

# Research • Practice • Policy: A Charge for the Future

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The Ohio State University

Charlotte, NC • June 20, 2012

**AAIDD 136th Annual Meeting**  
June 18-21, 2012 Charlotte, NC

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GRATIAS TIBI AGO  
GRACIAS  
ΕΥΧΑΡΙΣΤΩ  
THANK YOU  
ありがとう  
OBRIGADO  
MERCİ BEAUCOUP  
GRAZIE

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# AAIDD 136<sup>th</sup> Annual Meeting

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- Colleagues => presentations
- Conference Planning Committee
- Local Arrangements Committee
- Volunteers
- Maggie Nygren & AAIDD staff



# AAIDD 136<sup>th</sup> Annual Meeting

## *Research • Practice • Policy*

- Pre-conference workshops (Cont. Ed. Units)
  - **NTG on ID & Dementia**
  - **DirectCourse**
  - **PCP & SIS**
  - **Ethical Issues**
- Opening Plenary – ASD
  - **Drs. Piven, Kasari, & Parish**
- Federal Panel Plenary
  - **Drs. Parisi, Krahn, & Jesien**



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- Panel presentations N=24
  - Aging
  - Health
  - Employment
  - Quality of Life
  - Transition
  - Cross-Cultural Issues
  - End of Life
  - Forensic Issues
  - Supports Assessment
  - Direct Support Workforce
  - Community Supports
  - Inclusion
  - Self-Advocacy
  - Systems change
  - Spirituality
  - Parenting Issues
  - Funding Issues
  - Postsecondary Education



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### Poster Presentations:

- 150+ poster presentations
- students, recent graduates, early career professionals, established professionals & researchers
- presenters from 12 countries

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# AAIDD 136<sup>th</sup> Annual Meeting

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- Post-Conference ...

3:30 – 4:30pm

- Special showing 2012 Media Award Winner *“Academy of Country Music Lifting Lives”*
- *“Refrigerator Mothers”* – AAIDD 2003 Media Award Winner.

4:00 – 6:00pm

- Writing for publication
- Lessons learned from states using SIS



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- Post-Conference Workshops

Thursday, June 21, 2012:

- Assessment of ID in Capital Cases
- Religion & Spirituality Division Forum
- Positive Behavior Supports
- Trauma-Informed Care
- Dysphagia

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# Intellectual and Developmental Disabilities

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# PKU & the prevention of intellectual disability

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PKU => prevention of intellectual disability

1934 – Norwegian physician Dr. Asbjorn Folling.

Inherited – autosomal recessive gene.

Phenylketonuria (PKU) inability to properly break down an amino acid called phenylalanine.

Build-up of phenylalanine is toxic to CNS.



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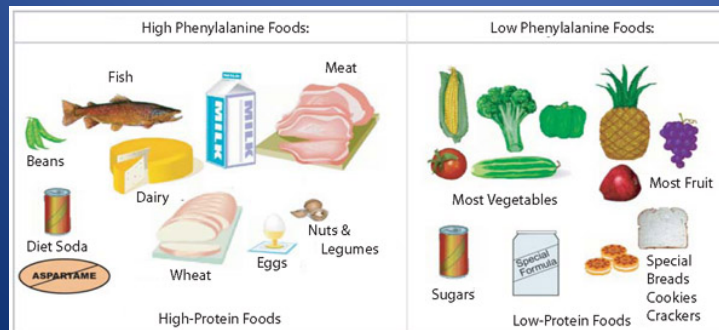
PKU => prevention of intellectual disability

Incidence: 1 : 10,000

TX: classic PKU diet - eliminates all of the very high protein foods since all protein contains phenylalanine.

2007: Kuvan received FDA approval.

Approx. 1963 => 1<sup>st</sup> infant screening test for PKU available....



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Popperfoto/Archive Photos

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## Montessori Method

Maria Montessori, MD  
(1870 - 1952)

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## Montessori Method:

- ⇒ Worked with children with intellectual disability.
- ⇒ Influenced by the work of Jean Itard & Edouard Séguin.
- ⇒ The Montessori method stresses the development of initiative and self-reliance by permitting children to do by themselves the things that interest them – self-paced learning, under the guidance of a teacher.



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Montessori Method:

⇒ Educational approach used around the world.

⇒ Highly coveted educational approach used with typically developing children.

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# Applied Behavior Analysis Positive Behavior Supports

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Operant Learning => Applied Behavior Analysis =>  
Positive Behavior Supports:

Defined: *the science of using principles of behavior analysis to understand the function of behavior to promote learning and behavior change.*

- We have used the science of Applied Behavior Analysis
  - teach new skills
  - promote pro-social behavior
  - understand and reduce problem behavior

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Operant Learning => Applied Behavior Analysis =>  
Positive Behavior Supports:

- Success in behavior supports => promote inclusion
- Success in early intervention strategies
  - Early intensive behavioral intervention
- Positive behavior supports

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Operant Learning => Applied Behavior Analysis =>  
Positive Behavior Supports:

Positive behavior supports:

- People with IDD
- Typically developing children (e.g., school-wide PBS)

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# Policy Changes & IDD

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Importance of Policy ... for researchers,  
practitioners ...

- **Developmental Disabilities and Bill of Rights Act (... trace back 1967)**
- Creation of NICHD => research in IDD
- IDEA (... 1970)
- Combating Autism Reauthorization Act (2011)
- Rose's Law (2010)



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# 2012 – 2013 Priorities

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# 2012-2013 - Priorities

- Build upon our strength as an interdisciplinary professional association=> research-practice-policy
- Renewed research emphasis at AAIDD => Tools for the field
- Students & Early Career Professionals
- DSM-5 ... ICD-11

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# 2012-2013 - Priorities

Founded in 1876, AAIDD is the oldest *professional association* concerned with intellectual and developmental disabilities.

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# 2012-2013 - Priorities

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# 2012-2013 - Priorities

The major functions of AAIDD are to:

- Support its members leadership in activities that affect people with IDD;
- Publish and promote cutting-edge research, tools, and materials that inform policy and practice.
- Develop and implement educational opportunities for professionals, policy makers, and others.
- Engage in activities that promote progressive public policy.

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A banner for the AAIDD 136th Annual Meeting. It features a city skyline at night with illuminated buildings. A large, white, curved architectural element, possibly a bridge or a modern building facade, arches over the skyline. The text is overlaid on the top left of the banner.

# 2012-2013 - Priorities

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- Support its members leadership in activities that affect people with IDD;
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# 2012-2013 - Priorities

Why AAIDD is the best place for “cutting-edge research, tools, and materials ...”:

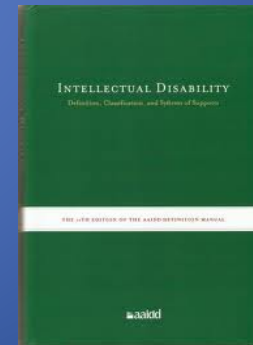
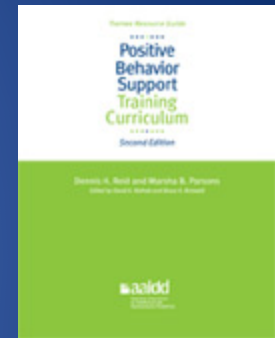
- Best practice journal in the field (IDD)
- Best research journal in the field (AJIDD)
- Interdisciplinary professionals – with focus on IDD.
- We are seen as the “authoritative organization” on intellectual and developmental disabilities.



# 2012-2013 - Priorities

Why AAIDD is the best place for “cutting-edge research, tools, and materials ...”:

- Positive Behavior Supports Curriculum
- Terminology & Classification Manual



# 2012-2013 - Priorities

Why AAIDD is the best place for “cutting-edge research, tools, and materials ...”:

- Death Penalty Guide (under way)
- Supports Intensity Scale
- DABS



The image shows a sample of the Supports Intensity Scale (SIS) Interview and Profile Form. The form is titled "Supports Intensity Scale Interview and Profile Form" and includes a header with the AAIDD logo and the text "AAIDD Member Login: 10/20/12". The form is divided into several sections for data entry, including "Individual Information", "Responsible Adult", "Supports Intensity Scale", and "Profile Information". It contains various fields for personal details, contact information, and specific data points related to the SIS assessment.



# 2012-2013 - Priorities

- Build upon our strength as an interdisciplinary professional association=> research-practice-policy
- Renewed research emphasis at AAIDD => Tools for the field
- **Students & Early Career Professionals**
- DSM-5 ... ICD-11

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# 2012-2013 - Priorities

## Student & Early Career Professional Members:

- Future of our Association and field
- Opportunities to lead and learn
- Research... Practice ... Policy

# 2012-2013 - Priorities

## Student & Early Career Professional Members:

- Continue the great work of previous Presidents in sustaining the Students and Early Career Professionals (have their own SIG).
- Ensure participation of student members and early career professionals on *ad hoc* committees, conference planning committee, and task forces.

# 2012-2013 - Priorities

## Student & Early Career Professional Members:

- Suggestions ... ideas ... to increase participation of Students & Early Career Professionals in association life and Annual Meetings.

# 2012-2013 - Priorities

## Student & Early Career Professional Members:

- How Can You Support Students and Early Career Professionals??
  - If you are a Fellow - become a guide
  - Help support by making a contribution to the Student Scholarship Fund
  - Take extra time to chat with them
  - Go to their presentations
  - Support a student's membership
  - Support a student's travel to conference.



# 2012-2013 - Priorities

- Build upon our strength as an interdisciplinary professional association=> research-practice-policy
- Renewed research emphasis at AAIDD => Tools for the field
- Students
- **DSM-5 ... ICD-11**

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# 2012-2013 - Priorities

## DSM-5: (April 2012)

### *Neurodevelopmental Work Group*

- Intellectual Developmental Disorders (April 2012)
  - Significant deficits in intellectual functioning – profile of cognitive abilities.
  - Significant deficits in adaptive behavior ... daily life, communication, social participation, functioning at school/work, personal independence home/community.... limitations result in need for ongoing support at school, work, or independent life.
  - Age of onset ... developmental period.

# 2012-2013 - Priorities

## DSM-5 (April, 2012 draft definition of IDD):

- **May 16, 2012 – AAIDD Letter to APA & DSM-5**
- **May 17, 2012 – AAIDD Press Release**
  - **Recommendations & Rationale**
    - Concerns with choice of terminology (ref. consensus, Rose's law)
    - Intellectual functioning
    - Adaptive behavior: conceptual, social, practical
    - Age of onset – operationally defined – prior age 18

# 2012-2013 - Priorities

## DSM-5 (April, 2012 draft definition of IDD):

- May 16, 2012 – AAIDD Letter to APA & DSM-5
- May 17, 2012 – AAIDD Press Release
- **May 30, 2012 – Response Letter from APA**
  - Referenced “rationale” posted on website (May 18, 2012)
    - Intellectual developmental disorder => ICD-11
    - Minimize formal assessment – emphasis on clinical assessment
    - Elimination of IQ levels – replaced with AB levels (3)
    - Mention of AB – conceptual, social, & practical
    - No mention age of onset

# 2012-2013 - Priorities

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- May 16, 2012 – AAIDD Letter to APA & DSM-5
- May 17, 2012 – AAIDD Press Release
- May 30, 2012 – Response Letter from APA
- **June 14, 2012 – AAIDD Letter to APA & DSM-5**

# 2012-2013 - Priorities

## June 14, 2012 – AAIDD Letter to APA & DSM-5

- Adopt “intellectual disability” .... concerns with choice of terminology – confusion at state ID eligibility, education, SSA, forensic, research / communication, etc...
- Developmental period be defined – prior to age 18.
- Adaptive behavior - defined consistently as conceptual, social, and practical.
- Stronger language around “measurement error” of standardized assessment instruments.

# 2012-2013 - Priorities

**June 14, 2012 – AAIDD Letter to APA & DSM-5**

**Other Stakeholders – adopting AAIDD’s talking points**

- Arc of US
- Special Olympics
- Inclusion International
- American Psychological Association – Division 33
- Amer. Academy of Develop. Medicine & Dentistry

# 2012-2013 - Priorities

**NEXT STEPS: IASSID & other international partners to provide clear input in the Draft of ICD-11**

- Discussion with IASSID – Halifax, Canada (July)
- Inclusion International
- Work with Ruth Luckasson – member of the ICD-11 Task Force on Neurodevelopmental Disorders





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# Concluding remarks

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