The Role of the Public Mental Health System in Caring for Children with Autism

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Presentation and Prevalence of ASD
- Characteristics of ASD (APA, 2000)
  - Range of impairments in communication and social interactions
  - Restrictive and stereotyped patterns of behavior
- Increase in prevalence (Fombonne, 2003)
  - As much as a 20-fold increase in last 40 years
  - Current estimates 4-6 per 1,000
- Parallel increase in number of children with ASD served in public service systems (e.g., US Department of Education, 2003)
  - Important to understand the service system for ASD

ASD in Public Service Systems
- Complexities in understanding and navigating service system
  - Differences across states
  - Debate about who pays and who qualifies for what services
- Children with ASD may be served in multiple public systems
  - Special Education
  - Mental Health

Special Education Services
- Entitled to receive all supports necessary for a free and appropriate education (1975 Education of All Handicapped Children Act)
- Autism as a separate eligibility category (exceptionality) under 1990 Individuals with Disabilities Education Act
- US Supreme Court - SE system not responsible for providing intervention to treat children’s disabilities, or maximize functioning (Lord & McGee, 2001)
- Children with ASD don’t qualify for SE services if educational performance is not “affected”

Public Mental Health Services
- Little info on whether and how children with ASD served in systems other than education
- 1% of children in SGCs with ASD (same as SE)
- Funding for public mental health services for ASD
  - EPSDT
    - Medicaid waivers (46 states with DD, 4 with autism-specific)
- Potential MH services for Children with ASD
  - Behavioral & psychotropic interventions
  - Treatment for co-occurring problems
- Some children may be served exclusively in MH services if they don’t qualify for SE services

Current Study
- The extent of the overlap between these MH & SE systems and relationships to service utilization and expenditures has not been examined
- Purpose of current study
  - Estimate the overlap among children with ASD served in both systems
  - Describe expenditures and services provided through the public mental health system for children with ASD
Data Sources
- Philadelphia County special education database
- Demographic and exceptionality information for all children receiving SE services in Philadelphia during 2002
- The Pennsylvania Medicaid database
- All adjudicated Medicaid MH claims for Philadelphia during 2002
- Claims information
  - Provider and service type
  - Associated diagnoses
  - Expenditures
- Individuals matched across databases
  - Name, sex and birth date

Sample
- All children ages 6-17 years on January 1, 2002 who received at least one of the following:
  - Medicaid-reimbursed MH service for a primary diagnosis of ASD (ICD-10 code 299)
  - OR
  - SE services through the autism exceptionality during the study year

Variables
- Special Education Exceptionality
  - 13 US Department of Special Education categories
- ASD diagnosis
  - Based on ICD-10 code 299 from the Medicaid claims
- Use of public MH services and related expenditures
- Demographic Characteristics
  - Age, race and sex abstracted from the claims and SE records

Analyses
- Cross-tabulations were used to calculate the number of children receiving
  - SE services in the autism exceptionality and in other exceptionals
  - MH services for a diagnosis of ASD and MH services for other diagnoses
  - Overlap among children in each category
- MH Expenditures
  - Sum of reimbursed charges per individual within each of the 7 categories of services
  - Chi square tests and ANOVA

Demographics & service use

<table>
<thead>
<tr>
<th></th>
<th>SE for autism (n=316)</th>
<th>SE &amp; MH for autism (n=129)</th>
<th>SE for autism, MH for other dx (n=57)</th>
<th>SE &amp; MH for autism, MH for other dx (n=16)</th>
</tr>
</thead>
</table>
| Age
|Less than 5 | 27.4% | 31.3% | 43.8% | 79.5% | 71.8% |
| 5-9 | 37.2% | 37.1% | 50.9% | 42.6% | 37.1% |
| 10-14 | 23.4% | 19.5% | 17.8% | 3.9% | 2.8% |
| 15-17 | 12.0% | 3.2% | 3.1% | 2.8% | 2.3% |
| Race
| Black | 10.7% | 13.8% | 14.9% | 7.9% | 12.8% |
| White | 42.0% | 35.7% | 45.6% | 56.5% | 37.6% |
| Hispanic | 18.2% | 21.3% | 21.6% | 4.0% | 2.6% |
| Other | 29.1% | 29.0% | 24.7% | 11.6% | 16.7% |
| % Receiving medication
| Yes | 45.8% | 50.7% | 63.4% | 64.2% | 60.0% |
| No | 54.2% | 49.3% | 36.6% | 35.8% | 40.0% |
Expenditures

<table>
<thead>
<tr>
<th>Expenditure</th>
<th>SE &amp; MH for autism (n=124)</th>
<th>SE for autism, MH for other disabilities (n=77)</th>
<th>MH for autism, SE in other categories (n=12)</th>
<th>MH for autism, SE in other categories (n=6)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inpatient care</td>
<td>$17,256 ($3,450)</td>
<td>$20,706 ($3,248)</td>
<td>$15,150 ($2,982)</td>
<td>$14,765 ($2,859)</td>
</tr>
<tr>
<td>ED visits</td>
<td>$329 ($57)</td>
<td>$52 ($35)</td>
<td>$105 ($68)</td>
<td>$0</td>
</tr>
<tr>
<td>Case management</td>
<td>$70 ($13)</td>
<td>$635 ($107)</td>
<td>$95 ($58)</td>
<td>$0</td>
</tr>
<tr>
<td>Partial hospitalization</td>
<td>$183 ($31)</td>
<td>$107 ($17)</td>
<td>$0 ($0)</td>
<td>$0</td>
</tr>
<tr>
<td>Home services</td>
<td>$510 ($100)</td>
<td>$222 ($42)</td>
<td>$0 ($0)</td>
<td>$0</td>
</tr>
<tr>
<td>Outpatient therapy</td>
<td>$274 ($54)</td>
<td>$0 ($0)</td>
<td>$0 ($0)</td>
<td>$0 ($0)</td>
</tr>
<tr>
<td>Total</td>
<td>$22,238 ($3,277)</td>
<td>$23,277 ($3,977)</td>
<td>$18,150 ($3,321)</td>
<td>$15,010 ($2,961)</td>
</tr>
</tbody>
</table>

Summary

- Complexity of the service system for children with ASD and potential gaps in services
  - Most served exclusively in one system
  - Many children receiving MH services for an ASD received either no SE services or SE through a category other than autism

- Patterns of expenditures
  - Suggest that children with highest expenditures may present with diagnostic complexity/intensive treatment need or there is confusion about appropriate diagnosis and care

- Importance of race/ethnicity in service utilization
  - AA children less likely to receive SE services under autism

Implications

- Importance of MH system
  - MH professionals have limited training in ASD treatment

- Need for coordination between systems
  - Improve efficiency and effectiveness of care
  - Identify gaps in care

- Future epidemiologic research
  - Limitations of relying on SE data

- Lack of knowledge about usual care for ASD

- Role of Medicaid in funding services for children in SE