2012 Indiana Parent/Family Needs Assessment Survey

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Indiana’s University Center for Excellence on Disabilities
www.iidc.indiana.edu
Participants

- 237 Families Participated
  - Respondents
    - Parents- 94%
    - Grandparents- 4%
    - Other- 2%
  - 65 Counties Represented
  - 15% of families have multiple children with an autism spectrum disorder
  - 87% of children live at home with parents
  - 15% have more than one child on the autism spectrum (up to 5)

- The Children
  - Gender of Child
    - Male-79%
    - Female- 21%
  - Mean Age- 13.3
  - Age Range- 2 to 43
  - Primary Disability

<table>
<thead>
<tr>
<th>Condition</th>
<th>In 2009</th>
<th>In 2006</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism</td>
<td>59%</td>
<td>57%</td>
</tr>
<tr>
<td>Asperger Syndrome</td>
<td>22%</td>
<td>25 %</td>
</tr>
<tr>
<td>Pervasive Developmental Disorder-Not Otherwise</td>
<td>14%</td>
<td>15 %</td>
</tr>
<tr>
<td>Other</td>
<td>5%</td>
<td>4%</td>
</tr>
</tbody>
</table>

- 60 % of the Children had a Co-Morbid Disability
  - ADHD- 35%
  - Mental Retardation- 15%
  - Learning Disability- 14%
  - Obsessive Compulsive Disorder- 16%
  - Anxiety Disorder- 27%
  - Seizure Disorder- 11%
  - Depression- 15%
  - Bi-Polar Disorder- 5%
  - Other- 23% (e.g., medical, neurological, genetic, and sensory disabilities)
Sources for Autism Related Information

- Information Sources for Families
  - Indiana Resource Center for Autism- 75%
  - Books- 89%
  - Internet- 87%
  - Newspaper/Magazines- 52%
  - Journal Articles- 53%
  - Television- 31%
  - Conferences/Workshops- 63%
  - Autism Society of America- 40%
  - Autism Society of Indiana- 51%
  - Local School District Autism Consultant- 26%
  - Private Therapists- 47%
  - School Personnel- 43%
  - Autism Support Group- 52%
  - Pediatrician- 44%
  - Other- 17% (Easter Seals Crossroad, Logan Center)

- Primary Information Source

<table>
<thead>
<tr>
<th>Source</th>
<th>2009</th>
<th>In 2009</th>
</tr>
</thead>
<tbody>
<tr>
<td>Internet</td>
<td>31%</td>
<td>35%</td>
</tr>
<tr>
<td>Books</td>
<td>16%</td>
<td>15%</td>
</tr>
<tr>
<td>Indiana Resource Center for Autism</td>
<td>11%</td>
<td>11%</td>
</tr>
<tr>
<td>Conferences/Workshops</td>
<td>7%</td>
<td>6%</td>
</tr>
<tr>
<td>School Personnel</td>
<td>3%</td>
<td>4%</td>
</tr>
<tr>
<td>Autism Society of America</td>
<td>1%</td>
<td>1%</td>
</tr>
<tr>
<td>Autism Society of Indiana</td>
<td>3%</td>
<td></td>
</tr>
<tr>
<td>Autism Support Group</td>
<td>9%</td>
<td>5%</td>
</tr>
<tr>
<td>Newspaper/Magazines</td>
<td>3%</td>
<td>1%</td>
</tr>
<tr>
<td>Journal Articles</td>
<td>1%</td>
<td></td>
</tr>
<tr>
<td>Pediatricians</td>
<td>5%</td>
<td>4%</td>
</tr>
<tr>
<td>Television</td>
<td>0%</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>5%</td>
<td>1%</td>
</tr>
</tbody>
</table>
School Issues

School Placement

- **82%** were in Public School (Charter)
  - In 2009: 78%
  - In 2006: 81%
  - In 2003: 74%
- **4%** were in Private School
  - In 2009: 4%
  - In 2006: 5%
  - In 2003: 13%
- **3%** were in College or at a University
  - In 2009: 1%
  - In 2006: 2%
  - In 2003: 4%
- **3%** were in Separate, Special Needs School
  - In 2009: 3%
  - In 2006: 4%
  - In 2003: 3%
- **3%** were in Home School
  - In 2009: 4%
  - In 2006: 4%
  - In 2003: 3%
- **1%** were in a Residential Program
  - In 2009: 4%
  - In 2006: 1%
  - In 2003: 2%

- **Classroom Placement**
  - **32%** were in Full-time General Education Classes
    - In 2009: 27%
    - In 2006: 26%
    - In 2003: 25%
  - **14%** were in Full-time Self-Contained Classes
    - In 2009: 19%
    - In 2006: 24%
    - In 2003: 26%
  - **1%** were in Full-time Resource Rooms
    - In 2009: 3%
    - In 2006: 2%
    - In 2003: 2%
  - **40%** were in Combined Placements
    - In 2009: 37%
    - In 2006: 48%
    - In 2003: 48%

- **Discipline**
  - **8%** had been Suspended in the Last Year
    - In 2009: 8%
    - In 2006: 9%
    - In 2003: 8%
  - **7%** had been Expelled
    - In 2009: 3%
    - In 2006: 2%
    - In 2003: 4%

- **Parental Satisfaction with Educational Programming**
  - **33%** were Dissatisfied or Very Dissatisfied
    - In 2009: 23%
    - In 2006: 26%
    - In 2003: 26%
  - **51%** were Satisfied or Very Satisfied
    - In 2009: 62%
    - In 2006: 56%
    - In 2003: 51%

- **“What additional service does your child need to be successful at school?”**
  - Social Skills Training - 64%
  - Occupational Therapy/Sensory Integration - 57%
  - Behavior Consultation - 49%
  - One-On-One Paraprofessional - 24%
  - Counseling - 23%
  - Speech Therapy - 9%
  - Intensive Early Intervention Behavior Therapy - 15%
Mental Health and Legal Issues

- **Mental Health**
  - 5% of the Children had Received a Short-term Crisis Management intervention at a Hospital in the Past Three Years
  - **In 2009** | **In 2006** | **In 2003**
  - 5% | 6% | 7%

- **Legal**
  - 1% of the Children had been Arrested or Charged With a Crime in the Past Three Years
  - **In 2009** | **In 2006** | **In 2003**
  - 1% | 1% | 2%

Employment Issues

- **Employment**
  - 81% of the Children (age 18 and older) were Unemployed
  - **In 2009** | **In 2006** | **In 2003**
  - 69% | 61%
  - 5% Work in Sheltered Workshops
  - 11% | 14%
  - 26% Work in Community Jobs
  - 20% | 25%
  - Those who work, work an average of 17 hours per week
  - 21% | 21%
  - Median Annual Income was $7,957
  - $7687 | $6,516

- “Does your son receive services through Vocational Rehabilitation? 44%”
- “How would you rate the quality of VR services for your son/daughter? 30% Good or Very Good. 41% Neutral. 29% Poor or Very Poor.”
- “What supports or services does your child need in finding and keeping a job?”
  - One-on-One Job Coach-74%
  - Social Skills Training- 66%
  - Behavior Consultation- 36%
  - Vocational Training- 52%
  - Occupational Therapy- 10%
  - Counseling- 26%
  - Speech Therapy- 7%
  - Physical Therapy- 3%
Insurance and Expenses

- General Expenses and Insurance Coverage

  - 18% had been Denied Insurance Coverage for their Child with ASD in the Past Three Years
  - 67% of the Families Purchased Private Services in the Past Three Years
  - “What do you estimate as the monthly cost of services that you need to successfully support your son or daughter at home?” $1005 (Mean)

- Insurance Coverage for Specific Services:

<table>
<thead>
<tr>
<th>Service</th>
<th>Full Coverage</th>
<th>Partial</th>
<th>No Coverage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Speech Therapy</td>
<td>11%</td>
<td>52%</td>
<td>37%</td>
</tr>
<tr>
<td>Occupational Therapy</td>
<td>10%</td>
<td>56%</td>
<td>33%</td>
</tr>
<tr>
<td>Social Skills Training</td>
<td>8%</td>
<td>19%</td>
<td>73%</td>
</tr>
<tr>
<td>Physical Therapy</td>
<td>11%</td>
<td>44%</td>
<td>44%</td>
</tr>
<tr>
<td>Counseling</td>
<td>12%</td>
<td>55%</td>
<td>33%</td>
</tr>
<tr>
<td>Behavior Consultation</td>
<td>18%</td>
<td>32%</td>
<td>50%</td>
</tr>
<tr>
<td>Assessment/Evaluation</td>
<td>21%</td>
<td>29%</td>
<td>50%</td>
</tr>
<tr>
<td>Medical Treatment</td>
<td>16%</td>
<td>59%</td>
<td>25%</td>
</tr>
<tr>
<td>Medications</td>
<td>15%</td>
<td>66%</td>
<td>19%</td>
</tr>
<tr>
<td>In-Home Behavior Therapy</td>
<td>18%</td>
<td>29%</td>
<td>53%</td>
</tr>
<tr>
<td>Sensory Integration</td>
<td>8%</td>
<td>15%</td>
<td>77%</td>
</tr>
<tr>
<td>Psychiatric/Medications</td>
<td>7%</td>
<td>75%</td>
<td>18%</td>
</tr>
</tbody>
</table>

Most have difficulty with accessing and paying for quality psychiatrists, behavior consultants, and occupational therapists.
### Medicaid Waiver

- **Applying**

<table>
<thead>
<tr>
<th>In 2009</th>
<th>In 2006</th>
<th>In 2003</th>
</tr>
</thead>
<tbody>
<tr>
<td>80% of Families were Aware of Medicaid Waivers</td>
<td>88%</td>
<td>82%</td>
</tr>
<tr>
<td>80% of the Families who Applied were on the Waiting List</td>
<td>66%</td>
<td>50%</td>
</tr>
<tr>
<td>20% of the Families who Applied are Currently Receiving Waivered Services (32 Families)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Autism Waiver</td>
<td>34%</td>
<td></td>
</tr>
<tr>
<td>Developmental Disability</td>
<td>13%</td>
<td></td>
</tr>
<tr>
<td>Support Service Waiver</td>
<td>53%</td>
<td></td>
</tr>
</tbody>
</table>

- **Length of Time on Waiting List**

  | Families on the Waiting List have been Waiting | 53 mo. | 44 mo. | 27 mo. |
  | an Average of 66 Months (up to 264 months). |
  | Families Currently Receiving Waivered Services were on the Waiting List an Average of 69 Months. |
  | Max was 15 years. |

- **Satisfaction with Waivered Services**

  | 35% were Satisfied with the “Availability and Quality of Waivered Services” | 45% | 46% | 50% |
  | 35% Stated that “Sufficient Funds are Available through Waivered Services to Purchase Needed Services” for Their Child with ASD | 44% | 41% | 63% |
  | 39% Stated That There Were a “Sufficient Number of Service Providers in Their Area” | 46% | 46% | N/A |
• Perceived Outcomes of Waiver

“As a Direct Result of the Waiver, our Son/Daughter…”

○ “Is Doing Better at Home”
  ▪ 72% Agree or Strongly Agree  2%  70%
  ▪ 16% Disagree or Strongly Disagree 15% 11%

○ “Is Doing Better at School”
  ▪ 23% Agree or Strongly Agree 35% 55%
  ▪ 31% Disagree or Strongly Disagree 24% 18%

○ “Behaviors Have Improved”
  ▪ 60% Agree or Strongly Agree 51% 66%
  ▪ 19% Disagree or Strongly Disagree 18% 12%

○ “Communication Has Improved”
  ▪ 47% Agree or Strongly Agree 45% 58%
  ▪ 25% Disagree or Strongly Disagree 20% 13%

○ “Is Doing Better in Social Situations”
  ▪ 57% Agree or Strongly Agree 54% 63%
  ▪ 16% Disagree or Strongly Disagree 16% 14%

○ “Is Better Able to Deal with Problems”
  ▪ 40% Agree or Strongly Agree 40% 54%
  ▪ 12% Disagree or Strongly Disagree 21% 16%

“As a Direct Result of the Waiver, our Family…”

○ “Has More Time for ourselves”
  ▪ 62% Agree or Strongly Agree 49% 62%
  ▪ 31% Disagree or Strongly Disagree 24% 23%

○ “Has More Time for Recreational Activities”
  ▪ 44% Agree or Strongly Agree 49% 52%
  ▪ 28% Disagree or Strongly Disagree 22% 24%

○ “Has More Time for Friends and Other Relatives”
  ▪ 38% Agree or Strongly Agree 38% 48%
  ▪ 31% Disagree or Strongly Disagree 27% 25%

○ “Has Been Better Able to Take Vacations”
  ▪ 18% Agree or Strongly Agree 32% 34%
  ▪ 47% Disagree or Strongly Disagree 31% 39%
<table>
<thead>
<tr>
<th>Survey Question</th>
<th>In 2009</th>
<th>In 2006</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Has More Time to Spend on Own Work and Chores”</td>
<td>55%</td>
<td>50%</td>
</tr>
<tr>
<td>• 55% Agree or Strongly Agree</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• 25% Disagree or Strongly Disagree</td>
<td></td>
<td></td>
</tr>
<tr>
<td>“Has Experienced Less Overall Stress”</td>
<td>53%</td>
<td>58%</td>
</tr>
<tr>
<td>• 53% Agree or Strongly Agree</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• 22% Disagree or Strongly Disagree</td>
<td></td>
<td></td>
</tr>
<tr>
<td>“Has Experienced Less Financial Worry”</td>
<td>55%</td>
<td>53%</td>
</tr>
<tr>
<td>• 55% Agree or Strongly Agree</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• 21% Disagree or Strongly Disagree</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>