

The Help Group Summit 2010

***“The Aging Out Process for Students with ASD:
A Leap into the Great Unknown”***

Panel of Presenters

Louis Vismara, MD – Moderator
Parent of 17 year old son with autism
Staff, Senator Darrell Steinberg


Pamela Clark, MA
Director of Autism Schools;
The Help Group

Peter Gerhardt, EdD
Director of Education;
The McCarton School in New York City

Linda Andron-Ostrow, LCSW
Director, F.A.C.T.
Focus on All-Child Therapy

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The Autism Epidemic: A Personal Perspective



UC Davis M.I.T.D. 10/10/09

Autism Statistics in 1995

- Incidence ~ 1/750 births
- Calif. schools ~ 3,000 students
- Regional Centers ~ 4,700 consumers
- ASD lowest incidence developmental disability



Autism Statistics in 2010

- Incidence ~ 1/110 births
- Calif. schools ~ 57,000 students
- Regional Centers ~ 46,000 consumers
- ASD now 66% of all new Regional Center cases

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The Autism Epidemic: An Impeding Tsunami

> 70,000 Regional Center (RC) consumers with ASD – 2012

Currently, 84% of RC consumers with ASD < 22 years of age

Presently < 6,000 RC adults with ASD;
by 2018 >19,000 adults with ASD

R C costs related to age & diagnosis

- children No ASD: \$3,447
- children with ASD: \$6,993
- adults No ASD: \$15,935
- adults with ASD: \$36,704

Unemployment among RC adults 84%;
with ASD >90%

Presently 89% of RC consumers with ASD live
with parents/family members

R C serve only ~ 20% of individuals with ASD

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Causes Of Poor Outcomes For Transitional Youths with ASD

- Poorly implemented transition from school to adult life*
- 67% families no knowledge of transition programs*
- Lack of coordination between educational behavioral, mental health, & vocational rehabilitation services*
- Lack of understanding about employment potential*
- 78% no knowledge of job development agencies or professionals*
- Lack of adequate and appropriate supports*
- Absence of qualified staff*

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Senate Select Committee on Autism & Related Disorders
(Adopted: March 4, 2009)

A legislative forum for research, analysis, deliberations, and outreach; to promote policies/legislation to better assist individuals with ASD & their families

- To focus on the following issues:
- Early Identification & Intervention*
 - Insurance Coverage*
 - Training & Employment*
 - Housing*

Report to the Senate – Nov. 30, 2010

Website: www.senate.ca.gov/autism



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Senate Select Committee on Autism & Related Disorders

Members

- President Darrell Steinberg**
Committee Chair (D – Sacramento)
- Republican Leader Dennis Hollingsworth**
Vice-Chair (R – San Diego)
- Sen. Elaine Alquist** (D – Santa Clara)
- Sen. Roy Ashburn** (R – Bakersfield)
- Sen. Gil Cedillo** (D – Los Angeles)
- Sen. Lou Correa** (D – Orange County)
- Sen. Mark DeSaulnier** (D – Concord)
- Sen. Robert Dutton** (R – Inland Empire)
- Sen. Dean Florez** (D – Central Valley)
- Sen. Mark Leno** (D – San Francisco)
- Sen. Carol Liu** (D – Pasadena)
- Sen. Alex Padilla** (D – Pacoima)
- Sen. Fran Pavley** (D – Agoura Hills)
- Sen. Curren Price** (D – Los Angeles)
- Sen. Lois Wolk** (D – Davis)

Regional Task Forces

- Sacramento (Steinberg)**
- San Francisco-Marin; (Leno)**
- East Bay/Oakland (DeSaulnier)**
- Peninsula/Santa Clara; (Alquist)**
- North Bay/Solano (Wolk)**
- Fresno (Florez; Asburn)**
- Bakersfield (Florez; Asburn)**
- North Los Angeles (Liu, Padilla, Pavley)**
- South Los Angeles (Price)**
- Orange County (Correa)**
- South Counties (Hollingsworth)**
- Inland Empire (Dutton)**



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**Senate Select Committee on Autism & Related Disorders:
Preliminary Taskforce Recommendations**
www.senate.ca.gov/autism

<p>Early Identification & Treatment</p> <ol style="list-style-type: none"> 1. <i>Integration & coordination between school & regional centers</i> 2. <i>Strategies to promote the improvement in early diagnosis & treatment of ASD</i> 3. <i>Technology: application & expansion</i>
<p>Autism Insurance Coverage for ASD by Private Health Plans</p> <ol style="list-style-type: none"> 1. <i>Legislation in 2011 to Mandate Behavioral Intervention Therapy</i> 2. <i>Knox-Keene Certification/Licensure for Behavior Intervention Therapists</i> 3. <i>Healthcare coverage under the policy of their parents or conservatorship</i>
<p>Employment</p> <ol style="list-style-type: none"> 1. <i>Earlier Implementation of Individualized Transition Program (ITP)</i> 2. <i>Implementation of social skills curriculum as part of the ITP</i> 3. <i>Pilot project to implement an Integrated Employment Model</i>
<p>Appropriate & Affordable Housing</p> <ol style="list-style-type: none"> 1. <i>Establish a Permanent Source of funding for Affordable Housing.</i> 2. <i>Passage of the Federal Achieving A Better Life Experience (ABLE) Act</i> 3. <i>Extend the Duration of the Senate Autism Committee and Regional Taskforces</i>


What is an Individual Transition Plan (ITP)?

A transition plan is the section of the Individual Education Plan (IEP) that outlines transition goals and services for the student.

A template for mapping out long-term adult outcomes from which annual goals and objectives are defined.

- *Employment & Education*
- *Home & Family*
- *Leisure Pursuits*
- *Personal Responsibility & Relationships*
- *Physical & Emotional Health*
- *Community Involvement*

The Help Group Summit 2010



**“DIGNITY, HOPE,
OPPORTUNITY AND LOVE
ARE THE BIRTHRIGHTS OF
ALL INDIVIDUALS ”**

~ Dr. David Firestone

Transitioning

Keys to Successful Planning

When Should Planning Begin?

Ideally, the implementation of the IEP Individual Transition Plan (ITP) should begin as early as Middle School.

Rated as a #1 priority from a webinar survey done by members of the Autism Taskforce.

Reality – The current timeline for the Individual Education Plan ITP to begin is at the age of 16.

Where Do We Start?

A transition plan will only be successful if it is **“Student Focused”**

Assessment Should Drive Instruction

- 1) Academic Assessments
- 2) Interest Assessments
- 3) Ability Assessments
- 4) Situational Assessments

Key Ingredients for Successful Transition

Any good transition plan and program should have the following components:

Social Skills

To include leisure, grooming, personal relationships, sex ed.

Communication Skills

Appropriate verbal interactions in the workplace.

Key Ingredients for Successful Transition

Work Skills

To include work ethics

Community Skills

To include mobility training

Academic Skills

To include Reading, Math/Money, Time and Written Language

Transition Curriculum Matrix

Programming should promote growth and development using a structured curriculum that incorporates instruction with real life experiences. There should be a progression of skills and expectations.

It is important that the plan involves the student and his family.

The Vocational component should offer the opportunity for the student to receive on-the-job training both within the program and in the community.

Transition Curriculum Matrix

Career Development
 Work habits
 Personal Strengths
 Interests and Preferences

Independent Living
 Self- Advocacy
 Budgeting
 Workplace Management
 Rec/Leisure

Transition Curriculum Matrix

Adult Living
 Personal Responsibility
 Health and Hygiene
 Personal Relationships

Outcome Measures

As with any instruction, Transition curriculum should include a way to measure outcome.

Some typical outcome measures may include:

- Data Collections
- Informal Assessments
- Self-Evaluations
- Employer Evaluations

Transitional Support Beyond School

- Transition Support cannot stop when a student graduates from a school or program with a Certificate of Completion or a Diploma
- Examples of supports that span beyond school years may include:
 - Regional Center
 - Centers for Independent Living
 - Advance LA – The Help Group

Individualized Programs

- Success in any transition plan or program depends on how much the program offers specialized instruction designed to meet students' individualized needs at various levels.
- Dr. Peter Gerhardt to speak on the full-spectrum ITP



Tools for Transition



Linda Andron-Ostrow, LCSW
Executive Director, F.A.C.T.
factfamily.org



Tools for Transition



- Self Advocacy Begins with Self Awareness and Self Acceptance
- Discovery and GAP Year Address Life After High School



Self Advocacy

- Development of Self Advocacy should be a goal in Transition Planning, and be considered as a core subject in high school.
- There is no way to advocate for yourself without self awareness and self-acceptance.
- Only with these skills can one present their challenges, and offer alternative strengths to meet curriculum requirements.



Prototypes for Self Advocacy

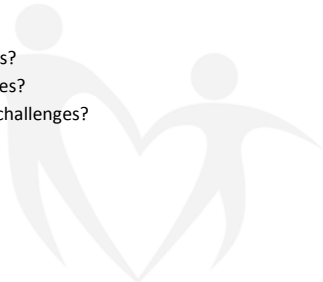
- Self Awareness
- Self Acceptance





Self Awareness

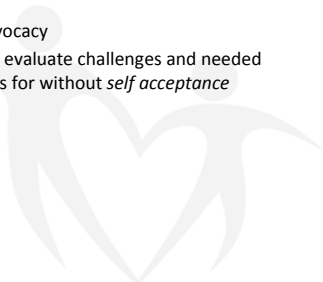
- Who am I?
- What are my strengths?
- What are my challenges?
- How do I meet those challenges?





Self Acceptance

- Foundation of self advocacy
- No way to realistically evaluate challenges and needed support one advocates for without *self acceptance*





Meeting the Challenge Being Assigned a Difficult Task

- Student asks for a different way to demonstrate comprehension – one of the protections under Section 504
- Student needs to know what their *challenges* are in order not to appear to be avoiding the assignment
- Most Important – individuals must propose using alternative strengths
 - To demonstrate the same academic competence
 - To demonstrate the same work competence



Meeting the Challenge Possible Accomodations

- Get professor to accept a PowerPoint presentation in lieu of a 10 page essay
- Arrange for essay questions on final instead of multiple choice
- Request taking a “verbal” mid term



Have A Strong Belief in Yourself

- Courage to walk into professors office disclosing disabilities
- Understanding that self advocacy is not a crutch, but a *springboard to success*
- Knowing that you are *not less than other students*, in fact self advocacy shows you have a higher level of maturity

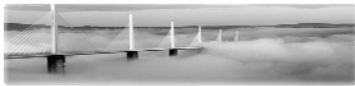
Critical Prerequisites

- Learn how to look at and assess a task
 - what you CAN do
 - where you need HELP
 - if you need ACCOMODATION
- This is the prerequisite for successful self advocacy.
- Practice the skills of advocating with teachers
- Work with teachers to determine accommodations

Mantra For Empowering Students With ASD

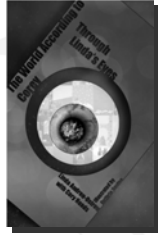
- A.S.D. Is an **EXPLANATION**, not an **EXCUSE**
- When internalized, better educate faculty and general public
- “What should I tell the professor: I’m autistic so I should be allowed to sit in the back of the class and sleep and listen to my IPOD?”
- “If I don’t do well in class it’s because I have not studied.”

Along the Transitional Bridge



- “No amount of help is worthwhile if it is the wrong kind of help.”
- “OK mom, which is it, am I lazy or am I disabled?”
- “It’s about figuring out when to be a little fish in a big pond and when to be a big fish in a little pond”
- “If you miss enough appointments, start putting them in your phone.”
- “I want to be a writer but I know I need a day job”.
- “If you want a free bus pass register on line”

The World According to Corey Through Linda's Eyes





A High School Diploma Now What?

Student Finished High School. Now What?

- "Wow, I passed all my tests, I got all my units of credit and they are giving me my DIPLOMA!"
- "I worked so hard to get here"
- "But what does that piece of paper mean?"
- "What do I do next?"
- "I need a break"
- "I don't know what I want to do"
- "How about a GAP year?"



Parent

- “Wow we did it!”
- “All of those IEP’s, modifications/accommodations, aides, behaviorists, special classes, special schools, hours of homework, tutors....”
- “We reached the goal – A HIGH SCHOOL DIPLOMA”
- “NOW WHAT?”
- “What about these next 4 years of transition?”
- “College?... Without aides or an IEP”
- “Work? There are no jobs, and how could MY child be employed?”



What is a GAP Year?

For **typical students** accepted to a college

- A break
- A time to explore
- A chance to mature

For **special ed students** it is all this and MORE

- A chance to get their feet wet in many settings
- A chance to develop “real world” skills
- A time to grow self awareness self acceptance and self advocacy skills

“Generating All Possibilities” Defines the Transition Experience

- Especially at this time of life , NEVER lock in participants with ASD to any pre-set mold
- Urgent to identify strengths, challenges and interests
- It takes time and exposure to different settings to make realistic post-secondary life decisions
- Decisions must be based on”
“Person-centered planning”
Development of self awareness, self acceptance and through self advocacy
- Realistic assessment of student as a whole person AND pragmatic career choice alternatives optimize chances for long term success



Great GAP Year Must Deliver Actionable Next Steps

- Community College - actively work with Office of Disabled Students to devise tailored support plan
- Try Out Work? - arrange for apprenticeships with willing companies to see how different enterprises and industries work
- Go to Work - Coordinate with Regional Center and Dept of Rehab
- Volunteerism /National Service - help graduate with application process for organizations like AmeriCorps (Domestic peace Corps)
 - affiliations with thousands of local not-for-profits
- Start a "Micro" Business – line up Regional Center funding and a volunteer business mentor
- *Be sure to continue with social and living skills support*



Be All You Can Be



Thank You
