Challenges Facing Young Adults with Intellectual & Developmental Disabilities Transitioning into Adult Life: The State of the Research

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Introduction
Definition and Developmental Factors

“Transition” has been commonly described as the crucial task of moving from the protected life of a child to the autonomous and independent life of an adult. Individuals vary substantially in their experiences and the rate at which they transition (Foley, Girdler, & Leonard, 2012).

“Transitional age youth” are young people between the ages of 16-24.

Changes:

- Physical Functioning and Cognitive Development
- Emotional Development
- Family and Social Relationships
- Work (Career Development)
Background

● These changes are often more difficult for youth with disabilities, including those with intellectual or developmental disabilities (ID/DD), who face considerably poorer post school outcomes across different life areas relative to their peers with and without disabilities (Newman et al., 2011).
  ○ sexuality/reproduction
  ○ Identity formulation/Emotional regulation
  ○ Career decisions
  ○ Intimate/social relationship

● Despite the implementation of numerous initiatives over the past two decades to facilitate smooth and successful transitions, these challenges persist.
The range of issues related to transition to adulthood for individuals with ID/DD are complex and multifaceted. For example, supportive services such as rehabilitation, special education, and specialized pediatric services often are terminated in adulthood (Bottos et al., 2001).

Without these supports, young adults with ID/DD may experience new problems with daily activities, or exacerbations of existing problems. The new social roles of young adulthood, coupled with the vulnerabilities created as result of declining support systems, underscore the need to examine challenges and intervention gaps for this population.
Purpose and Overview

This presentation will review the unique challenges faced by youth with ID/DD and their families as they transition to adulthood. Promising interventions will be described, along with a discussion of the considerable gaps in research and practice—with a particular emphasis on three key areas: employment, community integration, and family considerations.

Outline of The presentation:

● Employment
● Community integration
● Family/caregiver issues
Employment

85% of families reported that their adult family members with I/DD were not employed.
Family and Individual Needs for Disability Supports (FINDS) survey (2010)

- 85% adults with I/DD were not employed.
  - Lack of employment services and unmet needs in the areas of job support.
  - 52% is unable to get the job training or other assistance they need to find and keep a job.

- Even among those who are employed, regular jobs in the community with competitive wages remain elusive.
  - Only 41% work in a regular job in the community, 1% are self-employed, 54% work in sheltered workshops and enclave settings.
  - Only 57% earns at least minimum wage.
Falling Short in Employment

- Authorized by Rehabilitation Act of 1973, VR program provides employment support to people with disabilities since their transition age (Lawer et al., 2009, Wehman et al., 2014).
- It allocates more than **US$2.5 billion** annually to fund state VR agencies (Burgess & Cimera, 2014).

However, according to FIND Survey...

- Long waitlist for employment supports and services for people with mild, moderate and severe IDD.
- Dissatisfaction with the quality and amount of employment supports and services.


Satisfaction with the quality of gov’t funded VR services

- 57% dissatisfied with the quality of gov’t funded employment services available to people with ID/DD.
- Family caregivers supporting people with ASD were more likely to be dissatisfied with the quality of government-funded employment services (69% dissatisfied) or transportation (55% dissatisfied) than were the other ID/DD groups.

Satisfaction with the amount of gov’t funded VR services

- 77% family caregivers were dissatisfied with the amount of gov’t funded employment services available to people with ID/DD.
- Family caregivers supporting people with ASD were more likely to be dissatisfied with the amount of services for employment supports and services paid for by private funds (86% dissatisfied).

How about privately paid VR services?

- More than half (53%) of family caregivers dissatisfied with the quality of privately paid employment supports.
- Family caregivers supporting people with ASD were significantly less satisfied with the quality transportation and employment supports and services paid for by private funds.
NLTS-2 Survey

- Disappointing postsecondary education compared to their nondisabled peers
  - Only 7.7% were attending a 4-year college or university, while only slightly more (12.8%) were attending a 2-year community college
- Employment rates lower than non-disabled peers
  - Internship experience while in school improve employment outcome (Carter et al., 2011; Wehman et al, 2014)
- Large majority (72.6%) of young adults with disabilities continue to live with parents after high school
## Employment-related support provided in school settings

<table>
<thead>
<tr>
<th>Support Provided</th>
<th>freq mean</th>
<th>freq SD</th>
<th>imp mean</th>
<th>imp SD</th>
<th>prep mean</th>
<th>prep SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Develop jobseeker employment profile (supported employment)</td>
<td>.73</td>
<td>1.086</td>
<td>2.06</td>
<td>1.148</td>
<td>1.13</td>
<td>1.161</td>
</tr>
<tr>
<td>b. Vocational/Situational assessment</td>
<td>.88</td>
<td>1.173</td>
<td>2.13</td>
<td>1.126</td>
<td>1.19</td>
<td>1.211</td>
</tr>
<tr>
<td>c. Providing instruction on job skill building</td>
<td>1.06</td>
<td>1.191</td>
<td>2.32</td>
<td>1.072</td>
<td>1.35</td>
<td>1.219</td>
</tr>
<tr>
<td>d. Providing employment readiness skills training</td>
<td>1.08</td>
<td>1.206</td>
<td>2.38</td>
<td>1.051</td>
<td>1.31</td>
<td>1.235</td>
</tr>
<tr>
<td>e. Shaping appropriate behavioral skills</td>
<td>2.54</td>
<td>1.132</td>
<td>2.88</td>
<td>.957</td>
<td>2.29</td>
<td>1.185</td>
</tr>
<tr>
<td>f. Providing individualized supports</td>
<td>2.16</td>
<td>1.258</td>
<td>2.61</td>
<td>.959</td>
<td>2.03</td>
<td>1.162</td>
</tr>
<tr>
<td>g. Collaboration among agencies</td>
<td>1.03</td>
<td>1.218</td>
<td>2.27</td>
<td>1.026</td>
<td>1.24</td>
<td>1.142</td>
</tr>
<tr>
<td><strong>MEAN</strong></td>
<td><strong>1.57</strong></td>
<td><strong>2.49</strong></td>
<td><strong>1.65</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Challenges to Successful Employment

Internal Challenging Factors

- Challenging Behaviors (Chiang et al., 2013; Hendricks, 2010; Test et al., 2014; Wehman et al., 2014)
- Social Difficulties (Hendricks, 2010; Patterson & Rafferty, 2001; Chiang et al., 2013)
- Educational Level (Holwerda et al., 2012; Lawer et al., 2009; Migliore et al., 2012)

External Challenging Factors

- Vocational Services (Howlin 2013; Lugas et al. 2010; Patterson & Rafferty 2001)
- Disability-Related Benefits (Migliore et al., 2012)
- Family Socioeconomic Status (Shattuck et al. 2012, 2011; Taylor & Mailick 2012; Taylor & Schry, 2010)
What does that mean to individuals with IDD?
Strategies for Successful Employment

- **Supported Employment** (Cimera et al., 2012; Hillier et al., 2007; Howlin et al., 2005; Wehman et al., 2012)
- **Transition Services** (Cimera et al., 2013; Hendricks & Wehman, 2009; Wehman et al., 2014; Westbrook et al. 2014)
- **Assistive Technology** (DiGennaro Reed et al., 2011; Goldsmith and LeBlanc 2004; Hopkins et al., 2011; Parsons 2006)
- **Multidisciplinary Collaboration** (Friedman et al., 2013; Test et al., 2014)
Effect of SE on VR Outcomes of Transition-Age Youth With IDD (Wehman, Chan, Ditchman, Kang, 2014)

Table 2
Effect of Supported Employment on VR Outcomes of Transition-Age Youth With IDD

<table>
<thead>
<tr>
<th>Strata No./N</th>
<th>Participants</th>
<th>Group count</th>
<th>Estimated propensity score&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Employment outcome</th>
<th>Difference in employment outcome&lt;sup&gt;b&lt;/sup&gt;</th>
<th>Weight for each difference&lt;sup&gt;c&lt;/sup&gt;</th>
<th>Weighted employment difference&lt;sup&gt;d&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spec edu &amp; w/ SS benefits</td>
<td>SE</td>
<td>2300</td>
<td>0.62</td>
<td>58%</td>
<td>21%</td>
<td>.16</td>
<td>3.36%</td>
</tr>
<tr>
<td>$N_4$ = 3687</td>
<td>No SE</td>
<td>1387</td>
<td></td>
<td>37%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HS grad, w/SS benefits, w/ ID/ASD</td>
<td>SE</td>
<td>954</td>
<td>0.54</td>
<td>63%</td>
<td>20%</td>
<td>.08</td>
<td>1.60%</td>
</tr>
<tr>
<td>$N_6$ = 1760</td>
<td>No SE</td>
<td>806</td>
<td></td>
<td>43%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spec edu &amp; w/o SS benefits</td>
<td>SE</td>
<td>1137</td>
<td>0.44</td>
<td>50%</td>
<td>11%</td>
<td>.11</td>
<td>1.21%</td>
</tr>
<tr>
<td>$N_3$ = 2604</td>
<td>No SE</td>
<td>1467</td>
<td></td>
<td>61%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-HS grad, w/SS benefits, w/ ID/ASD</td>
<td>SE</td>
<td>1281</td>
<td>0.37</td>
<td>54%</td>
<td>17%</td>
<td>.15</td>
<td>2.55%</td>
</tr>
<tr>
<td>$N_{10}$ = 3427</td>
<td>No SE</td>
<td>2146</td>
<td></td>
<td>37%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HS edu, w/SS benefits, w/ CP/TBI</td>
<td>SE</td>
<td>294</td>
<td>0.24</td>
<td>50%</td>
<td>11%</td>
<td>.05</td>
<td>0.55%</td>
</tr>
<tr>
<td>$N_8$ = 1228</td>
<td>No SE</td>
<td>934</td>
<td></td>
<td>39%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HS edu &amp; w/o SS benefits</td>
<td>SE</td>
<td>2496</td>
<td>0.24</td>
<td>61%</td>
<td>7%</td>
<td>.46</td>
<td>3.22%</td>
</tr>
<tr>
<td>$N_5$ = 10592</td>
<td>No SE</td>
<td>8096</td>
<td></td>
<td>54%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total direct adjustment estimator&lt;sup&gt;e&lt;/sup&gt;</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>12.49%</td>
</tr>
</tbody>
</table>
Study Summary

- Results yielded six homogeneous subgroups, and receipt of supported employment was found to increase the employment rates across all of the groups.
- The effect of supported employment was especially strong for youth who were Social Security beneficiaries, special education students, and individuals with intellectual disabilities or autism who were high school graduates.
- Findings suggest that supported employment is an effective service for enhancing the vocational rehabilitation outcomes of young adults.
VR Service Patterns and Outcomes for Individuals with Autism of Different Ages (Chen, Sung, & Pi, 2015)

<table>
<thead>
<tr>
<th>Odd Ratio</th>
<th>Transition youth (n = 2,718)</th>
<th>Transition young adults (n = 2,162)</th>
<th>Adults (n = 801)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>0.69 (0.53-0.90)**</td>
<td>0.98 (0.73-1.31)</td>
<td>0.85 (0.53-1.37)</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black/African American</td>
<td>0.98 (0.70-1.37)</td>
<td>0.66 (0.46-0.96)*</td>
<td>0.82 (0.40-1.65)</td>
</tr>
<tr>
<td>Co-occurring Psychiatric Disabilities</td>
<td>0.81 (0.60-1.10)</td>
<td>0.71 (0.52-0.97)*</td>
<td>0.60 (0.39-0.93)*</td>
</tr>
<tr>
<td><strong>Educational level at closure</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Special education</td>
<td>1.83 (1.28-2.61)**</td>
<td>1.43 (0.81-2.51)</td>
<td>1.18 (0.08-17.80)</td>
</tr>
<tr>
<td>HS diploma or equivalency</td>
<td>2.05 (1.55-2.72)**</td>
<td>1.73 (1.04-2.86)*</td>
<td>2.54 (0.20-32.24)</td>
</tr>
<tr>
<td>Postsecondary education</td>
<td>2.80 (1.96-3.99)**</td>
<td>3.27 (1.73-6.16)*****</td>
<td>3.52 (0.25-49.82)</td>
</tr>
<tr>
<td><strong>Work disincentives</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Work disincentives</td>
<td>0.50 (0.41-0.62)**</td>
<td>0.63 (0.50-0.79)*****</td>
<td>0.47 (0.32-0.69)*****</td>
</tr>
<tr>
<td>Rehabilitation Counseling &amp; Guidance</td>
<td>1.74 (1.40-2.16)**</td>
<td>1.75 (1.37-2.25)*****</td>
<td>2.00 (1.32-3.03)*****</td>
</tr>
<tr>
<td>College or University Training</td>
<td>1.48 (1.09-2.02)*</td>
<td>0.86 (0.56-1.33)</td>
<td>0.96 (0.34-2.73)</td>
</tr>
<tr>
<td>Occupational/Vocational Training</td>
<td>1.72 (1.22-2.42)**</td>
<td>0.98 (0.64-1.49)</td>
<td>2.13 (0.96-4.74)</td>
</tr>
<tr>
<td>On-the-job Training</td>
<td>1.56 (1.02-2.39)*</td>
<td>0.95 (0.60-1.50)</td>
<td>2.07 (0.77-5.53)</td>
</tr>
<tr>
<td>Job Placement Assistance</td>
<td>2.85 (2.32-3.51)**</td>
<td>3.03 (2.39-3.85)*****</td>
<td>3.30 (2.23-4.89)*****</td>
</tr>
<tr>
<td>On-the-job support</td>
<td>4.02 (3.21-5.03)*****</td>
<td>3.06 (2.42-3.87)*****</td>
<td>3.75 (2.47-5.70)*****</td>
</tr>
<tr>
<td>Info and Referral</td>
<td>0.88 (0.68-1.14)</td>
<td>0.65 (0.48-0.88)*****</td>
<td>1.08 (0.64-1.81)</td>
</tr>
<tr>
<td>Other Services</td>
<td>1.25 (1.00-1.56)*</td>
<td>1.25 (0.96-1.64)</td>
<td>1.01 (0.64-1.61)</td>
</tr>
</tbody>
</table>
Taylor et al., 2015

![Balance Scale]

Gender Differences in VR Predictors of Competitive Employment for Transition Youth with Autism
(Sung, Sanchez, Kuo, Wang, & Leahy, 2015)

<table>
<thead>
<tr>
<th>Odd Ratio</th>
<th>Male (n = 857)</th>
<th>Female (n = 839)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Co-occurring Anxiety/Depression</td>
<td>0.47 (0.27-0.82)**</td>
<td>0.99 (0.60-1.64)</td>
</tr>
<tr>
<td>Pre-service Education Level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Special education</td>
<td>1.09 (0.69-1.74)</td>
<td>0.95 (0.59-1.55)</td>
</tr>
<tr>
<td>HS diploma or equivalency</td>
<td>1.49 (0.94-2.35)</td>
<td>1.21 (0.75-1.98)</td>
</tr>
<tr>
<td>Postsecondary education</td>
<td>2.08 (1.02-4.27)*</td>
<td>2.34 (1.17-4.66)*</td>
</tr>
<tr>
<td>Pre-service Employment Status</td>
<td>2.03 (1.13-3.65)*</td>
<td>4.05 (1.90-8.65)***</td>
</tr>
<tr>
<td>Rehabilitation Counseling &amp; Guidance</td>
<td>2.36 (1.61-3.46)***</td>
<td>1.48 (1.00-2.21)</td>
</tr>
<tr>
<td>Job Search Assistance</td>
<td>1.57 (1.05-2.37)*</td>
<td>0.98 (0.61-1.56)</td>
</tr>
<tr>
<td>Job Placement Assistance</td>
<td>2.54 (1.77-3.66)***</td>
<td>2.33 (1.58-3.43)***</td>
</tr>
<tr>
<td>On-the-job support</td>
<td>2.96 (1.99-4.40)***</td>
<td>3.84 (2.62-5.62)***</td>
</tr>
<tr>
<td>Other Services</td>
<td>1.79 (1.20-2.67)**</td>
<td>0.85 (0.57-1.27)</td>
</tr>
</tbody>
</table>
Study Summary

- Age-independent VR service predictors (counseling and guidance, on-the-job support, job placement more beneficial for for all groups).
- Age-specific predictors of employment (college/university training, vocational training, on-the-job training more beneficial for the transition youth group).
- Gender-independent VR service predictors (job placement and on-the-job supports more beneficial for both genders)
- Gender-specific predictors of employment (rehabilitation counseling and guidance, job search assistance, and other services more beneficial for the male group).
How VR Services Affect Employment Outcomes for Adults with Cerebral Palsy (CP) (Huang, Holzbauer, Lee, Chronister, Chan, & O’Neil, 2013)

<table>
<thead>
<tr>
<th>Demographic and vocational rehabilitation predictors of employment outcomes</th>
<th>B</th>
<th>SE</th>
<th>df</th>
<th>p</th>
<th>Exp (B)</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex (with female as the reference category)</td>
<td>0.24</td>
<td>0.08</td>
<td>1</td>
<td>0.002</td>
<td>1.27</td>
<td>1.09–1.48</td>
</tr>
<tr>
<td>Age at application (with 26–54y as the reference category)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16–20y</td>
<td>-0.39</td>
<td>0.09</td>
<td>1</td>
<td>&lt;0.001</td>
<td>0.68</td>
<td>0.56–0.81</td>
</tr>
<tr>
<td>21–25y</td>
<td>-0.15</td>
<td>0.12</td>
<td>1</td>
<td>0.200</td>
<td>0.86</td>
<td>0.69–1.08</td>
</tr>
<tr>
<td>Race (with European-, Asian-, and Hispanic-American as the reference category)</td>
<td>0.13</td>
<td>0.11</td>
<td>1</td>
<td>0.225</td>
<td>1.14</td>
<td>0.92–1.42</td>
</tr>
<tr>
<td>Education level (with lower than bachelor degree as the reference category)</td>
<td>1.01</td>
<td>0.16</td>
<td>1</td>
<td>&lt;0.001</td>
<td>2.74</td>
<td>2.02–3.71</td>
</tr>
<tr>
<td>Medical insurance (with ‘No’ as the reference category)</td>
<td>-0.12</td>
<td>0.07</td>
<td>1</td>
<td>0.105</td>
<td>0.89</td>
<td>0.77–1.03</td>
</tr>
<tr>
<td>Cash benefits (with ‘No’ as the reference category)</td>
<td>-0.61</td>
<td>0.10</td>
<td>1</td>
<td>&lt;0.001</td>
<td>0.55</td>
<td>0.45–0.66</td>
</tr>
<tr>
<td>Diagnostics and treatment (with ‘No’ as the reference category)</td>
<td>0.16</td>
<td>0.09</td>
<td>1</td>
<td>0.058</td>
<td>1.18</td>
<td>1.00–1.39</td>
</tr>
<tr>
<td>On-the-job training (with ‘No’ as the reference category)</td>
<td>0.43</td>
<td>0.20</td>
<td>1</td>
<td>0.031</td>
<td>1.53</td>
<td>1.04–2.25</td>
</tr>
<tr>
<td>Job placement assistance (with ‘No’ as the reference category)</td>
<td>1.03</td>
<td>0.08</td>
<td>1</td>
<td>&lt;0.001</td>
<td>2.80</td>
<td>2.39–3.28</td>
</tr>
<tr>
<td>On-the-job support (with ‘No’ as the reference category)</td>
<td>0.84</td>
<td>0.10</td>
<td>1</td>
<td>&lt;0.001</td>
<td>2.33</td>
<td>1.93–2.80</td>
</tr>
<tr>
<td>Maintenance (with ‘No’ as the reference category)</td>
<td>0.41</td>
<td>0.11</td>
<td>1</td>
<td>&lt;0.001</td>
<td>1.51</td>
<td>1.21–1.87</td>
</tr>
<tr>
<td>Rehabilitation technology (with ‘No’ as the reference category)</td>
<td>0.59</td>
<td>0.10</td>
<td>1</td>
<td>&lt;0.001</td>
<td>1.80</td>
<td>1.48–2.18</td>
</tr>
<tr>
<td>Constant</td>
<td>-0.65</td>
<td>0.15</td>
<td>1</td>
<td>&lt;0.001</td>
<td>0.52</td>
<td></td>
</tr>
</tbody>
</table>

B, logistic regression coefficient; CI, confidence interval; df, degrees of freedom; Exp (B), odds ratio; SE, standard error.
Study Summary

- VR services can positively impact the employment rates and quality of employment for adults with CP, especially when coordinated with services from special educators and health professionals.
- Five VR services were shown to play a central role in the employment success of people with CP: Job Placement, Assistance, On-the-Job Training, On-the-Job Support, Maintenance, Rehabilitation Technology
- Individuals’ gender, age, educational level, and receipt of cash benefits (SSDI/SSI) while receiving VR services also influenced their employment outcomes.
Use of EBP for transition-age students by Professionals in School Settings
Example of Promising Transition/Employment Services

Smith and colleagues -- http://www.waisman.wisc.edu/family/working-together.html

Kaehne, 2015; Persch et al., 2015; Schall et al., 2015; Wehman et al., 2013, 2014
Examples of an ongoing intervention study
Goal Setting:
Made me think about what kind of job I want to have and whether or not it pays.

Soft Skills:
Helped me with my soft skills that often it’s hard. We often forget, just try to catch up and develop hard skills what employers essentially want.

Teamwork:
Nice to be able to see how different personalities can work together.

Mental Health:
I am not as stressed and my smiling is more appropriate.

Employment Readiness:
Definitely helped me improve my ability to building and preparation for interviews, work well with others in job environment.

Networking:
I am going to try to keep in contact with people I have worked with such as peers, teachers.

Sense of Belonging:
I felt a little connected to the group members. The activities helped me feel connected to the group.
Take home messages

1. More focus should be put on transition population with IDD in addition to children and adult population.
2. Huge need for individualized VR programs.
3. More education and training on best practices for this population should be offered to service providers.
4. Better communications and coordination between Education System and VR System are needed to bridge gaps.
5. More research on evidence-based practices in VR and how to implement those practices are warranted.
Community Integration
Community Integration Outcomes Post-School

- **NLTS-2 Findings** (Newman et al., 2011; Grigal et al., 2011):
  - Less likely to be employed (especially at min wage)
  - Less likely to be enrolled in postsecondary education
  - Less likely to be engaged in volunteer activities
  - Nearly half report non-involvement in survey items related to community activities in past year
  - Over one-third not registered to vote

- Of those receiving services, vast majority remain in sheltered employment, nonwork services, or day program (Butterworth et al., 2011)

- Over half of young adults report at least one activity limitation (Van Naarden Braun, 2009)

- Limited friendship networks, often including staff members

- Risk for loneliness, estimates of up to 50% report feeling lonely (Sancliffe et al., 2007) & often related to absence of a partner (Mcvilly et al., 2006)

- Social support and peers rated as lowest aspects of QOL (proxy) (Biggs & Carter, 2016)

- Leisure pursuits are typically isolated activities (Wegner et al., 2005)
A litany of terms!

- Following deinstitutionalization, although people are in their communities, are they of their communities? (most living at home with family)
- Physical presence vs. belonging & meaning
- How do we measure?
- What communities are most important? (local community, school, work)
Measuring Integration & Inclusion (Amado et al., 2013)

- **Degree of inclusion**: frequency measures (e.g., “how often do you go shopping?”)
- **Choice measures**: e.g., “if you want to go out, can you?”
- **Satisfaction measures**: e.g., “how satisfied are you with your friendships?”
- **Belonging**: psychological sense of community, reciprocity measures
Factors impacting Inclusion/Integration

- - -

● **Personal characteristics**
  ○ Age (e.g., Stancliffe et al., 2012)
  ○ Degree of disability (e.g., Robertson et al., 2001; Van Naarden Braun et al., 2009)
  ○ Social skills
  ○ Challenging behaviors

● **Environment**
  ○ Residence type (Verdonschot et al., 2009)
  ○ Staff attention and assistance (Perry & Felce, 2005)
  ○ Opportunities for autonomy & choice making (Verdonschot et al, 2009)
  ○ Participation in early community-based experiences
  ○ Transportation access (Buttimer et al, 2005)
  ○ Cognitive accessibility of information (Yalon-Chamovitz, 2009)
  ○ Public stigma (social & structural) (Ditchman et al., 2013)
    ■ Employer preferences, access, expectations
  ○ Linkages prior to leaving school
  ○ Community characteristics (e.g., safety)
  ○ Family involvement and social support
  ○ Valued roles and opportunities for meaningful interaction
Interventions & Promising Strategies

- Supporting skill acquisition through instructional and behavioral techniques (e.g., Luce & Dyer, 1995)

- A number of interventions to improve social functioning (e.g., Rogers & Myles, 2001)
  - Including, technology based strategies & virtual environments (Moore et al., 2005)

- Peer-mediated support strategies (primarily used in school-based settings) (Carter et al., 2009; 2005)

- Changing culture of system/facility (Thorn et al., 2009)

- Increasing inclusion of individuals with disabilities in community organizations and activities
  - Community organizations (Amado et al., 2011)
  - Congregational initiatives (Vogel et al., 2006; Carter, 2007)
  - Community recreational programs (Abery & Fahnestock, 1994)
  - Supportive workplace culture (Butterworth et al., 2000)
Some ongoing studies

- Attitudes toward intellectual disability (the impact of cultural variables):
  - Individuals high on vertical-individualism associated with more negative attitudes toward sexuality of people with ID & general attitudes toward ID (even over familiarity)
  - Communal orientation directly impacts willingness to engage with people with ID and indirectly through its association with integration beliefs

- Mapping community activities-pilot project:
  - GPS tracking of community movements for 9 individuals with ID in sheltered workshop
  - Findings: little activity outside workshop, role of neighborhood context

- Civic engagement study:
  - Little research studying predictors and underlying mechanisms of civic engagement for young adults with IDD
  - Testing social cognitive theory model
Figure 1. Proposed path model based on social cognitive constructs
Gaps in the research & next steps

- Still relatively few studies documenting interventions to enhance community participation & integration
- Measurement issues & how do we account for individual preferences?
- Moving from community activities to sense of belonging
- Role of social media as facilitator vs. barrier to community inclusion
- Role of technology
- Involvement of individuals with IDD in research process
- Addressing role of family in supporting social relationships (e.g., cultural expectations)
- What is correct balance between protecting rights and safety of people with IDD?
- Examine impact of state service systems (cross-system comparisons)
- Need to scale up strategies that have been successful on small scale (and people need to be able to access them!)
Family Considerations
Significance of the Problem

Transition of young adults with ID/DD has been reported by families and caregivers as a time of upheaval, stress and important decisions. It is also a time of much confusion about services available beyond school setting.

The great majority of these individuals live at home with family members, making families the predominant providers of lifelong support (Heller, Caldwell, & Factor, 2007). State agencies support only 13% of the total number of families providing support at home (Braddock et al., 2013).
Significance of the Problem (cont.)

- Significance of caregivers’ role across lifespan and life domains for their children with IDD (Boehm et al., 2015; Smith et al., 2012)
- Ineffective and long-term caregiving affects caregiver's’ own health and mental health (Boehm et al., 2015; Smith et al., 2012; Tincani & Bondy, 2014; Volkmar et al., 2014)
- Poor caregiver outcomes affect caregivers’ ability to care for their children with IDD, indirectly affecting their children’s well being and success (Abbeduto et al., 2004; Boehm et al., 2015; Smith et al., 2012; Carter Austin, & Trainor, 2012)
- Poor outcomes for caregivers of children and adults with IDD, such as poor health, mental health, marital adjustment, stability and functionality of a family, life satisfaction, quality of life (e.g., Jellett et al., 2015; Khanna et al., 2011; Lee, 2009; Lee, Berry-Kaizmien et al., 2009; Lee, Lopata et al., 2012; Watson et al., 2011)
- Research on needs, challenges, how those factors interact and affect their overall adjustment, interventions to address those issues, are not well understood
Unique Challenges for Caregivers of Adults with IDD

- Mal-adaptive behaviors resulting from IDD (e.g., Taylor & Seltzer, 2010)
- Poor health, high comorbidity of health and mental health issues (e.g., Anderson et al., 2013; Biggs & Carter, 2016; Havercamp & Scott, 2015)
- Negative emotionality – family interaction and dynamics (Smith et al., 2012; Hastings & Lloyd, 2007)
- Low involvement and expectation from family (Doren et al., 2014)
- Poor transition services (Shattuck et al., 2012)
- Lack of services of independent living (Anderson et al., 2014), restricted social network/relationship (van Asselt-Groverts et al., 2015), and general fragmented services (Friedmen et al., 2013)
- Lack of knowledge and resources (Martinez et al., 2012)
- Legal matters (Frantz & Zellis, 2014)
- Future of children’s life (college, work, community, engagement, safety, independent living, relationship) (Tincani & Bondy, 2014; Volkmar et al., 2014)
Study 1: Caregivers of Children and Adults with ASD

(Lee and Shivers, in prep)

- National online survey through Interactive Autism Network on 194 caregivers of children and adults with ASD

- Psychosocial factors and outcomes:
  - Caregiving variables, caregiver burden, coping, caregiving needs, quality of life, behavioral outcome measures (healthy eating, leisure and exercise, alcohol consumption, smoking habits)

- Demographics:
  - 96.4% parents of individuals with ASD
  - 91.1% female, 80.7% White; average age=46.3
  - SES: 42.8% middle class; 28.9% upper middle class; 19.6% lower middle class
  - Education: 34.0 bachelor; 24.7% masters
  - 66% of participants of children younger than 18; 33% with adults children
**Study 1: Health and Mental Health Outcomes**

- **Caregiver Burden** was significantly correlated with both **Maladaptive Coping** and **Nutrition**
- However, Maladaptive Coping did not significantly mediate the relationship between Burden and Nutrition
- **Caregiver Needs** was significantly related to Nutrition, but did not mediate the relationship between Strain and other health behavioral outcomes
- **Effect of Burden on Mental Health (Mediated by Caregiver Needs)** (n=177):
  - Direct Effect: -.294, p<.001
  - Indirect Effect: .001; CI .95 {-0.040, 0.0049} - Non-significant
- **Effect of Burden on Mental Health (Mediated by Maladaptive Coping)** (n=180):
  - Direct Effect: -.176, p<.001
  - Indirect Effect: -.127; CI .95 {-0.268, -0.084} - Significant
Study 1: Comparison Group

- 129 caregivers of young children and 65 caregivers of adult children

  ● **Burden:**
    - Significant difference on overall burden (parents of children reported higher perceived burden ($M = 126.48$) than parents of adults ($M = 100.32$) ($t = 2.134$, $p = .037$))
    - Significant difference reported by parents of children on school-related items, temper tantrums, and potty training
    - Both groups reported high burden and concern on the child's ability to live independently and long-term coping in the future

  ● **Unmet Needs:**
    - Parents of children reported higher unmet needs on strained family relationships, financial burden, medical problems, denial of child’s condition, abnormal nonverbal communication, family member's need to stick to a routine, and toilet training
    - Both groups reported unmet needs for success in employment, services in the community, and romantic relationships
Study 2: Parental Involvement and Expectations (PIE) Project  

(Lee & Rispoli, in prep)

- Parent expectation and parental involvement in relations to their effects on the child of transition-age and the parent
- In-depth phenomenological study on how parental expectations and involvement influence the transition outcomes of the children and parents
- Recruitment from Ingham county school districts, MI and Summit Educational Resources, Buffalo, NY
- Focus on diploma track or Regents diploma (high functioning) students
Study 2: PIE Project (Lee & Rispoli, in prep)

- Common themes:
  1) Lower expectation for their children
  2) Positive support and involvement from and with current school districts in services
  3) Worry about child’s future post high school (work, living, vulnerability)
  4) Lack of knowledge and resources
  5) Increase caregiving burden - sandwich caregivers
  6) Marital strain and own health/aging issues despite positive family and spousal support
  7) Financial strain for continuous service post high school (e.g., ABA, vocational services, living arrangement)
  8) Need community and peer support
EVP Intervention for Children with IDD (Skotaczak & Lee, 2015)

- Meta-analysis on 11 Parental Management Training (PMT) studies:
- Main child effects: **moderate and significant** $g = 0.434$, $p = .0003$, 95% CI [0.196, 0.672]
- Behavior problems: $g = 0.570$, $p = .0063$, 95% CI [0.162, 1.979]
- Intensity: $g = 0.633$, $p = .0047$, 95% CI [0.194, 1.072]
- Parental well-being: **small and significant** $g = 0.283$, $p = .0045$, 95% CI [0.088, 0.477]
- Parenting practice: **large and significant** $g = 0.721$, $p < .0001$, 95% CI [0.458, 0.984]
Stress-Coping Model of Korean Caregivers (Lee et al., in prep)

- Across studies, parents caring for a child with a neurodevelopmental disability report higher rates of stress than parents of typically developing children.
- Factors associated with stress: Child behavior problems, child pro-social behavior, parenting support, family cohesion, satisfaction with health care, and depression.
- These caregivers also report higher rates of depressive symptoms (Bitskia & Sharpley, 2004).
  - Clinical rates of depression vary across studies (20-37%).
  - Caregivers of children with ASD report highest rates of depression.
Results: Mediation

- Dysfunctional coping was a significant partial mediator between stress and depressive symptoms
- Confirmed by a significant Sobel test, Z = 2.24, p < .05

Table 3
Mediation Analysis

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<th>Relationship</th>
<th>Variable</th>
<th>Coefficient</th>
<th>SE</th>
<th>CI</th>
<th>F</th>
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<td>Stress (IV)**</td>
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<td></td>
<td>Stress (IV)**</td>
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<tr>
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<td>Dysfunctional</td>
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<td>.06</td>
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<tr>
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<td>Coping (M)**</td>
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</tbody>
</table>

N = 161, *p < .05, **p < .01
Results: Moderation

- Dysfunctional coping was a significant moderator in the relationship between stress and depressive symptoms
- Significant $R^2$ Change = .04, $F$ Change = 8.89, $p < .01$
- Explained variance in depressive symptoms significantly improved from 12% to 17% with the moderator (4% increase in explained variance)

Table 4
Final Moderation Model

<table>
<thead>
<tr>
<th>Variable</th>
<th>Coefficient</th>
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<th>CI</th>
<th>F</th>
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<td>.01</td>
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N =161, *p <.05, **p <.01
Results: Moderation Relationships

Figure 1
Use of dysfunctional coping as a moderator between stress and depressive symptoms

Figure 1 displays use of dysfunctional coping as a moderator between stress and depressive symptoms for caregivers of adolescents with neurodevelopmental disabilities (n = 161).
Intervention - Family Psychoeducation (FPE)

- EVP for families and individuals with psychiatric disabilities for partnering with consumers and families to support recovery by learning about mental illnesses and learn problem-solving, communication, and coping skills (SAMHSA, 2009)
- Key components: Alliance, education and resources help families support consumers’ personal recovery goals, ongoing guidance and skills training, problem-solving skills, social and emotional support
- Joining Sessions, Educational Workshop and Ongoing Sessions

Effectiveness of FPE (psychiatric disabilities):
- Fewer consumer relapses and hospitalizations, decrease cost of care, increased consumer participation in vocational rehabilitation programs and employment rate
- Reduced medical illnesses and use of medical care of families, improved family well-being, greater family knowledge of serious mental illnesses, fewer feelings of stress and isolation
Various Selected Youth Transition Programs

1.) Transition Youth Toolkit (http://tknlyouth.sdsu.edu/)
   ● Topics: Education, Independent Living, Employment, Finances, Healthcare, Social/Recreation

2.) Building Independent Lives through Training (https://www.autismspeaks.org/family-services/bilt) - online

3.) Devereux CARES Transition Wiki (www.autismhandbook.org) - online

Implications/Issues:
● Youth transition programs designed to help multiple domains of transition
● Research on effectiveness?
● Involvement of families?
Examples of Promising Evidence-Based FPE

1) Waisman Center - Transitioning Together (age 14 to 21)
     ● 8 group sessions
     ● Topics: autism in adulthood, transition planning, problem solving, family topics, addressing risks to adult independence, community involvement, risk to health and legal issues

2) Waisman Center - Working Together (age 18-30)
   - http://www.waisman.wisc.edu/family/working-together.html
     ● Interview, 2 individual family sessions, 8 weeks group sessions, 3 follow-ups
     ● Topics: Planning for independence, problem solving, coping strategies, community and relationships, health and well-being, personal safety
Examples of Promising Evidence-Based FPE

3) Vanderbilt Kennedy Center (Treatment and Research Institute for ASD; TRIAD)

— Volunteer Advocacy Program – Transition (VAP-T)

— http://vkc.mc.vanderbilt.edu/notables/2015/03/improving-transition-for-youth-with-autism/

- 12 sessions of 2.5 hours each (both people with ASD and families attended)
- Person-centered planning and advocacy and self advocacy
- Topics: Postsecondary education, employment, SSI, SSDI, Medicare and Medicaid health insurance, Medicaid waiver, legal and future planning issues (e.g., conservatorship, special needs trust)
Conclusion
Employment
Community Integration
Family/Caregiver issues

1) Families often become primary caregivers of their adult children with IDD
2) Family and caregivers often experience poor physical/psychological health and quality of life.
3) Services and support for families of transition and youth adults with IDD are sparse
4) Challenges often stem from two overarching areas:
   ● Lack of knowledge about the vast domains of services for their adult children with IDD (college/work, independent living, social/relationship, legal matters)
   ● Neglect of services for caregivers themselves (aging parents, sibling responsibilities, own issues with health and mental health)
5) Caregivers encompass not only parents but also siblings, legal guardians and other types of non-traditional family unit
6) Empirical studies on evidence-based interventions for families are emerging but still at its infancy
Clinical Implications

1) Services for transitioning youths and young adults are sparse
2) Such services cover a diverse range including college/employment, independent living, social and community integration
3) Services should be individualized to accommodate the diverse functions and needs for individuals with IDD
4) True inclusion continues to be a challenge in practice
5) Family plays an important role in supporting their adult children with IDD
6) Community-based intervention is likely to be helpful to reach out to families and individuals with IDD
Research Implications

1) Evidence-based interventions for critical transition life domains are in need for this population
2) Employment-related interventions show promising evidence for effective outcomes
3) Other aspects of interventions may require more research work such as social and community inclusion, independent living
4) Research on interventions to help families to gain knowledge and skills to help with their children in transitioning are in needed
5) Research on interventions address the health and mental health needs for families are needed
Thank you!
References

  0.1352/1934-9556-51.5.385
References

References