Supports and Services for Kansans with ASDs:
Looking forward to a system that works.

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Autism Across the Lifespan
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DRC: 1977 to today ...

* DRC private, 501c3 nonprofit corporation
  Independent of government and disability service providers
* Official designated “Protection and Advocacy System” (P&A) for Kansas.
* Federal P&A powers to investigate abuse & neglect of people with disabilities – access to the person, their records and the place where they receive services
DRC: 1977 to today … (cont.)

* DRC obtains justice through disability rights advocacy – litigation, advocacy representation, self advocacy support and information & referral.

* DRC’s Core Services:
1. Legally-based Disability Rights Advocacy
2. Public Policy Advocacy / Education of Policymakers
3. Education, Training and Outreach
* Every state (and most territories) have a P&A.
* Everything I have described that DRC does, the P&A in every state does or can do.
* P&As have attorneys and advocates on staff to do legally-based advocacy for individual clients.
* P&As also educate the public and decision makers
* Vast majority P&As non-profit & separate from state govt.
* To find your State’s P&A go to www.ndrn.org
## DRC’s Growth in Core Services

### Training & Outreach

<table>
<thead>
<tr>
<th>Year</th>
<th>Number Trainings</th>
<th>Number Trained</th>
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<tbody>
<tr>
<td>2001</td>
<td>5</td>
<td>273</td>
</tr>
<tr>
<td>2002</td>
<td>6</td>
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<td>2003</td>
<td>17</td>
<td>846</td>
</tr>
<tr>
<td>2004</td>
<td>37</td>
<td>1,810</td>
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<tr>
<td>2005</td>
<td>58</td>
<td>2,215</td>
</tr>
<tr>
<td>2006</td>
<td>73</td>
<td>3,710</td>
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<tr>
<td>2007</td>
<td>51</td>
<td>5,105</td>
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<tr>
<td>2008</td>
<td>73</td>
<td>3,131</td>
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<tr>
<td>2009</td>
<td>69</td>
<td>3,001</td>
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### Public Education, Media and Communication

<table>
<thead>
<tr>
<th>Year</th>
<th>Radio/TV appearances</th>
<th>Newspaper Articles</th>
<th>Total Persons Getting Info</th>
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<tbody>
<tr>
<td>2002</td>
<td>3</td>
<td>5</td>
<td>442,000</td>
</tr>
<tr>
<td>2003</td>
<td>10</td>
<td>13</td>
<td>1.5m</td>
</tr>
<tr>
<td>2004</td>
<td>10</td>
<td>28</td>
<td>2.8m</td>
</tr>
<tr>
<td>2005</td>
<td>25</td>
<td>160</td>
<td>21.8m</td>
</tr>
<tr>
<td>2006</td>
<td>63</td>
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<td>2007</td>
<td>16</td>
<td>26</td>
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<tr>
<td>2008</td>
<td>10</td>
<td>4</td>
<td>4.5m</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td><strong>Total Since 2003</strong></td>
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<tr>
<td></td>
<td></td>
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<td><strong>108</strong></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td><strong>350</strong></td>
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<tr>
<td></td>
<td></td>
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<td><strong>71.55 Million</strong></td>
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### Outcomes on Customer Satisfaction Ratings

<table>
<thead>
<tr>
<th>Year</th>
<th>FY 04</th>
<th>FY 05</th>
<th>FY 06</th>
<th>FY 07</th>
<th>FY 08</th>
<th>FY 09</th>
<th>FY 10</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>89%</td>
<td>95%</td>
<td>95%</td>
<td>90%</td>
<td>95%</td>
<td>95%</td>
<td>95%</td>
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### Legally-Based Disability Rights Advocacy Services

<table>
<thead>
<tr>
<th>Services Provided</th>
<th>FY 03</th>
<th>FY 04</th>
<th>FY 05</th>
<th>FY 06</th>
<th>FY 07</th>
<th>FY 08</th>
<th>FY 09</th>
<th>FY 10</th>
<th>FY 11</th>
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<tbody>
<tr>
<td>Legal Representation:</td>
<td>4</td>
<td>46</td>
<td>87</td>
<td>102</td>
<td>125</td>
<td>115</td>
<td>90</td>
<td>82</td>
<td>74</td>
</tr>
<tr>
<td>Advocacy &amp; Self-Advocacy:</td>
<td>260</td>
<td>360</td>
<td>798</td>
<td>780</td>
<td>792</td>
<td>965</td>
<td>1216</td>
<td>1445</td>
<td>1499</td>
</tr>
<tr>
<td>Information and Referrals:</td>
<td>623</td>
<td>571</td>
<td>295</td>
<td>204</td>
<td>390</td>
<td>377</td>
<td>299</td>
<td>277</td>
<td>269</td>
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Focus areas

• An advocate’s overview of the historical development of Community Based supports and treatment programs for people with ASDs.

• Current climate under Medicaid Reform.

• What we want for the future.
Too many kids on the Autism Spectrum and children/youth with other serious disabilities are in restrictive settings in school and in out of home placements due to manifestations of their disorder(s).

- Children with ASDs are very frequently subjected to restraint and seclusion
- Schools, families, and multidisciplinary community service providers must work together under a system of care
- Efforts to improve coordination of services and supports would greatly reduce the risks to kids, families, educators, and service providers
A Systems of Care approach for children with ASDs and Dual Diagnosis

**Applied Behavior Analysis** is the process of systematically applying interventions based upon the principles of learning theory to improve socially significant behaviors to a meaningful degree, and to demonstrate that the interventions employed are responsible for the improvement in behavior (Baer, Wolf & Risley, 1968; Sulzer-Azaroff & Mayer, 1991).

- The problem for policy makers with funding ABA is that it isn’t a single service, it’s a *process of applying interventions* that requires ongoing planning and coordination of services.
A Systems of Care approach for children with ASDs and Dual Diagnosis

• A system of care is a coordinated network of community-based services and supports that are organized to meet the challenges of children and youth with serious mental health needs and their families.

• Systems of care is not a program — it is a philosophy of how care should be delivered. Systems of Care is an approach to services that recognizes the importance of family, school and community, and seeks to promote the full potential of every child and youth by addressing their physical, emotional, intellectual, cultural and social
Autism Waiver

• Only for children ages 3 to 5, with the opportunity to receive services until age 8.
• Very limited access to Autism Specialists in most areas of the state.
• Waivers are important, they give access to a Medical Card so that families can receive necessary treatments (Speech, OT, PT, Doctor’s Visits)
Positive Behavior Supports (PBS)

Positive Behavioral Support (PBS) is an empirically validated, function-based approach to eliminate challenging behaviors and replace them with prosocial skills.

Use of PBS decreases the need for more intrusive or aversive interventions (i.e., punishment or suspension) and can lead to both systemic as well as individualized change.
A Systems of Care approach for children with ASDs and Dual Diagnosis

• Habilitative services — ex. Supportive Home Care (MR/DD Waiver service)

• Rehabilitative services — ex. Community Psychiatric Support and Treatment & Crisis Intervention (Mental Health Community Based Services)

• Physical therapy, Occupational Therapy, Speech therapy

• All services coordinated with a Positive Behavior Plan
Assistive communication

• It’s the other missing piece for kids with ASDs who also are verbally limited or nonverbal
• More/better devices out there than only PECS
• Medicaid vs IDEA – who pays?
• Early identification of the need for assistive/augmentive communication devices during Kan-B-Healthy screens is important
Courts have recognized states responsibility to provide HCBS to children with Autism

A federal court has held that behavioral services for autism are a covered EPSDT benefit. In *Chisholm v. Hood*, 133 F.Supp.2d 894 (E.D. La. 2001), the court held that Louisiana was required to provide community-based behavioral and psychological services to Medicaid-eligible children diagnosed with autism. The services at issue included behavioral interventions used to teach children daily functional skills. The court found that these services “undeniably constituted medical assistance” as defined in the Medicaid Act. According to the court, the services fell under the definition of at least two of the service categories described in the Act; rehabilitation services and remedial services.
Courts have recognized states responsibility to provide HCBS to children with Autism

“Moreover, the court found that the services were necessary to “correct or ameliorate” the plaintiffs’ conditions, based upon provider testimony. Accordingly, the court held that the services qualify as EPSDT services, and, thus, that the state must, pursuant to the federal EPSDT mandate, provide the services to class members with autism.”
Reduce inappropriate and long stays in residential facilities

- Long and inappropriate stays often result in increased depressive symptoms, more acting out behaviors, more psychotropic medications, and more restraint and seclusion
- RT should be seen as short term respite option
- RT has the best outcomes when focus is on family participation and it is used as a rallying point for community based supports and service providers
- Community Based Services Teams (CBSTs)
Medicaid Reform in 2011

• Large reforms are currently being considered by Governor’s office and state agencies.

• The stated goal is to ‘Improve health outcomes, while at the same time making Medicaid more cost efficient’ and expanding Managed Care.

• What should we push to see from Reforms?
Medicaid Reform in 2011

Our state Government is up against two very strong sections of the law.

1. EPSDT (Early Periodic Screening Diagnosis and Treatment).

2. The Olmstead Decision
Care Coordination

Comprehensive care coordination enables people with special health care needs, especially those with chronic conditions, to navigate through complex Medicaid managed care systems.

A relatively new trend, care coordination can include brokering for social support and medical services, breaking down boundaries between systems of care, assisting families with transportation and telephones—in short, whatever it takes to keep patients at home and healthy. Although care coordination services are growing in significance for vulnerable groups, little is known about states’ experience designing and implementing them.
Managed Care?

• If done well, expanded Managed Care has the potential to solve some of our access problems.
• There is also serious risk involved.
• ‘Carve-in’ vs. ‘Carve-out’ debate.

• What’s the latest news?
Policymakers need to hear from us, now.

• Tell them about the problems you’ve had getting access to services.

• Then, give them the solutions.
  - Improved Care Coordination
  - Better access to intensive behavioral treatment services.
  - Lower institutionalization, happier and healthier families.
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