Transition to Adult Health Care for Youth with Autism Spectrum Disorders

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Study Overview

Aim: *Determine the current state of Health Care Transition (HCT) services* within autism specialty clinics and primary care settings and assess how HCT services are experienced and perceived by families and providers.

Methods:
- Conducted *in-depth interviews* with pediatric and adult providers of youth and adults with ASD
- Developed and administered a *HCT survey* for parents of youth with ASD
- Created *Transition Resource Guide* for parents of youth with ASD and contributed several entries to the transition toolkit on the AUCD website

*In general we were looking for best practices.*
Primary Research Questions Pediatric and Adult providers:

1) What are the current strategies or interventions taking place to facilitate successful transition from pediatric to adult health care for youth with ASD?

2) What strategies or interventions are needed or would be most helpful in facilitating the transition from pediatric to adult health care for youth with ASD?
Providers identified 5 different interventions as currently in place and 7 different interventions as needed.

Most common interventions being used included
- Medical records/summary
- Creating resource links

Overlap between the strategies being used at some sites/locales and those desired in others. For example, creating resource links

Training for families, adult providers and medical students is needed

3 of the HCT interventions identified as needed would operate within the pediatric practice, 2 would operate outside of the practice, and 1 would operate within and outside of the practice.
## Table 1: Transition Strategies/Interventions by Implementation Status and Location

<table>
<thead>
<tr>
<th>Strategies or Interventions Identified as Needed</th>
<th>#</th>
<th>Internal to Pediatric Practice</th>
<th>#</th>
<th>External to Pediatric Practice</th>
<th>#</th>
<th>Internal &amp; External to Pediatric Practice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Written materials (care binder, transition plan, checklists)</td>
<td>9</td>
<td></td>
<td>6</td>
<td>Training adult providers</td>
<td>4</td>
<td>Care coordination</td>
</tr>
<tr>
<td>Education/Training for families/youth (information sessions, workshops)</td>
<td>6</td>
<td></td>
<td>3</td>
<td>Training medical students</td>
<td>4</td>
<td>Transition center</td>
</tr>
<tr>
<td>Creating resource links (list of providers, community resources)</td>
<td>5</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Strategies or Interventions Identified as in Place</td>
<td>8</td>
<td>Medical records/summary</td>
<td>8</td>
<td>Creating resource links</td>
<td>5</td>
<td>Care coordination</td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>Transition specific appts.</td>
<td>4</td>
<td>Checklists</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Adult Providers: Findings

- Challenges were identified at the systems and practice/provider levels as well as with training and education.

- The lack of adult providers and the financial disincentives to provide care to adults with ASD were seen as related.

- Challenges identified at the practice/provision level focused on how to best meet the various needs of adults with ASD as efficiently as possible.

- The solutions suggested have implications for medical school and residency training programs and the development of best practices.
<table>
<thead>
<tr>
<th>Challenges to Providing Care</th>
<th>Systems Level</th>
<th>Practice/ Provision Level</th>
<th>Training &amp; Education Level</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>-Shortage of services &amp; supports</td>
<td>-Time constraints and inefficiency</td>
<td>-Lack of formal education and training</td>
</tr>
<tr>
<td></td>
<td>-Financial disincentives</td>
<td>-Complexity of family involvement</td>
<td></td>
</tr>
<tr>
<td></td>
<td>-Lack of adult providers</td>
<td>-Physical environment</td>
<td></td>
</tr>
<tr>
<td></td>
<td>-Time &amp; reimbursement</td>
<td>-Communication barriers</td>
<td></td>
</tr>
<tr>
<td>Solutions and Interventions</td>
<td>-Providing financial incentives, resources, &amp; supports to providers, families, and individuals with ASD</td>
<td>-Customized lists of resources and services</td>
<td>-Increased awareness</td>
</tr>
<tr>
<td></td>
<td></td>
<td>-Reviewing patient lists frequently</td>
<td>-Early exposure to ASD population</td>
</tr>
<tr>
<td></td>
<td></td>
<td>-Facilitating communication among families &amp; physicians</td>
<td>-Set expectation of provision of care</td>
</tr>
<tr>
<td></td>
<td></td>
<td>-Enhancement of physical environment</td>
<td>-Provision of broad-based training early and often for physicians and staff</td>
</tr>
</tbody>
</table>

Table 2: Specific HCT Challenges and Solutions Identified by Adult Providers
Parents/Guardians: *Data Analysis*

**Data Collected/Analyzed:**
1) Demographic, family and clinical characteristics
2) Health care utilization
3) Exposure to transition services
4) HCT services received and satisfaction with those services
5) HCT services desired but not received
6) HCT obstacles and challenges

Collected data
1) From parents affiliated with one of two autism specialty clinics and one parent advocacy organization
2) From 184 parents
3) Via mailed paper survey with small incentive payment
Parents/Guardians: Findings

Figure I: Overall Exposure to Health Care Transition

- Full sample
- 13-15 yrs
- 16-18 yrs
- 19+ yrs

- Provider discussed how child's needs might change?
- Provider discussed how to manage HCT process?
Table 3: Services Received vs. Services Desired

<table>
<thead>
<tr>
<th>Transition Service</th>
<th>% Who Received Service</th>
<th>% Who Did Not Receive Service but Would Like to</th>
</tr>
</thead>
<tbody>
<tr>
<td>Informative materials about transition process</td>
<td>17.1</td>
<td>90.4</td>
</tr>
<tr>
<td>Written transition plan</td>
<td>3.3</td>
<td>87.2</td>
</tr>
<tr>
<td>Written medical summary</td>
<td>8.8</td>
<td>87.2</td>
</tr>
<tr>
<td>Support in searching for an adult PCP</td>
<td>7.3</td>
<td>80.0</td>
</tr>
<tr>
<td>Info. on adult medical specialists</td>
<td>11.0</td>
<td>82.0</td>
</tr>
<tr>
<td>Help w/ teaching child to manage own health care needs</td>
<td>19.4</td>
<td>73.3</td>
</tr>
<tr>
<td>Info. about obtaining guardianship</td>
<td>9.0</td>
<td>67.0</td>
</tr>
<tr>
<td>Other transition-related services or support</td>
<td>13.3</td>
<td>N/A</td>
</tr>
</tbody>
</table>
Parents/Guardians: Findings

- **Obstacles:** Parents reported the biggest obstacles to transition to be:
  1.) a general lack of information on the transition process (51%)
  2.) difficulty finding an adult provider who is knowledgeable about ASDs (31%)
  3.) difficulty finding an adult provider who is ASD-friendly (29%)

- **Preparation:** Of the 184 parents surveyed, 23% reported that their child was adequately prepared to make the switch to adult health care and 68% reported that their child was not. The remaining 9% had already made the transition to adult care.
Summary

Existing Interventions and Strategies to Facilitate Transition

1) Written materials
2) Family and youth education
3) Care Coordination Strategies
4) Provider and community resource lists

Needs

1) Increase workforce capacity
2) Disseminate existing strategies
3) Put in the context of youth self-determination skills and participation in transitions.
Thank you!

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