Down Syndrome and Autism

Susan Hepburn, Ph.D.

Associate Professor, Dept. of Psychiatry
Director of Research for JFK Partners
University of Colorado School of Medicine

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Why study co-occurrence of Down Syndrome and Autism?

- Could tell us about the genetics or neurobiology of both conditions

Clinical Relevance

- Distinct presentation
- Different response to interventions
- Different outcomes
- Different everyday experience

Family Perspective

"swimming against a social stereotype"

"...outsiders in our own community"

General Development in DS

- Most domains develop in same order as typical kids, but at a slower pace (Tien et al, 1999)
- IQs usually range from 30-70; mean is 50 (Chapman, 1999)
- Most children make about 4-5 months of developmental progress per 12 months
- Receptive language (not just vocabulary) is usually strongly associated with overall IQ (Abbeduto et al, 2003)

Social Strengths in DS

- Core relating (e.g. person-to-person, back and forth connections) (Dykens & Kasari, 1997; Gibbs & Thorpe, 1983)
- Imitation (Wright et al, 2006)
- Socialization is usually a relative strength in adaptive behavior in middle and high school (Dykens et al, 1994)

- Can do pretty well with peers, if supported (Freeman & Kasari, 2002)
What if the Individual Also Has an Autism Spectrum Disorder??

General Development in DS+ASD
- Development is uneven and "spotty"
- IQs usually range from 20-60; mean is 40 (Hepburn et al., 2009)
- Most children make about 1-2 months of developmental progress per 12 months (Molloy, 2009)
- Receptive language is often very impaired

Social Challenges in DS & ASD
- Core relating
- Imitation
- Socialization
- Peer interaction

Quick Glance:
Screening and Prevalence Study Of Down Syndrome and ASD

Estimated Prevalence of Autism and ASD in Down Syndrome
- Approximately 7% of children with Down Syndrome met criteria for Autism
- Approximately 18% of children with Down Syndrome met criteria for Autism Spectrum
- The rate is 30 X greater than general population!!
  DiGuiseppi et al., (2011)
Children with DS and ASD

- Have difficulties in core social relating that cannot be explained by their overall developmental level
- Have difficulty becoming intentional communicators
- Can be very challenging to motivate
- Tend to really “get stuck” in routines/behavior chains

Next Steps for Research:
1. Improve Screening & Evaluation Tools

We think children with DS and ASD need.... (Hepburn & Fidler, in preparation)

- More direct intervention in social and communication, with an emphasis on functional, preverbal communication
- Active facilitated social support with peers

Next Steps for Research:
2. Test Impact of Specific Interventions

We think children with DS and ASD need....

- Planful approaches to instruction, focused on filling in developmental gaps
- More time on teaching intentional requesting in lots of different ways
- Use of simple, clear visual supports and predictable routines

Overall, interventions designed for children with Autism are usually a better fit...but have not been systematically studied!

Next Steps for Research:
3. Investigate Genetic Markers

- Multi-site Genetics/Proteomics study led by Dr. Tamim Shaikh, Dr. Ellen Elias, Dr. Kathleen Gardiner, Susan Hepburn, Ph.D., Deborah Fidler, Ph.D.

For more information: Angela.Rachubinski@ucdenver.edu
Next Steps for Practice

- Disseminate information regarding the DS and AUT phenotype:
  - to parents
  - to educators
  - to therapists
  - to physicians

- Continue to collaborate with the DS-Autism Connection and other community partners to:
  - Build awareness of DS & ASD around country
  - Provide support to families of complex children
  - Support school districts

For more information on the DS-Autism Connection:
www.ds-asd-connection.org

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