Transition from Pediatric to Adult Healthcare for Young Adults with Down Syndrome

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Background

Significance

• Transition

• Youth with Special Health Care Needs
  • 2009/2010 National Survey of Children with Special Health Care Needs
  • 4.5 million 12-18 year olds
  • >33% with emotional, behavioral, or developmental condition
  • 90% live into adulthood

• Consequences of delayed/poor transition process (Gabriel et al, 2017)
Background

Current state of the science

• A consensus statement on health care transitions for young adults with special health care needs (2002)

• Supporting the health care transition from adolescence to adulthood in the medical home (2011)

• Six Core Elements for Health Care Transition (2014)

• Outcome evidence for structured pediatric to adult health care transition interventions: A systematic review (2018)
Background

Six Core Elements

GotTransition.org

1. Transition policy
2. Transition tracking and monitoring
3. Transition readiness
4. Transition planning/integrating
5. Transfer of care
6. Transfer completion

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Methods

Specific aims
Investigate experiences of young adults with Down syndrome and their caregivers surrounding a) transition and b) transition support received from pediatric and adult providers

Research design
Qualitative exploratory study
Semi-structured interviews

Approach
Recruitment
Implementation
Incentive
Data Analysis

- Audio-recorded interviews
- Transcribed by interviewer
- Analyzed thematically
  - 3 independent reviewers
  - Discrepancies resolved
# Results

**Sample characteristics** Young adults with Down syndrome

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<tbody>
<tr>
<td><strong>Age, M(SD)</strong></td>
<td>19.8(2.6)</td>
</tr>
<tr>
<td><strong>White, n(%)</strong></td>
<td>6 (100%)</td>
</tr>
<tr>
<td><strong>Male, n(%)</strong></td>
<td>5 (83.3%)</td>
</tr>
<tr>
<td><strong>Single/never married, n(%)</strong></td>
<td>6 (100%)</td>
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<tr>
<td><strong>Highest level of education, n(%)</strong></td>
<td></td>
</tr>
<tr>
<td>Some Junior High</td>
<td>1 (16.7%)</td>
</tr>
<tr>
<td>Some High School</td>
<td>3 (50%)</td>
</tr>
<tr>
<td>High school graduate</td>
<td>1 (16.7%)</td>
</tr>
<tr>
<td>Some college</td>
<td>1 (16.7%)</td>
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<tr>
<td><strong>Work, n(%)</strong></td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td>4 (66.7%)</td>
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<tr>
<td>Part-time</td>
<td>1 (16.7%)</td>
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<tr>
<td>Volunteer</td>
<td>1 (16.7%)</td>
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## Results

### Sample characteristics Parents

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<thead>
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</thead>
<tbody>
<tr>
<td>Age, M(SD)</td>
<td>56.5(2.6)</td>
</tr>
<tr>
<td>White, n(%)</td>
<td>6(100%)</td>
</tr>
<tr>
<td>Female, n(%)</td>
<td>6(100%)</td>
</tr>
<tr>
<td>Married, n(%)</td>
<td>5(83.3%)</td>
</tr>
<tr>
<td>Highest level of education, n(%)</td>
<td></td>
</tr>
<tr>
<td>College degree</td>
<td>3(50%)</td>
</tr>
<tr>
<td>Masters degree</td>
<td>2(33.3%)</td>
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<tr>
<td>Doctoral degree</td>
<td>1(16.7%)</td>
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<tr>
<td>Employment, n(%)</td>
<td></td>
</tr>
<tr>
<td>Full-time</td>
<td>3(50%)</td>
</tr>
<tr>
<td>Part-time</td>
<td>3(50%)</td>
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</tbody>
</table>
Results

Theme #1: Anxiety

“I would have liked to have had an easier transition, without last minute feeling like I’m out there rushing around to try to find somebody. And not being able to find somebody.”

“I can’t recall talking to any of the doctors about [transition]; we might this time since he will be 18… I don’t know what we’ll do.

“It is really hard finding a doctor that treats adults with disabilities.”

“It is a big deal, and I wish I could train some more independence into my person, but it’s risky.”

“I know, it’s a hard transition. It is hard for parents to transition in schools and everywhere; it’s hard.”

“…having a child with a disability, you choose your battles, and I got so many other ones right now <laughs>.”
Results

Theme #2: Isolation

“[I would] like a database of providers who have at least indicated that they’ve done some work to understand a particular condition; somebody that other parents would recommend.”

“So we’re thinking about that, and I would highly value my pediatrician’s recommendation for what to do about that.” (unable to obtain recommendation/referral from this pediatrician)

Having special needs makes transition harder “because there’s such a lack of information...we just have to go find it. I just have to cold call doctors' offices, you know ‘Do you have any other patients that have Down syndrome; can you handle it?’”
Results

Theme #3: Inadequate communication

“I found out that [the pediatrician] could no longer see my 21-year-old son when I called to make his annual appointment.”

“I would hope the family would bring [transition] up, but if they fail to, the pediatrician should. I mean if there is going to be a day when...the receptionist is going to refuse to make the appointment, you know, I mean warn them for goodness sake <laughs>.”

“[Would be easier] knowing ahead of time what we needed to know... because when you are transitioning like that, your thought processes are on numerous things, so there’s always something [forgotten] and it’s probably the most important thing.”

“I brought [transition] up to [the pediatrician], and that’s when he told us their pediatrics policy.”
Results

Theme #4: Parents required to advocate

“... because I have that capacity to know that if we didn’t like this doctor we’d just try another one.”

That’s my personal transition plan is go find another parent who has already has done this.

“I think [transition has] been as smooth as it can be, we’re pretty proactive, and I can understand that’s not everybody's personality.”
Results

Theme #5: Sadness upon leaving pediatric practice

“It was kind of bittersweet when we walked out of her door, because she’s been following her since birth.”

“From a parent point of view, it was just very emotional. Somebody that literally saved your child’s life….From a medical point of view, the pediatrician knows, they know which tests need to be done at what time; what immunizations, and what special needs they may need to look at. I can’t expect an adult general practitioner to know those things.”

“I think its going to be difficult since he has gotten such great care with his pediatrician.”
Results

Theme #6: Desirable characteristics of adult provider

“Let me just say that I like Dr. [name redacted] because he thinks outside the box, he was a little different than all the other doctors.”

“I want someone to be able to listen to what I’m trying to say is going on with him. Because I know him better than any medical book.”

“For me, I would like a provider that will speak to [young adult with DS]. That’s gonna listen for my input but for the initial conversation that’s gonna be looking at him and asking him the questions, because he is a person. He’s an adult now.”

“I don’t know, I really don’t know. I wish I could say, except for maybe more education in medical school or something.”

“…[specific provider] goes towards, through more natural remedies as opposed to going directly to medication, which is huge for us.”
Discussion

Recurring parental concerns

• Family-centered health care team
• Family-centered transition team
• Preparation
• Maintenance of pediatrician-like relationship
• Continuity of care
• Multiple specialty areas
• Insurance
Limitations

Sample was
• Homogenous
• Regional
• Small

Impact on generalizability
Implications for Practice

Improving the transition experience

Pediatric providers

Adult providers

Researchers
References


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