Transition for Youth with Complex Support Needs

NTACT Ask the Expert Series 2019-20
Today’s Presenters

Linda O’Neal, San Diego State University

Michael Stoehr, NTACT

Charlie Walters, University of South Carolina
Agenda

• **Who** are students and youth with the most complex needs?

• **What** are the barriers to successful transition outcomes for students with complex needs?

• **How** can we work to overcome the barriers?

• **What** are current effective practices to support the transition of students and youth with the most complex needs?
Who are students and youth with the most complex needs?

VR – Perspective

- Students with disabilities who may require:
  - Line of site supervision
  - Extra support for their physical and personal care
  - Communication support to fully participate
  - Individualized strategies for behavioral supports
  - Consideration of risk/safety issues
  - Contingencies for crisis management
  - Medication management supports
Who are students and youth with the most complex needs?

Education – Perspective

▪ Students with disabilities who have/require:
  ▪ 1:1 assistance for all activities of daily living
  ▪ Very limited physical and/or mental stamina
  ▪ Significant behavior issues
  ▪ Limited communication response (1-2 second eye gaze for yes/no answers)
  ▪ Daily required supports from a medically trained professional
  ▪ 1:1 supports for social engagement activities
The Big Picture: Guiding Questions

Ask yourself:

- What is it that we are actually doing to support this student/youth?

- Is it meaningful?

- Will it really help the student to achieve his/her post-secondary goals and to enjoy a quality of life?
• What are critical outcomes for these students?
• What are your students’ hopes and dreams for their future?
• What are their parents’ hopes and dreams for their sons and daughters?
• Think about the transition to a supported adulthood
  • Supported employment
  • Supported living
  • Supported membership in the community
  • Supported self-determination
Data-Based Decision Making in Transition

“[T]eachers must acknowledge that evidence-based special education is a decision-making process that involves a framework developed from research-based principles (i.e., Kohler’s Taxonomy for Transition Programming; Kohler, 1996), the best available research evidence, professional judgment, and students’ needs and values. With this in mind, data-based decision making should be used to determine if a selected EBP is effective for specific students” (Mazzotti, Rowe & Test, 2013)
A Starting Point for Data-Based Decision Making

• What can we say about outcomes for youth with complex support needs?
  – Lots! But how much of it comes from our own evaluation of transition programing?
  – For our local area/state, what can we say about this specific population in terms of:
    • Interagency support and collaboration?
    • Self-determination skills?
    • Career exploration, awareness, and work experiences?
    • AT acquisition?
    • Independent living?
    • Post-school outcomes?
  – The Long Game: Issues we address should be identified by the same/similar metrics that can ultimately show change as we try new approaches
Strategies for Data-Based Decision Making for Transition Programs

- Use existing data in novel ways to gain group-specific info
- Develop clear, simple means for collecting data that live in the heads of teachers and service providers
  - Outcomes: Disaggregate I14 data by disabilities of interest, collect information on outcomes at the time of exit (e.g. Employed? Enrolled?), data sharing with service providers
  - Agency connections: Collect data on agency connectedness over time (e.g. Current client of x agency?, on Medicaid Waiver waitlist?)
    - Note: Waitlists for HCBS can be years long
  - Access to interventions: Taxonomy/EBP-based
    - Example: Collecting data on types of work experiences students encounter each month by student, class, etc.
Age of Majority Conversations for the Modern Age

- IDEA mandates about transfer of rights and delegation of educational rights place IEP teams front and center for conversations about guardianship
- For youth approaching the age of majority with complex support needs, guardianship is often assumed to be a needed
- Little research exposing these processes at play, but some common scenarios might be:
  - Outright recommendations from school personal, service providers, doctors, and other parents for guardianship without discussion of implications or alternatives (Jameson et al., 2015)
    - Hasty, misinformed conversations about transfer of rights
    - No studies have shown guardianship to lead to increased safety or quality of life
  - “Logical” criteria for guardianship being needed (e.g. student is non-verbal, student is in x classroom, etc.) (NCD, 2017)
Guardianship As A Last Resort

• Guardianship as a front line for adult decision-making support versus guardianship as a last resort
  – The first listed purpose of IDEA is “To ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living” (34 CFR § 300.1)
• Need to understand state policy on 18-21 transfer of education rights in the IEP process
• Implement transition assessments and corresponding annual goals that reflect decision making support needs
  – Self-determination skill building early and often
  – “Alan desperately needs guardianship, but we’ve never addressed the primary reasons for this need in his IEP”
• Find your toolkit to ensure that the IEP team’s role is based on a truly individualized understanding of a person
Resources and Sources

NTACT Student Progress Monitoring Toolkit

Example SC Employment First Initiative Pilot Program Tool

SCEFI Tool Template (blank)

OSERS “Transition Guide” – Includes Guidance on SDM

NRC-SDM Website – Tons of Resources and State Specific Info

SDM Crash Course with Jonathan Martinis


Sharing Effective Practices

California
Work-Based Learning Experiences for 1,233 CaPROMISE Youth Participants

- Total Work Experiences: 3,677
- @ least 1 work experience: 95%
- Paid: 89%
- Unpaid/Volunteer: 78%

Data taken as of 6-30-2019
Challenges Implementing CIE in Schools

- Local Education Agency focus on academic achievement and graduation attainment
- Restrictions of agencies serving youth and accountability systems
- Education staff lack of knowledge of Social Security and work incentives for youth
- Educators low expectation for individuals with significant disabilities and students in poverty
- Educators expectations for students on Certificate of Completion track versus Diploma track
- Educators lack of knowledge of community resources & services and how to assist families, with multiple barriers, to access them
- Board of Education and administrative knowledge & buy-in of the transition services needed to promote short & long term positive life outcomes
Work-Based Learning Experiences for 1,233 CaPROMISE Youth Participants

- Total Work Experiences: 3,677
- @ least 1 work experience: 95%
- Paid: 89%
- Unpaid/Volunteer: 78%

Data taken as of 6-30-2019
Riverside County Office of Education...Dog Grooming Training Program
CHOC Hospital Employee

Michelle

Working in a sheltered workshop for 90 cents /hour...after Project Search $15/hr., 30 hrs. per week
Christopher...
Traveling to Work Experience at Pretend City Children’s Museum
Irvine USD

Partnerships in Employment (PIE) Grant with UCLA
Challenges Working with PROMISE Families

- Families mistrust of the benefit system
- Families dependence on benefits and misinformation or no information regarding work incentives
- Families low expectations for students and lack of knowledge of available school & community resources
- Families expectations for students to achieve a high school diploma and go to college and that work experience would interfere
- Families fear for student's safety in the work environment & accompanying travel
- Multi barriers of the families, lack of education, resources, support
- Misunderstanding of employer expectations regarding time off; i.e., vacation, holidays, evenings & weekends
Family Workshop...
Learning about Person Driven Planning
Successful CIE Practices from a School Perspective

■ Person Driven Planning – Utilize PDP/PCP planning with a family focus

■ Family Engagement – Engage families to learn about how they can assist their children to become self-sufficient, including use of available resources & services

■ Culture Change – Increase & expand expectations for all students...assume competence. *(We had more CaPROMISE students achieving success in education, higher graduation rates with a High School Diploma and reduced drop out rates.)*

■ Collaboration – Work with agencies such as Vocational Rehabilitation, Regional Centers and other service agencies to share responsibilities *(We are seeing improved outcomes for CaPROMISE students/young adults.)*

■ Work experience/Work-based Learning - Students must participate in work experience/work-based learning and CIE *(We found CaPROMISE students were more likely to be engaged in school and complete their education.)*

■ Benefits Planning – Educate students and parents about benefits and work incentives. *(We found reduced fears and misconceptions regarding SSI and work.)*

■ Increased participation in post-secondary education & training *(We found increased CaPROMISE Student/Young Adult PSE participation.)*
Policy and Practice Recommendations from a School Perspective

■ Student Driven Planning including the family

■ Collaboration and communication between schools and community agencies including data sharing to prevent duplication and redundancy, reduce families’ fear of the system, and increase systems’ effectiveness and responsiveness to families’ needs

■ Special Education law should include work-based learning, self determination, family engagement and benefits/financial planning as part of transition planning

■ Work-based learning, internships, apprenticeships and employer paid work experience a priority for all students

■ Promote CIE prior to school exit
BEST PRACTICES & SUPPORT STRATEGIES
COMPETITIVE INTEGRATED EMPLOYMENT (CIE)

Goal: To ensure that students and adults with intellectual disabilities and developmental disabilities (ID/DD) can have the opportunity to, participate in work-based learning and employment opportunities in community-based, integrated work settings.

Competitive Integrated Employment (CIE), “real work for real pay”, is the gold standard of transition outcomes for students with disabilities. The work should align with the post-school employment goals of the student and is the desired transition outcome for all students with disabilities who choose to work, regardless of disability or needed accommodations or supports. CIE should be a realistic and desirable expectation for all students. CIE options should be individualized. As families, schools, VR and other partners plan and engage in transition planning with students, it is important to understand that individual needs and employment goals will be different for each student. By making the connection between students’ interests, skills, and preferences with business needs, good job matches can be brokered so that employment is a mutually beneficial outcome for both the student and business. (CIE Toolkit: February 2017, National Transition Technical Assistance Center on Transition)

The California PROMISE (CaPROMISE) Program, funded by the US Department of Education, has been operational for over 5 years. The following list of strategies have proven beneficial for all program participants, especially for students with significant disabilities. The following strategies have been identified, implemented and verified by the CaPROMISE Staff who have worked together in community teams throughout the state.

Ongoing Community Collaboration and Planning Efforts:
- Participate in Community Collaborative Local Partnership Agreement (LPA)
- Develop/participate in a Business Advisory Committee
- Identify all Work Force Development (WFD) opportunities including regional center (RC), Department of Rehabilitation (DOR), Local Education Agency (LEA), America’s Job Center of California (AJCC), post-secondary education (PSE), College to Career (C2C), WorkAbility III (WAIII), etc.
- Provide cross-agency work-based learning (WBL) and CIE training
- Develop mechanism to brainstorm and address issues, programing and policy change needs
- Participate in DOR, RC and other service agency partnerships
- LEA/PSE partner with RC to become a vendor to access funding
- Review employment success stories
- Educate and update school district, PSE and other partner agency officials on WBL successes

Pre-WBL and CIE Placement Preparation and Supports:
- Promote high expectations for individuals with disabilities & assume competence
- Provide family training and support through workshops, webinars and individual planning
- Utilize ongoing Person Driven Planning (PDP)/Discovery Process
- Participate in employment related soft skills/job readiness training, i.e., Job Applications, Interviewing, Resumes, References, and Letters of Recommendations
- Provide practice in using self-determination skills to access workforce development services from AJCC, DOR, PSE, etc.
- Practice grooming and professional dress
- Train classroom staff to serve as Job Coaches
- Practice disability disclosure and needed accommodation requests
Questions to Consider

• How are experiences integrated in IEPs, IPEs, ISPs?
• Have we created and/or selected the most appropriate experiences?
• Are “next steps” clearly apparent to all stakeholders and the youth regarding work-based learning/assessment and transition implementation?
• Has the youth helped direct the experience?
• What difficulties does the student/youth with a disability experience?
• What accommodations are available to reduce or eliminate these issues?
• Once accommodations are in place evaluating the effectiveness of the accommodations and determine whether additional accommodations are needed?
Potential Barriers

- Communication challenges
- One-to-one assistance necessary, staffing capacity issues
- Time and scheduling issues
- Physical ability, limitations
- Family needs/expectations
- Lack of allocation of resources
- Low expectations
- Systems—“Not our job”, lack of interagency collaboration/data sharing
- Lack of transportation options
Strategies and Resources

what's in your TOOLBOX?
Addressing Communication Challenges

- Additional time
- Quieter place
- Assess language skills
- Assistive technology

* Accommodations make a difference
Addressing Employment Challenges

Employers may be asked to make certain changes, including:

– providing or modifying equipment or devices;
– job restructuring;
– part-time/modified work schedules;
– reassignment to a vacant position;
– adjusting or modifying examinations, training materials or policies;
– providing readers and interpreters; and
– making the workplace readily accessible to and usable by people living with disabilities.
Community-Based and Work-Based Learning Experiences

• Start talking early about the possibility of employment in the community for a paycheck!
• Set expectations high
• Exposure Early:
  – Volunteering
  – Job shadowing
  – Service Learning/Internships
  – General Work Experience
  – Matched Work Experience
  – Customized Job Experience

• Consider:
  – Conditions for success
  – Potential contributions
  – Tasks person can do
  – How individual learns best
  – Support strategies to ensure success
  – Things to avoid
  – Natural supports
Addressing the Need for 1:1 Assistance – Staffing Issues and Family Expectations

• One-to-one assistance necessary, staffing issues
  – Customized Employment
  – Supported Employment
  – Long-term supports from DD agency

• Family needs/expectations
  – Benefits Planning, SEIE, Going to Work
    https://www.communityinclusion.org/article.php?article_id=211
  – Respite from DD agency and other resources/supports
  – Groups, clubs, organizations
Addressing the Lack of Allocation of Resources and Low Expectations

• Lack of allocation of resources
  – Interagency Agreement Toolkit
  – Blending and Braiding Funds
  – Partnerships with other schools and organizations

• Low expectations
  – Assessments to identify skills and abilities, WBL, mentoring, job shadowing, paid work experiences, Project SEARCH, service learning/volunteering, Guided Group Discovery
Addressing Systems Issues and Transportation Challenges

• Systems—“Not our job”, lack of interagency collaboration/data sharing
  – Integrated Employment Toolkit
  – Competitive Integrated Employment Toolkit

• Lack of transportation options
  – Travel training, Uber/Lyft (new safety feature), deduct expense from SSA (IRWE)
Additional Resources
Preference Indicators

- Child Preference Indicators
- Personal Preference Indicators
- Employment Support Indicators

Assistive Technology Protocol for Transition Planning

### Mobility

<table>
<thead>
<tr>
<th>MOBILITY ACTIVITIES</th>
<th>Can the student independently...</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes No Navigate at a reasonable pace?</td>
<td></td>
</tr>
<tr>
<td>Yes No Navigate outside on varied terrain (i.e., college campus)</td>
<td></td>
</tr>
<tr>
<td>Yes No Tolerate and be mobile at this pace to 3 city blocks?</td>
<td></td>
</tr>
<tr>
<td>Yes No Carry a 5-pound backpack while being mobile?</td>
<td></td>
</tr>
<tr>
<td>Yes No Operate controls to activate community building access devices? (i.e., electronic doors, elevator, walk light)</td>
<td></td>
</tr>
</tbody>
</table>

### Mobility Adaptations

<table>
<thead>
<tr>
<th>MOBILITY ADAPTATIONS</th>
<th>Not applicable</th>
<th>Possibly could use</th>
<th>Using but could be improved</th>
<th>Using independently</th>
</tr>
</thead>
<tbody>
<tr>
<td>Power Wheelchair</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Manual Wheelchair</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Powered Scooter</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Walker</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cane/Crutches</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Grab Rails</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Environmental Controls</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Communication

<table>
<thead>
<tr>
<th>ORAL COMMUNICATION ACTIVITIES</th>
<th>Can the student...</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes No Communicate wants &amp; needs to non-familiar communication partner?</td>
<td></td>
</tr>
<tr>
<td>Yes No Independently operate a telephone?</td>
<td></td>
</tr>
<tr>
<td>Yes No Independently communicate with non-familiar person on the telephone?</td>
<td></td>
</tr>
<tr>
<td>Yes No Understand and remember simple verbal instructions?</td>
<td></td>
</tr>
<tr>
<td>Yes No Understand and remember complex verbal instructions?</td>
<td></td>
</tr>
</tbody>
</table>

### Communication Adaptations

<table>
<thead>
<tr>
<th>COMMUNICATION ADAPTATIONS</th>
<th>Not applicable</th>
<th>Possibly could use</th>
<th>Using but could be improved</th>
<th>Using independently</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eye-Gaze Board</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Picture or Spelling Board</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Electronic Voice Output Device</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Computer-Based Speech Device</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adaptive Telephone</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adaptive Writing Devices</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Laptop Computer</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TTY</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relay System</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Voice Output Reminders</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Electronic Organizers</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Others</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Person-Centered/Directed Planning

Life Course Framework

- **Daily Life and Employment**
  (school/education, employment, volunteering, routines, life skills)
- **Community Living**
  (housing, living options, home adaptations and modifications, community access, transportation)
- **Social and Spirituality**
  (friends, relationships, leisure activities, personal networks, faith community)
- **Healthy Living**
  (medical, behavioral, nutrition, wellness, affordable care)
- **Safety and Security**
  (emergencies, well-being, legal rights & issues, guardianship options & alternatives)
- **Citizenship and Advocacy**
  (valued roles, making choices, setting goals, responsibility, leadership, peer support)
Trajectory towards Good Life

Friends, family, enough money, job I like, home, faith, vacations, health, choice, freedom

Vision of What I Don’t Want

www.supportstofamilies.org
www.lifecoursetools.org
Resources

• **Accessing the Dream**
• **Best practices for reevaluations**
• **NTACT joint presentation containing sample goals, scenarios, and resources**
• **Zarrow Center resources** - transition assessments and other resources for students with complex support needs in transition
• **Quick Guide on Competitive Integrated Employment for multiple audiences**
Resources

• A Life for Me!
• Evidence-based practices
• Examples and non-examples of students with the most significant disabilities
• NCWD-Youth: Communicating With and About People with Disabilities
• Significant Disabilities Planning Assessment Form
Resources

- NCWD-Youth: A Young Person’s Guide to Health Care Transition
- NCWD-Youth: Tapping into the Power of Families: How Families of Youth with Disabilities Can Assist in Job Search and Retention
- NCWD-Youth: Strategies for Youth Workforce Programs to Become Employer-Friendly Intermediaries
- Project 10 resources on employing youth with significant disabilities
CONTACT

Linda O’Neal, San Diego State - linda_oneal@interwork.sdsu.edu

Michael Stoehr, NTACT – mstoehr@uncc.edu

Charlie Walters, University of South Carolina - charlesblayne@gmail.com