22q11.2DS Translational Clinic at the MIND Institute
Introduction

• Started as TJS research project at CHOP
  – Isolated from clinical practice
• Moved to M.I.N.D. Institute early 2005
  – Immediate inclusion of Beh/Dev Peds Fellow
• July 2008 added clinical neuropsych assessment
Now fully collaborative team communicating via staffings & research/educational activities
Research & Clinical support both enhanced
Families benefitting from both
Study participants

• Children aged 7-14 years, FISH positive
• Recruited from all 50 states & Canada
  – Driven from research recruitment
  – Currently have NIH funds
    • NIH travel/accommodation funds child & 1 parent
      i.e. no study costs borne by families
  – ALL study related inquiries handled via:
    cabil@ucdmc.ucdavis.edu
CABIL Team members

- Tony J. Simon, Ph.D. – Director, Cognitive Neuroscientist
- Marisol Mendoza, M.A. - Study Coordinator
- Elliott A. Beaton, Ph.D. - Postdoctoral Scholar
- Margie Cabaral, B.S. - Research Assistant
- Heather Shapiro, B.A. - Graduate Student
CABIL team members

- Roger S. Akins, D.O. - Developmental Behavioral Pediatrics Fellow
- Kathy Angkustsiri, M.D. - Developmental Behavioral Pediatrician
- Janice Enriquez, Ph.D. - Psychologist
- Ingrid Leckliter, Ph.D. - Psychologist
- Joel Stoddard, M.D. - Psychiatrist/Postdoctoral Fellow
Video clip of 2 day visit
Clinic visit

Center for Excellence in Developmental Disabilities
Clinic visit

Center for Excellence in Developmental Disabilities
Staffing

- Role and Function
- Who attends
- What do we discuss
- What have we learned
- How do clinicians benefit, How does research benefit, How do families benefit
- Bottom line: get involved in research – everyone wins!
Parent feedback

• Common topics
  – Understanding developmental delay
  – Dealing with the diagnosis (and new diagnoses-comorbidities)

• Individualized recommendations
  – School recommendations and local resources
  – Medical treatments
  – Evidenced-based interventions when possible

• Written report to share with local providers
CABIL Translational Clinic Impact

• Evaluated via electronic questionnaire supported by SurveyMonkey.com
• E-mailed SurveyMonkey.com link (x 3) to 19 participants
  – 7 replied
The evaluations helped parents feel more encouraged for their child.
The evaluations helped parents understand their child’s problems.
The evaluations advised families how to obtain more information.
The evaluations identified other helpful professionals or groups.
The evaluations improved access to school services.
Teaching video clip

Medical Symptoms of Chromosome 22q11.2 Deletion Syndrome

Center for Excellence in Developmental Disabilities
Teaching video

• Target audience: families and primary care physicians

• Goals: increase awareness and diagnosis
  – Guide medical work-up and treatment, educational interventions, and identify mental health issues
  – Provide resources
    • Links to websites
Future plans

• Telemedicine follow-up goals
  – 6-9 month follow-up for study participants seen at the MIND
    • Teleconference with child’s educators and physicians if possible
  – Limitations (age, geography, etc)
    • Western US
    • Families enrolled in research
  – Possibility to expand in future
    • Dependent on future funding/donations
Cognitive Analysis and Brain Imaging Laboratory (CABIL)

- BREAKING NEWS
- CABIL Team Members
- Publications by CABIL Team
- Research Projects at CABIL
- What Will My Child Experience at CABIL?
- Family Meetings
- Resources
- Directions
- Media Coverage of CABIL
- Research Tools

The MIND Institute's Cognitive Analysis and Brain Imaging Laboratory (CABIL, pronounced “cable”) is directed by Dr. Tony J. Simons and funded by the National Institutes of Health. CABIL's mission is to investigate, explain, and eventually treat the impairments in cognitive function experienced by children with neurodevelopmental disorders.

The cognitive analysis part of our research involves developing theory-driven experiments that are presented to children as computer games. These experiments test the functioning of specific brain circuits under different conditions, and predict characteristic patterns of performance depending on how well the system is functioning. The brain imaging part of our research is achieving a great deal of progress using safe, radiation-free neuroimaging methods to characterize the changes in brain development that affect the neural structure, connectivity, and function of such children. Knowing how the brains of children with neurodevelopmental disorders differ from those of their typically developing peers helps us to generate possible explanations for the impairments in cognitive function.

Click here to play a video to learn more about CABIL (requires Adobe Flash)