

Nonverbal (Nonspeaking) Children with Autism

Summary of NIH Workshop

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Boston University

IACC Meeting

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Planning Committee

Co-Chairs:

Judith Cooper – NIDCD

Connie Kasari (UCLA) & Helen Tager-Flusberg (BU)

Committee Members

Frank Avenilla (NIMH), Lisa Gilotty (NIMH), Dan Hall (NIMH/NDAR), Alice Kau (NICHD), Lana Shekim (NIDCD), Ann Wagner (NIMH)

Goals

Focus: Nonverbal (nonspeaking) school-aged children with ASD

1. What do we know?
2. What are the gaps in our knowledge based on current research?
3. What are the critical opportunities for advancing knowledge in this area?

Format: Invited presentations and discussants
Group Discussions

Participants

Grace Baranek (UNC)

April Benasich (Rutgers)

Nancy Brady (U Kansas)

John Connolly (McMaster)

Nicole Gage (UCI)

Barry Gordon (Hopkins)

Portia Iversen

Rebecca Landa (KKI)

Janice Light (Penn State)

Catherine Lord (U MACC)

Mark Mahone (KKI)

Stewart Mostofsky (KKI)

Rhea Paul (Yale)

MaryAnn Ronski (GSU)

Laura Schreibman (UCSD)

Larry Shriberg (UW)

Three Major Topics

1. Who are these individuals?
2. How can we assess their skills and knowledge across different domains, with special reference to abilities related to language?
3. What interventions are potentially effective in improving spoken language and communication in these children?

Who Are These Individuals?

[Lord, Gordon, Iversen]

- This is highly heterogeneous population with no single set of defining characteristics
- It is a significant challenge to assess their underlying skills and knowledge – current measurement tools have low validity/reliability
- It *is* possible to begin speaking after age 5 - almost all who do begin to between 5 and 7; only 1 case after puberty
- Almost no research focuses on this group

Why Don't They Speak?

Many *potential* explanations; for example:

- Lack of motivation/understanding intentional communication/joint attention
- Symbolic deficits
- Impaired imitation of sounds/movements
- Intellectual disability
- Severe social impairment; presence of challenging behaviors
- Specific language or motor/movement factors

Novel Technologies



Eye-Tracking

MEG



EEG/ERP

Assessment

[Tager-Flusberg, Gage, Benasich]

Implicit measures of cognitive and brain function

1. Eye-tracking measures of language comprehension and processing – demonstrated reliability and validity
2. Magnetoencephalography (MEG) – to assess auditory processing impairments
3. Electroencephalography (EEG/ERP) – to assess brain processing of language – words, grammar and discourse

Sensory, Motor, and Apraxia

- No published studies on this populations – limitations in the current methods of assessment
- Motor skills may provide a window into brain mechanisms; it may be important to distinguish voluntary and involuntary movements
- No strong evidence that nonverbal ASD is associated with Childhood Apraxia of Speech (CAS) – but relevant data are not available

Future Directions on Assessment Research

- Further research on novel implicit measures of language comprehension; extend to cognition and move from the lab to the clinic
- Develop appropriate methods for assessing sensory and motor skills and investigate in this population
- Use dynamic assessment approaches of vocal repertoires with special attention to parameters associated with CAS
- Incorporate novel assessments into treatment/intervention research

What Interventions are Effective?

Non-Augmentative: [Schreibman, Kasari]

- Behavioral approaches – classic DTT; newer naturalistic (PRT; milieu etc.) are effective with some children (e.g., those who engage with toys prior to intervention).
- Ongoing SMART design study (Kasari, Landa, & Kaiser) is comparing JA+milieu to JA+AAC in 5-7 year olds in a 6 month protocol

What Interventions are Effective?

Augmentative: *[Brady, Ronski]*

- Covers all non-speech means for communication (e.g., PECS, Sign, SGD – speech generating devices etc.)
- Can be effective in increasing communication; and decreasing challenging behavior; and can lead to speech or literacy
- Limited real world use in the classroom and sometimes in homes

Future Directions in Interventions Research

- Insufficient description of participants
- Limitations in study designs (mostly single case) – need for flexible designs; RTI etc., longer term outcomes
- Predictors of responses to specific interventions – match intervention to child characteristics
- Measurement issues – what is meaningful change – in spoken language; communication; other areas?
- Urgent need for *novel* interventions for this population, who are often excluded from research studies, even on efficacy of EI

Next Steps....

1. Working group to develop recommended measures and benchmarks to describe phenotypes in population; research participants; outcome measures
2. Summary of current knowledge and gaps – to promote further research and enhance clinical/educational practices
3. New research needed on advancing assessments; mechanisms underlying nonverbal phenotypes; comprehensive treatment/interventions research with special emphasis on novel approaches

Final Words

- We do not know what % of the ASD populations remains nonverbal after age 5 – though diminishing, this should be a priority area for future research
- Having even *a single spoken word* is a significant predictor of progress in treatment studies
- There is a great deal that we need to learn, and can learn from studies that begin to target this population- that will translate into genuine benefits for the individuals and their families

Thank You!



Boston Globe, April 20, 2010