Transitions to adulthood for autistic youth: Improving outcomes by supporting families

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VT Center for Autism Research Biennial Spring Conference, April 2023
Agenda

• Why support families of youth with autism during the transition to adulthood?

• Development of a services advocacy intervention to help families better support their autistic youth in gaining services
  – Pilot work
  – Multi-state RCT
    • Feasibility and acceptability
    • Preliminary outcome analyses
Increased Attention Paid to Autism in Adulthood

Autistic Kids Learn To Survive, And Thrive, In College

In many ways, Mark Heim is a typical senior at Colorado State University. He has the kind of smart humor you’d expect from someone who excels in computer science, engineering and math, his T-shirt reads, “Department of Redundancy Department.”

But as a student living with Asperger’s syndrome, a high-functioning form of autism, the everyday social interactions of college life can be awkward. He is part of a new influx of kids with autism who are heading off to college, creating a new demand for college services to help students with autism fit in, graduate and find jobs.

Colorado State is one of a handful of schools that have adopted programs to help ease autistic students’ transitions in and out of college.
Why Focus on Autism in Adulthood?

https://www.cdc.gov/ncbddd/autism/data/index.html
The Services Cliff
Many Autistic Adults Struggle

Challenges in Adulthood

- Employment
- Post-secondary Education
- Mental health problems
- Social Relationships
- Physical health problems
- Financial Independence

How can we improve outcomes?
How can we improve outcomes?
What does research tell us about the importance of families during transition?
Families Support the Post-secondary Activities of Their Son/Daughter

• 38 families of youth with autism diagnosis who had data collected at 3 time points
  – Last year of high school, within 12 months after exit, about 2.5 years after exit

• Coded youth into “disruption” versus “no disruption” groups
  – 50% of youth had a disruption

Taylor & DaWalt, JADD, 2017
Maternal Mental Health Predicts Disruption

• Usual cast of characters did not distinguish group
  – IQ
  – Autism symptoms
  – Problem behavior
  – Daily living skills

• Instead...
  – Maternal mental health mattered

Taylor & DaWalt, *JADD*, 2017
Role of Parental Advocacy

• 185 parents of transition-aged youth on the autism spectrum

• After controlling for known predictors of service access, how strongly does parent advocacy predict services?

(known factors = Intellectual disability, adaptive behavior, autism severity, high school exit, family income, race/ethnicity)

Lee et al., Autism, 2022
To Best Support Individuals, We Need to Support Families

Families take over coordinating services after transition - often with little or no help
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  – Pilot work
  – Multi-state RCT
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    • Preliminary outcome analyses
The Services Cliff

Adult services are:

1. Underfunded

2. Difficult to understand and navigate
   - Poorly integrated between school-based and adult services
   - Poorly integrated between agencies
Example: The Winding Road to Medicaid Insurance

1. Youth is coming off parents’ insurance and needs medication management
2. Receive advice that he might be eligible for Medicaid
3. Research different Medicaid programs

4. Learn that to get Medicaid insurance, you need to apply for SSI
5. Research SSI
6. Apply for SSI


8. Appeal is granted and SSI is approved!
9. NOW need to find a provider...
Volunteer Advocacy Program-Transition (VAP-T) 2014-2017

• Parent training to improve transition outcomes for youth on the autism spectrum (funded by NIMH)
  – Teaches parents about adult disability services and supports, how they interrelate, and the most effective ways to access them.
  – Based on Volunteer Advocacy Project (VAP)
  – Developed with extensive community input
  – In most session, program facilitator aided by local expert who present specifics of topic at hand.
Our Approach

Parent Advocates
Our Approach

- Parent Advocates
- Medical
- Secondary Education
- Housing
- Financial Support (SSI, SSDI)
- Person-Centered Thinking
- Special Needs Trusts
- Employment
- Non-Adversarial Advocacy
- Models of Decision Making
- Post-Secondary Education
- Medical
- Secondary Education
Our Approach

- Medical
- Secondary Education
- Housing
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- Person-Centered Thinking

Parent Advocates

Youth across the spectrum
VAP-T Pilot Randomized Controlled Trial

- Recruited 45 families of youth with autism within two years of high school exit (in TN)
  - Randomized to treatment or wait-list control group (who got VAP-T after 12 months)
  - Families participated in groups in Nashville, Memphis, Chattanooga
  - 41 families were retained at post-test

- Does participating in the VAP-T lead to:
  1. Improvements in intervention targets of knowledge, advocacy skills/comfort and empowerment?
     - Measured at post-test (right after treatment)
  2. Improved services access?
     - Measured 6 months after treatment group took VAP-T
### Participants

<table>
<thead>
<tr>
<th></th>
<th>Treatment (n=20)</th>
<th>Control (n=21)</th>
<th>T-value or $\chi^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Youth age</td>
<td>18.14 (1.74)</td>
<td>18.34 (2.02)</td>
<td>-0.34</td>
</tr>
<tr>
<td>Youth is in high school</td>
<td>80%</td>
<td>91.5%</td>
<td>0.90</td>
</tr>
<tr>
<td>Youth has intellectual disability</td>
<td>35%</td>
<td>28.6%</td>
<td>0.20</td>
</tr>
<tr>
<td>Youth sex= male</td>
<td>85%</td>
<td>81%</td>
<td>0.12</td>
</tr>
<tr>
<td>Parent sex = female</td>
<td>100%</td>
<td>95.2%</td>
<td>0.98</td>
</tr>
<tr>
<td>Parent has completed bachelor’s degree</td>
<td>90%</td>
<td>61.9%</td>
<td>6.27</td>
</tr>
<tr>
<td>Parent race = white</td>
<td>90%</td>
<td>85.7%</td>
<td>2.31</td>
</tr>
</tbody>
</table>
Measures

• Baseline and post-test
  – Knowledge measure: 22 multiple-choice questions about adult services and supports (Taylor et al., 2017)
  – Advocacy skills: 10-item, Likert-scale measure assessing parents’ comfort and skills with advocating (Taylor et al., 2017)
  – Empowerment: Family Empowerment Scale (Koren et al., 1996)

• 6-month follow-up
  – Number of services from list of 22 services from NLTS-2 (e.g., mental health, speech/language, vocational training)
  – Post-secondary education (PSE) or employment (1 = enrolled in PSE or employed)
    • Just those who had exited high school
Question 1 – Effects on Intervention Targets

Intervention F = 17.41**
Cohen's D = 1.06

Intervention F = 15.02**
Cohen's D = 1.10

Intervention F = 9.24*
Cohen's D = 0.77

Taylor et al., 2017, JADD
Question 2 – Group Differences in Service Access and Employment/PSE

Number of Services

<table>
<thead>
<tr>
<th></th>
<th>Pre-test</th>
<th>6-month follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treatment</td>
<td>1.5</td>
<td>3.5</td>
</tr>
<tr>
<td>Control</td>
<td>2</td>
<td>3.5</td>
</tr>
</tbody>
</table>

61% increased versus 35%

Employment or PSE

<table>
<thead>
<tr>
<th></th>
<th>Treatment (n=6)</th>
<th>Control (n=10)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>X² = 4.36, p &lt; .05</td>
</tr>
</tbody>
</table>
Challenges

• Curriculum only worked in Tennessee

• Need a more streamlined way to leverage expertise/experience of our community experts

• Control group was a challenge
Next Step (funded by NIMH)

• Revise the curriculum to be nationally relevant
  – Called ASSIST - Advocating for SupportS to Improve Service Transitions

• Large-scale randomized-controlled trial of the parent advocacy program in three states (TN, IL, WI)
  – Control group gets all materials

• Focused on parents of transition-aged youth with autism both before and after high school exit

• Incorporating perspective of autistic youth into intervention and data collection

• Support community implementation
Collaboration

• ASSIST was developed through a collaboration with the
  – Vanderbilt Kennedy Center at Vanderbilt University Medical Center
  – University of Illinois Urbana Champaign
  – Waisman Center at the University of Wisconsin-Madison
  – The Arc Tennessee
  – The Autism Program of Illinois
## Intervention Delivery Differences

<table>
<thead>
<tr>
<th></th>
<th>VAP-T</th>
<th>ASSIST</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Curriculum Delivery</strong></td>
<td>PowerPoints</td>
<td>• 10-minute introductory video with nationally relevant information</td>
</tr>
<tr>
<td></td>
<td>• developed by research team</td>
<td>• Local expert provides state specific information</td>
</tr>
<tr>
<td></td>
<td>• delivered by local subject matter experts</td>
<td></td>
</tr>
<tr>
<td><strong>Duration</strong></td>
<td>12 weeks</td>
<td>12 weeks</td>
</tr>
<tr>
<td></td>
<td>2.5 hours each week</td>
<td>2 hours each week</td>
</tr>
<tr>
<td><strong>Location</strong></td>
<td>University</td>
<td>Community</td>
</tr>
</tbody>
</table>
## Participants for RCT

185 families of youth with autism ages 16-26 from TN, IL, WI

<table>
<thead>
<tr>
<th></th>
<th>Treatment (n=91)</th>
<th>Control (n=94)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Youth age</td>
<td>19.47 (2.85)</td>
<td>19.47 (2.59)</td>
</tr>
<tr>
<td>Youth gender = male</td>
<td>76%</td>
<td>73%</td>
</tr>
<tr>
<td>Youth race = white</td>
<td>69%</td>
<td>79%</td>
</tr>
<tr>
<td>Youth in high school</td>
<td>59%</td>
<td>61%</td>
</tr>
<tr>
<td>Youth has intellectual disability</td>
<td>40%</td>
<td>40%</td>
</tr>
<tr>
<td>Parent gender = female</td>
<td>88%</td>
<td>92%</td>
</tr>
<tr>
<td>Parent has bachelor’s degree or greater</td>
<td>66%</td>
<td>72%</td>
</tr>
</tbody>
</table>
Project Timeline and Study Design

- **Intervention Development**
- **Pre-test and random assignment**
- **Treatment groups**
  - Participate in ASSIST
- **Materials control groups**

- **2019**
- **2019-2020**
- **2020**
- **2020-2021**
- **2021-2022**
- **2022-2023**

- Follow-up data collection (post-test, 6-mo, 12-mo)
- Follow-up data collection 2 (post-test, 6-mo, 12-mo)
Project Timeline and Study Design

**Intervention Development**
- Pre-test and random assignment
- Materials control groups
- Treatment groups

2019

2019-2020

2020

2020-2021

2021-2022

2022-2023

**Follow-up data collection (post-test, 6-mo, 12-mo)**

**Follow-up data collection 2 (post-test, 6-mo, 12-mo)**

**Participate in ASSIST**
Implementation Outcomes

Do local experts cover the learning objectives? – YES!

<table>
<thead>
<tr>
<th>ASSIST session</th>
<th>% of local expert learning objectives met</th>
</tr>
</thead>
<tbody>
<tr>
<td>Session 1- Intro and Person-Centered Planning</td>
<td>100</td>
</tr>
<tr>
<td>Session 2 - Models of Decision Making</td>
<td>98.1</td>
</tr>
<tr>
<td>Session 3 - Supplemental Security Income (SSI)</td>
<td>97.6</td>
</tr>
<tr>
<td>Session 4 - SSDI)&amp; SNAP</td>
<td>100</td>
</tr>
<tr>
<td>Session 5 - Health Insurance Options</td>
<td>77.8</td>
</tr>
<tr>
<td>Session 6 - Medicaid Waiver</td>
<td>96.7</td>
</tr>
<tr>
<td>Session 7 - Employment 1</td>
<td>95.8</td>
</tr>
<tr>
<td>Session 8 - Employment 2</td>
<td>83.3</td>
</tr>
<tr>
<td>Session 9 - Post-secondary Education</td>
<td>100</td>
</tr>
<tr>
<td>Session 10 - Housing &amp; Enabling Technology</td>
<td>100</td>
</tr>
<tr>
<td>Session 11 - Special Needs Trust &amp; ABLE accounts</td>
<td>100</td>
</tr>
<tr>
<td>Session 12 - Advocacy</td>
<td>100</td>
</tr>
</tbody>
</table>

Taylor et al., JADD, 2022
### Implementation Outcomes

- **Are participants able to attend?**
  - **YES!** 86% of the participants attended 75% or more of the sessions

<table>
<thead>
<tr>
<th>Reason</th>
<th>% (Number)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Work conflict</td>
<td>15% (9)</td>
</tr>
<tr>
<td>Family emergency</td>
<td>15% (9)</td>
</tr>
<tr>
<td>Other</td>
<td>15% (9)</td>
</tr>
<tr>
<td>Medical issue</td>
<td>10% (6)</td>
</tr>
<tr>
<td>Vacation</td>
<td>8% (5)</td>
</tr>
<tr>
<td>COVID-related</td>
<td>8% (5)</td>
</tr>
<tr>
<td>Technology issues</td>
<td>6% (4)</td>
</tr>
<tr>
<td>No respite care</td>
<td>3% (2)</td>
</tr>
</tbody>
</table>

Taylor et al., JADD, 2022
- 60% of those who had both methods of delivery would prefer in-person ASSIST

- 33% of those who only had online ASSIST would prefer in-person ASSIST
Project Timeline and Study Design

- 185 families of youth with autism ages 16-26 from TN, IL, WI
Are ASSIST Families Better Able to Advocate?

Those who took ASSIST knew significantly more about adult services and felt more skilled and comfortable using that information.
Those Least Prepared to Advocate Seemed to Benefit Most
Next Steps

• Does taking ASSIST lead to better service access and youth outcomes?
  – Government programs and direct services

• Who seems to benefit most?
  – New grant (Burke, PI) to develop a culturally responsive version for Spanish-speaking Latinx families

• What are barriers to using this information to improve outcomes?
Summary

• Families play many important roles during the transition to adulthood

• Supporting families helps them better support their youth

• Promising program are available to support families
  – Teaching parents about adult services (soon)
  – Reducing parental stress (Parenting Stress Intervention Project: Dykens)
  – Psychoeducation to help parents understand the transition years (Transitioning Together: DaWalt)
Acknowledgements

Collaborators
- Meghan Burke (U of IL)
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- Kate Szidon (U of WI)
- Molly Buren (U of IL)
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- The Arc TN
- TAP Illinois
- Wisconsin DD Council
- TN Boling Center
- Chattanooga Autism Center

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- Vanderbilt Kennedy Center for Excellence in Developmental Disabilities (UCEDD)
- The Autism Project of IL

Many thanks to our research participants!!
ASSIST Videos

http://assist.vkcsites.org/preview/
## Local Expert Learning Objectives for SSI

<table>
<thead>
<tr>
<th>Objective</th>
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</thead>
<tbody>
<tr>
<td>LO 1. Share information about current SSI amount</td>
</tr>
<tr>
<td>LO 2. Discuss specifics of applying and the importance of an appeal</td>
</tr>
<tr>
<td>LO 3. Dispel myths about employment and SSI</td>
</tr>
<tr>
<td>LO 4. Discuss how to keep benefits in place – effects of income, living expenses, in-kind support &amp; avoiding overpayment</td>
</tr>
<tr>
<td>LO 5. Explain work incentives offered by SSI - 1619 A&amp;B, Earned income exclusion, IRWE, PASS, EXR</td>
</tr>
<tr>
<td>LO 6. Discuss how representative payee should keep accounting of SSI</td>
</tr>
</tbody>
</table>
Other Promising Programs

• Parenting Stress Intervention Project
  – Elisabeth Dykens, Vanderbilt University
  – Tested MBSR intervention against a positive psychology intervention in reducing stress and distress among parents of children with disabilities
  – Both interventions were effective

• Transitioning Together
  – Leann Smith DaWalt, University of Wisconsin
  – Used group psychoeducational method aimed at educating parents about the transition to adulthood and problem-solving
  – Participating led to improvements in family climate and greater understanding of service systems and of son/daughter with autism