Perspectives of Developmental and Behavioral Pediatric Providers on transition of care for youth with developmental disabilities

**Background**

- Healthcare transition is the purposeful, planned movement of adolescent and young adults with chronic physical and medical conditions from child-centered to adult-oriented health-care systems.
- On the 2016 National Survey of Children’s Health 17% of youth with SCN met standards on Transition of Care (TOC).
- Common challenges in the transition process for children with chronic conditions are lack of preparation for the transfer; lack of experience of adult clinicians in pediatric diseases; the loss of a longstanding relationship with pediatricians; poor communication between adolescents and their adult clinicians.

**Objectives**

1. Evaluate current TOC practices among clinicians within Developmental Behavioral Pediatrics (DBP) section of Children’s Specialized Hospital (CSH).
2. Identify barriers and opportunities in implementing quality TOC for youth with disabilities.
3. Evaluate DBP provider’s perspectives on TOC for youth with disabilities.

**Methods**

- Data collected via anonymous electronic survey
- CSH DBP section includes 30 clinicians: 14 DBPs, 4 Neurologists, 12 APNs.
- Response rate of 67% (n= 20)
- Descriptive statistics data analysis.

**Results**

**Q1:** Age of initiation of discussion on TOC planning

- 12-13 yo: 15%
- 14-16 yo: 35%
- >=17 yo: 50%

**Q2**

**Box 1. Needs assessment survey**

1. What age do you start talking to your patients about transition of care?
2. Please mention transition of care resources you utilize the most.
3. What barriers do you face with transition of care planning for children (multiple choice question, see table 3):
   - 12-13 years old
   - 14-16 years old
   - >17 years old
4. What would be the most helpful in your practice to better assist you guide your patients with transition of care? (Open ended question).

**Table 3. Barriers with Transition of Care planning by age group**

<table>
<thead>
<tr>
<th>Barriers</th>
<th>12-13 yo</th>
<th>14-16 yo</th>
<th>&gt;17yo</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not familiar with local and regional resources</td>
<td>52.6% (n=10)</td>
<td>52.6% (n=10)</td>
<td>84.2% (n=16)</td>
</tr>
<tr>
<td>No list of adult providers</td>
<td>52.6% (n=10)</td>
<td>58% (n=11)</td>
<td>73.4% (n=14)</td>
</tr>
<tr>
<td>I do not know where to start and algorithm of TOC</td>
<td>42% (n=8)</td>
<td>36.8% (n=7)</td>
<td>15.8% (n=3)</td>
</tr>
<tr>
<td>No checklist in EMR to remind and track</td>
<td>42% (n=8)</td>
<td>47.4% (n=7)</td>
<td>47.4% (n=9)</td>
</tr>
<tr>
<td>No time to do it</td>
<td>42% (n=8)</td>
<td>36.8% (n=7)</td>
<td>26.3% (n=5)</td>
</tr>
<tr>
<td>No care coordination/support staff</td>
<td>42% (n=8)</td>
<td>42% (n=8)</td>
<td>57.95% (n=11)</td>
</tr>
<tr>
<td>No adequate infrastructure and training</td>
<td>31.6% (n=6)</td>
<td>36.8% (n=7)</td>
<td>47.9% (n=9)</td>
</tr>
<tr>
<td>Forget to do it</td>
<td>15.8% (n=3)</td>
<td>21% (n=4)</td>
<td>5.3% (n=1)</td>
</tr>
<tr>
<td>No comfort talking to patients about TOC</td>
<td>10.5% (n=2)</td>
<td>10.5% (n=2)</td>
<td>15.8% (n=3)</td>
</tr>
</tbody>
</table>

**Graph 2. Resources used by DBP providers**

- SW transition checklist (n=5)
- Guardianship (n=3)
- Do not have any (n=3)
- DVRS (n=2)
- Neurology (n=2)
- Transition algorithm (n=1)
- SPAN (n=1)
- AAP transition resource (n=1)
- Autism Speaks (n=1)
- ARC (n=1)
- DDS (n=1)
- Family Practice (n=1)
- Psychiatry (n=1)
- Physical (n=1)
- List of adult providers (n=1)
- No specific resource (n=1)

**Conclusion**

- Plan to collaborate with NJ Transition to Adult Coordinated care Program at CHOP.
- Distribute TOC algorithm by age and corresponding resources with clinicians New Jersey (autismspeaks.org)