DEVELOPING LIFE SKILLS IN THE YOUNGER STUDENT

Donna Cutler-Landsman, M.S.
MIND Institute, UC Davis
22q Family Foundation
www.cutlerlandsman.com
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UNDERSTANDING THE SYNDROME

• Limited research is available to predict outcomes for students with 22q11.2 deletion.
• Many anecdotal stories and information from the community, including data collected from my work with families
• Adaptive skill acquisition is limited, even in children with higher IQ levels
• Functional study showed limitations
• Quality of life can be compromised
• Anxiety plays a key role
An examination of the relationship of anxiety and intelligence to adaptive functioning in children with chromosome 22q11.2 deletion syndrome


• Study found that there was no relationship between WISC IQ scores and adaptive functioning, but anxiety had a negative correlation with adaptive scores.

• “The presence of anxiety symptoms, but not intelligence levels, in children with 22q11.2DS is negatively correlated with adaptive function and impacts everyday living skills.”
More than 75% of the subjects scored in the functional deficit range. Although personal, vocational, and financial demographics confirmed widespread functional impairment, daily living skills and employment were relative strengths.

Mediating factors—intelligence and mental health

Deficits across all levels, but especially in social and communication skills
Quality of Life among Children with Velocardiofacial Syndrome (22q11.2ds)

Wendy S. Looman, PhD, RN, CNP, Anna K. Thurmes, MA, CCC-SLP, Speech-Language and
Susan K. O'Conner-Von, PhD, RN,  May 2010

- Compared quality of life among children with 22q11.2 to healthy and chronically ill children
- QoL was generally lower across all domains. Boys with VCFS scored significantly lower than girls on school functioning and cognitive fatigue (attending, remembering, thinking quickly), although both groups scored lower than the other two subgroups
- Compared to chronically ill children, children with VCFS scored lower on emotional, social and school functioning (but not on physical health).
- Education should address the dimensions of quality of life along with self-care, transition to adult care and healthy coping skills
WHAT ARE ACTIVITIES OF DAILY LIVING?

- Eating with utensils
- Toileting
- Selecting proper clothing
- Grooming
- Putting on clothes
- Bathing
- Walking and transferring
- Speaking

These skills are taught at home, in school and in OT, PT and Speech Therapy and should be mostly mastered by kindergarten.
# Vineland Adaptive Scales

**Ages 3-21**

<table>
<thead>
<tr>
<th>Domain</th>
<th>Subdomains</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication</td>
<td>Receptive</td>
</tr>
<tr>
<td></td>
<td>Expressive</td>
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<tr>
<td></td>
<td>Written</td>
</tr>
<tr>
<td>Daily Living Skills</td>
<td>Personal</td>
</tr>
<tr>
<td></td>
<td>Domestic</td>
</tr>
<tr>
<td></td>
<td>Community</td>
</tr>
<tr>
<td>Socialization</td>
<td>Interpersonal Relationships</td>
</tr>
<tr>
<td></td>
<td>Play and Leisure</td>
</tr>
<tr>
<td></td>
<td>Coping Skills</td>
</tr>
<tr>
<td>Motor Skills (Optional)</td>
<td>Fine</td>
</tr>
<tr>
<td></td>
<td>Gross</td>
</tr>
<tr>
<td>Maladaptive Behavior (Optional)</td>
<td>Internalizing</td>
</tr>
<tr>
<td></td>
<td>Externalizing</td>
</tr>
</tbody>
</table>

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Three adaptive domains (Conceptual, Social, and Practical) are tested:

- Communication
- Community use
- Functional academics
- Health and safety
- Home or school living
- Leisure, motor
- Self-care
- Self-direction
- Social
- Work
- Ages 0 - adult
Adaptive tests are not usually done for children in the general education setting, who are academically just slightly behind classmates.

Often reserved for only children who are more severely impaired.

Eligibility for cognitive impairment requires both an IQ below 70 and low scores in more than one environment on adaptive measures.

70% of young children with 22q11.2ds have IQ scores above 70 and are in the low average range.

Evidence that over time IQ drops and functional ability lags further behind age level peers with 22q11.2ds students.

Staff does not understand syndrome or long-term implications.
PROACTIVE INTERVENTIONS ARE KEY

• Pre-school therapy interventions are often needed

**IDEA law:**

Sec. 300.324 Development, review, and revision of IEP.

General: in developing each child’s IEP, the IEP team must consider:

• The strengths of the child

• The concerns of the parents for enhancing the education of their child

• The results of the initial or most recent evaluation of the child and

• The academic, developmental and **functional** needs of the child
EDUCATE SCHOOL STAFF

- Must do proper evaluations for this syndrome and recognize long-term issues associated with functional outcomes.
- Must address anxiety in the school setting including functional behavioral assessments.
- Must set goals in IEP that address issues related to independence and self help along with academic goals—even though students are functioning academically at a higher level.
- OT, PT and Speech/Language therapy are key elements to long-term independence and should not only address “in school” skills.
- Parents may need to find community supports to address deficit areas if school will not provide services or if scheduling is taking away too much classroom instruction time.
SCHOOL BASED THERAPY

- In IEP as a “related service”

- **Speech and Language Therapy**—(articulation, expressive, receptive, pragmatic)—may last several years even into high school

- **Occupational therapy**—not just handwriting and fine motor skills. Visual perceptual deficits, classroom accommodations, activities of daily living

- **Physical therapy**—gross motor skills, balance, coordination, hypotonia, axial instability
ACADEMIC SKILLS

• Focus on functional skills
• Reading for information
• Researching important facts
• Money skills
• Understanding time
• Using math around the home and in the community
• Writing to complete forms
• General knowledge—calendar, community, phone number, address, how to access help, etc.
PRACTICE AT HOME

Foster independence using direct instruction in skills

• Role play, modeling
• Backwards chaining
• Talk out loud when doing tasks—explain thinking
  • Structure household
  • Allow mistakes and choices
• Explain emotions and reasons for feelings
  • Resist over scheduling
• Set up a behavioral reward system
RESOURCES: ADAPTIVE SKILLS

- Ages 2-21
- 148 pages with checklists of age appropriate skills
- Social competence (interactions, self concept, emotions, values, sexuality, etc.)
- Self-care (time, money, health and safety, etc.)
- Play and Leisure (music, pets, drama, speaking, etc.)

Assessment & Ongoing Evaluation booklet:

Texas School for the Blind

© TSBVI 1993 - 148 pages Order # 59421ILE (18 oz.),
or database Order # 59421AED $15.00
RESOURCES: SOCIAL SKILLS
CAROL GRAY

www.carolgraysocialstories.com

- Originally designed for children with autism
- 10 defining aspects to writing a social story
- Stories are safe and supportive

*The Social Story Goal.* Authors follow a defined process to share accurate information using a content, format, and voice that is descriptive, meaningful, and physically, socially, and emotionally safe for the child.
RESOURCES—MICHELLE GARCIA WINNER

Social Thinking  www.socialthinking.com

- social self-awareness
- perspective taking/theory of mind
- self-regulation
- executive functioning
- social-emotional understanding
- social skills
- organizational systems
- reading comprehension
- written expression

Uses concepts of expected and unexpected behaviors to help guide children in social competence
(ages 4 to adulthood)
University of Geneva—Dr. Bronwyn Glaser, Dr. Stephan Eliez

Vis-à-Vis targets three main skills, or domains, that are important for improving socio-emotional and reasoning skills: focusing on the eyes of the face, emotion recognition and understanding, and working memory.

Vis-à-Vis ("face-to-face") is a socio-emotional cognitive training program for children and adolescents with autism and developmental delay.

Direct research done with 22q11.2 population and this program

48 computerized sessions (approximately 20-25 minutes)

Research based

Ages 7-16

Adult support needed for 22q11.2 population
RESOURCES: ANXIETY

- **Coping Cat**—Researched based program to deal with anxiety using cognitive behavioral therapy. 16 sessions including situation cards, a feelings barometer, cut-outs and certificates (ages 7-13)

- **Camp Cope-A-Lot** is a 12-session interactive CD-ROM-assisted treatment for use with children suffering from anxiety. The computer program provides cognitive behavioral therapy (based on the *Coping Cat* treatment) for 7 - 13 year old anxious youth. Child users advance on their own and at their own pace through the first 6 sessions, and through the last 6 sessions with therapist (coach) guidance.

- Users complete interactivities that communicate skills for managing anxiety. Along with other campers at Camp Cope-A-Lot, the child goes to an amusement park, puts on a talent show, meets someone new, speaks in public, sleeps in the dark, and experiences other adventures.
Dr. Tony Simon

- Video game to address deficits in the mental representation of space and time
- Deficits in number concepts, time, arithmetic
- Video game format is an approach to target these areas that are impaired in the deletion
- Currently one game prototype has been produced, but the plan is to produce a much more robust game that will better target affected areas.
FOCUS LONG TERM

- Dream big and set outcome goals
- Set realistic expectations
- Focus on the whole child—not just academics
- Try not to overschedule
- Advocate for functional support in schools
- Recognize that the 22q11.2 deletion is complex and will require specialized support throughout the lifespan
- Assistance is available
ADDITIONAL RESOURCES AND HELP

- www.cutlerlandsman.com
- www.22qfamilyfoundation.org
- Mind Institute at UC Davis 22q clinic
- cutlerlandsman@gmail.com