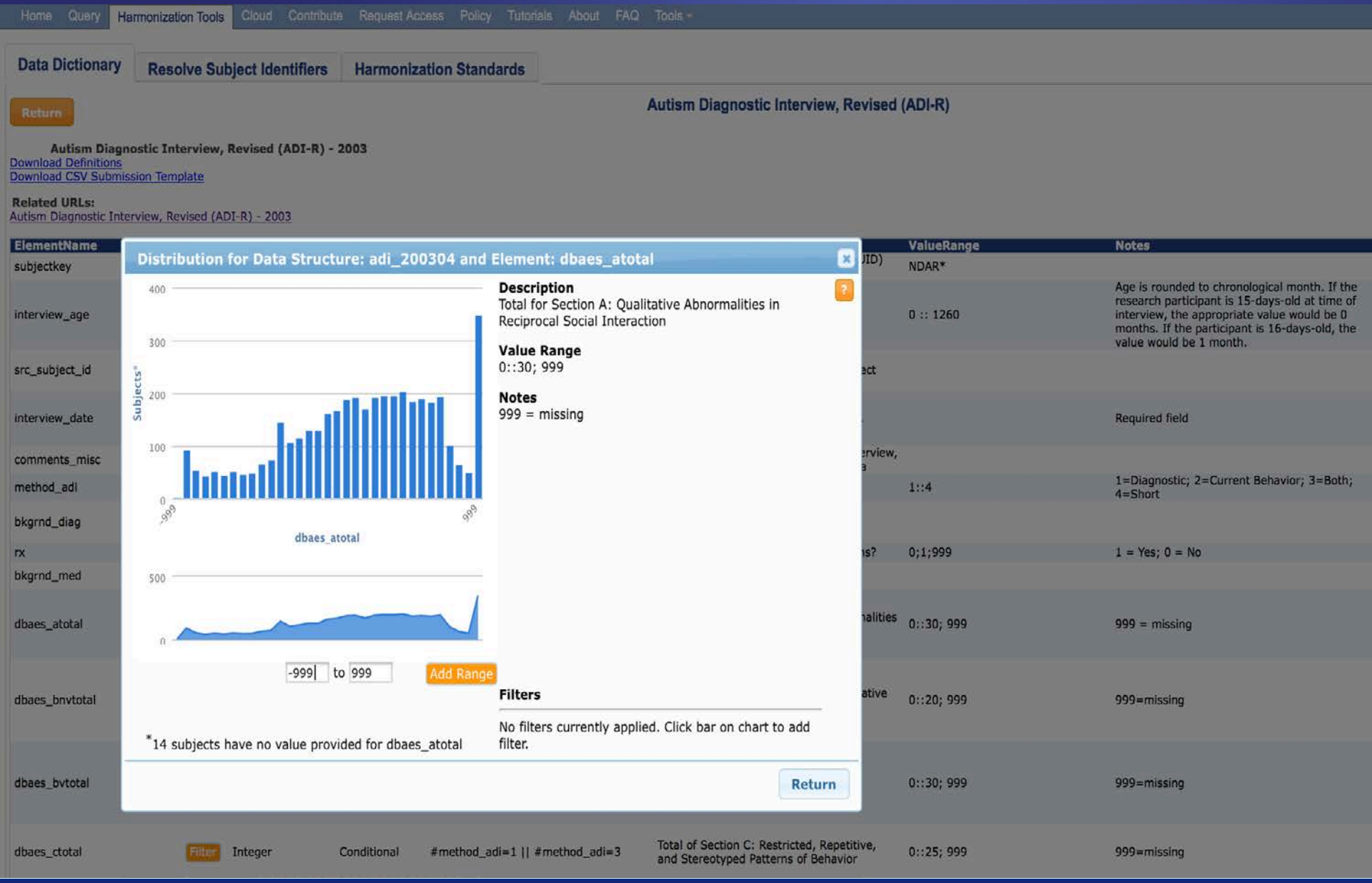
Listed below are the data structures supporting NDAR's autism data definition. To see other definitions in NDAR, select Source. Select Category to see the different types of data structures now available.

Type: All | Source: NDAR | Category: All

ADHD, Acoustics, Adverse Events, Aggression, Anxiety, Behavior, Cognitive, Conflict, Coping, DTI, MRI, fMRI, Demographics, Depression, Diagnostic, EEG, EGG, EMG, ERP, Emotions, Evaluated Data, Exposure, Eye Tracking, Fear, Food, Gen Test, IQ, Life Events, Loneliness, MEG, Med History, Network, OCD, Omics, Personality, Phobia, Phys Characteristics

DOWNLOAD	FILTER	TITLE	SHORT NAME	SOURCE	CATEGORY	SUBMISSION
Download	Filter	A Developmental NEuroPSYchological Assessment	nepsy01	NDAR	Cognitive	Allowed
Download	Filter	ACE Family Medical History	ace_fammedhist01	ACE Common Measures V2, NDAR	Med History	Allowed
Download	Filter	ACE Subject Medical History	ace_subjmedhist01	ACE Common Measures V2, NDAR	Med History	Allowed
Download	Filter	ACE Subject Physical Exam	ace_physexam01	ACE Common Measures V2, NDAR	Phys Exam	Allowed
Download	Filter	ADHD Rating Scale	adhdrs01	NDAR	ADHD	Allowed
Download	Filter	AIR Self-Determination Scale	airsds01	NDAR	Questionnaire	Allowed
Download	Filter	Aberrant Behavior Checklist (ABC) - Community	abc_community02	NDAR, NDCT	Behavior	Allowed
Download	Filter	Abnormal Involuntary Movement Scale	aims01	NDAR, NDCT, RDoC	Questionnaire	Allowed
Download	Filter	Academic Support Scale	asups01	NDAR	Questionnaire	Allowed
Download	Filter	Acceptability Questionnaire	acquest01	NDAR	Questionnaire	Allowed
Download	Filter	Adaptation Phase Protocol and Interview	appi01	NDAR	Questionnaire	Allowed
Download	Filter	Adapted ADOS Module 1	aados_m101	NDAR	Diagnostic	Allowed
Download	Filter	Adapted ADOS Module 2	aados_m201	NDAR	Diagnostic	Allowed
Download	Filter	Adaptive Behavior Assessment System, Second E	abas01	NDAR	Behavior	Allowed
Download	Filter	Adolescent Symptom Inventory	asi01	NDAR	Questionnaire	Allowed
Download	Filter	Adult Adolescent Parenting Inventory *new*	aapi01	NDAR, RDoC	Questionnaire	Allowed
Download	Filter	Adult Behavior Check List	abcl_men_200301	NDAR	Behavior	Allowed
Download	Filter	Adult Impairment Rating Scale	airs01	NDAR, NDCT	Questionnaire	Allowed
Download	Filter	Advanced Normalization Tools (ANTs) Cortical Thi	antsvol01	NDAR	Evaluated Data	Allowed
Download	Filter	Adverse Events	adev01	NDAR, NDCT	Adverse Events	Allowed
		Advocacy Form	advoc01	NDAR	Questionnaire	Allowed
Download	Filter	Age Differentiation Test	adt3601	NDAR	Task Based	Allowed

Data Inspection – Available to All



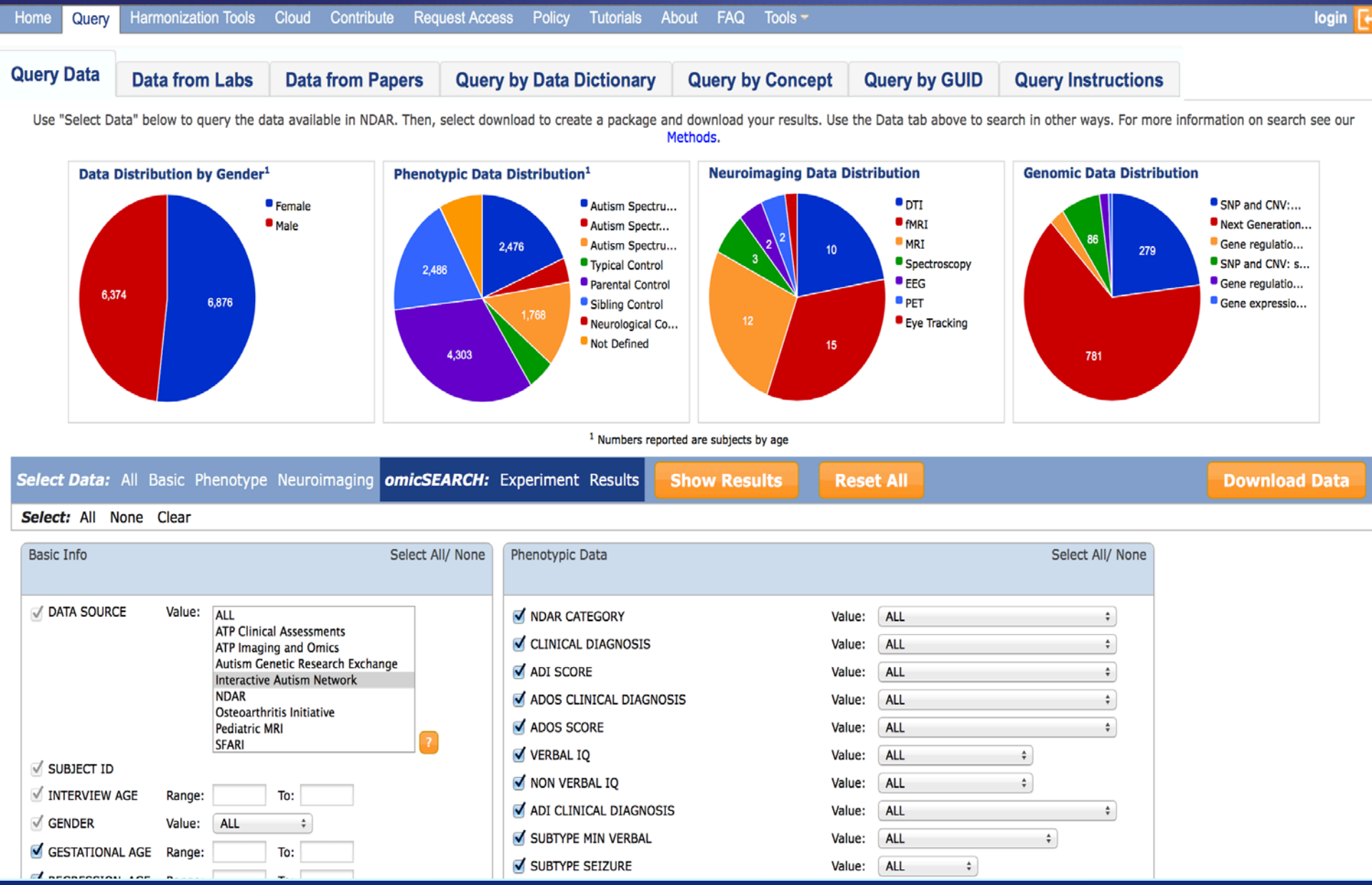
The Data Dictionary is a key component of improving rigor and reproducibility

- NDA makes a validation tool available to all, so that if a data dictionary exists, anyone can test their data using the tool to make sure that the recorded information for a subject is consistent with the allowed values in the data dictionary.
- The large number of data dictionaries already available as well as our willingness to create additional data dictionaries as necessary makes this validation very useful.

Global Unique Identifier – the Other Building Block

- The NDA GUID software allows any researcher to generate a unique identifier using some information from a birth certificate.
- If the same information is entered in different laboratories, the same GUID will be generated.
- This strategy allows NDA to aggregate data on the same subject collected in multiple laboratories without holding any of the personally identifiable information about that subject.
- NDA also assigns unique identifiers that do not allow data aggregation (pseudo-GUID) in cases where the GUID could not be generated.
- The GUID is now being used in other research communities (see http://www.youtube.com/watch?v=Tb6euCVoous)

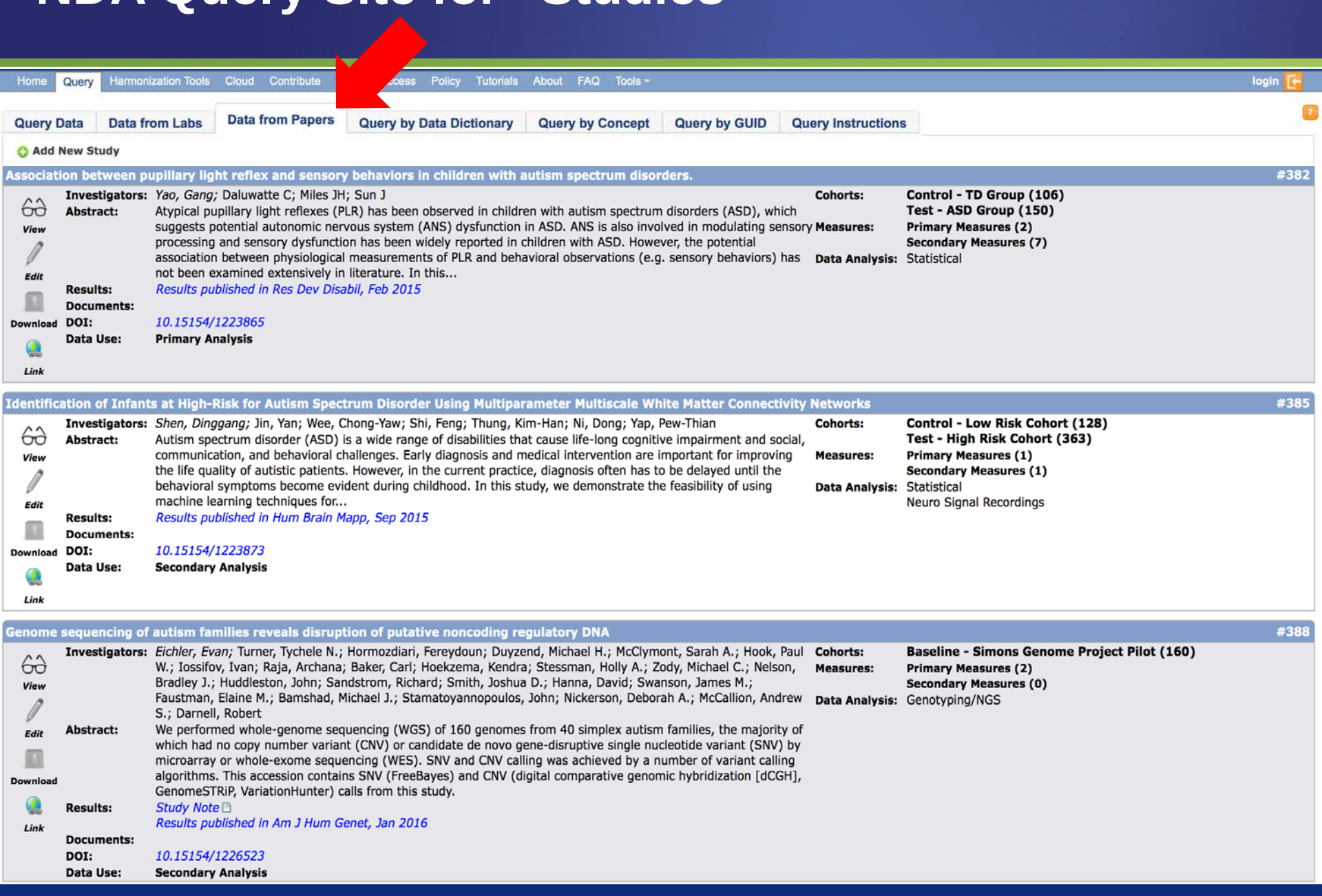
General Query – IAN Example – GUID Works



Data Archives also Allow Data to be Aggregated in Ways not Anticipated by those who Measured the Data

- The NDA allows a user to aggregate data into a “study”.
- The data could all come from a single laboratory, or could come from a variety of sources.
- Digital Object Identifiers are assigned to each study, so it is very easy for an author to deposit data into the NDA and then get a unique identifier that can be referenced in a publication.
- The NDA is happy to accept any data related to mental illness (broadly defined), so the archive does provide a data storage infrastructure that could be useful for many journals.

NDA Query Site for “Studies”



Details of a Study Showing the doi as well as the source of the data from 3 different laboratories

Home Query Harmonization Tools Cloud Contribute Request Access Policy Tutorials About FAQ Tools login

Owner: Niklas Krumm **Owner E-mail:** *nkrumm@uw.edu* **State:** Shared

Transmission disequilibrium of small CNVs in simplex autism. #312

Summary | Cohorts (3) | Measures (6) | Types | Data Analysis

Investigators: *Eichler EE;* Krumm N, O'Roak BJ, Karakoc E, Mohajeri K, Nelson B, Vives L, Jacquemont S, Munson J, Bernier R

Abstract: Cohorts: 411 ASD Quads from Simons Simplex Collection 177 Quads from Sanders et al. (PubMed ID: 22495306) 166 Quads from I. Iossifov et al. (PubMed ID: 22542183) 71 Quads from O'Roak et al. (PubMed ID: 22495309) Publication Abstract: We searched for disruptive, genic rare copy-number variants (CNVs) among 411 families affected by sporadic autism spectrum disorder (ASD) from the Simons Simplex Collection by using available exome sequence data and CoNIFER (Copy Number Inference from Exome Reads). Compared to high-density SNP microarrays, our approach yielded ¿2× more smaller genic rare CNVs. We found that affected probands inherited more CNVs than did their siblings (453 versus 394, p = 0.004; odds ratio [OR] = 1.19) and that the probands' CNVs affected more genes (921 versus 726, p = 0.02; OR = 1.30). These smaller CNVs (median size 18 kb) were transmitted preferentially from the mother (136 maternal versus 100 paternal, p = 0.02), although this bias occurred irrespective of affected status. The excess burden of inherited CNVs among probands was driven primarily by sibling pairs with discordant social-behavior phenotypes (p < 0.0002, measured by Social Responsiveness Scale [SRS] score), which contrasts with families where the phenotypes were more closely matched or less extreme (p > 0.5). Finally, we found enrichment of brain-expressed genes unique to probands, especially in the SRS-discordant group (p = 0.0035). In a combined model, our inherited CNVs, de novo CNVs, and de novo single-nucleotide variants all independently contributed to the risk of autism (p < 0.05). Taken together, these results suggest that small transmitted rare CNVs play a role in the etiology of simplex autism. Importantly, the small size of these variants aids in the identification of specific genes as additional risk factors associated with ASD.

Results: *Results published in Am J Hum Genet, Oct 2013*

Documents:

DOI: *10.15154/1163542*

Data Use: Secondary Analysis

Cohorts: **Control - Parental Controls (822)**
Age: 0 to 1,200 months
Gender: Both
Control - Probands (411)
Age: 0 to 1,200 months
Gender: Both
Control - Sibling Controls (411)
Age: 0 to 1,200 months
Gender: Both

Measures: **Primary Measures: (3)**
Secondary Measures: (3)

Data Analysis: Genotyping/NGS
Type: CNV, Exome Sequencing
NGS Analysis
Variant filtering: De novo variants, Inherited variants
Variant validation: Targeted aCGH
Test Statistics: Pearson's chi-square test, Fisher's exact test
Test Correction: FDR
Software: CoNIFER, mrsFAST
Statistical
Method: Student's t-test, Binomial test

Attribution Report

ID	Collection	Subjects
1878	*Genomic Identification of Autism Loci*	1,644
1936	*Deep sequencing of autism candidate genes in 2000 families from the Simons Simplex Collection (SSC)*	462
1895	*Genomic Profiling and Functional Mutation Analysis in Autism Spectrum Disorders*	53

NIMH Data Archives Staff

NDA Summary

The NDA is a useful data archive that makes human subjects data:

A) Discoverable – federation, useful queries, XML web services

B) Useful to Others – data access, data QC, data analysis pipelines, APIs

C) Citable – data from labs that conduct experiments, data from papers, dois for groupings of data

D) Linked to the Literature – data link in PubMed as well as data dois in specific publications

National Institute of Mental Health

Meeting of the IACC

Afternoon Agenda - continued

4:00 Round Robin

4:30 Closing Remarks and Adjournment

These slides do not reflect decisions of the IACC and are for discussion purposes only.

Meeting of the IACC

Round Robin

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Meeting of the IACC

Closing Remarks

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Meeting of the IACC

Adjournment

These slides do not reflect decisions of the IACC and are for discussion purposes only.