Parenting with Intellectual and/or Developmental Disabilities (IDD) in Washington State

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LEND Core Seminar

**Seminar Topics**

- Background to Parenting with IDD
- Washington State Efforts & Concerns of Individuals with IDD
- Arc Trust Fund of Washington Project
- Relevant Laws
- Discussion

**Background**

- Parents with intellectual/developmental disabilities (IDD):
  - Are overrepresented in the child protective services (CPS) system (Azar, Stevenson & Johnson, 2012).
  - Experience an increased risk for having their child removed from the home (Azar & Read, 2009; Callow, Buckland & Jones, 2011; National Council on Disability, 2012).
  - Removal rates where the parent has an intellectual disability is 40 percent to 80 percent. (National Council on Disability, 2012).
Background

□ Reasons for the removal of the child may stem from assumptions made by social systems caseworkers and hospital personnel.
   □ The National Council on Disability found that, "(M)any removals occur simply on a categorical or diagnostic basis, without any individualized assessment or observation of parenting" (2012).
   □ "Frequently, the only basis for removal is the parent’s disability and a baseless speculative concern that the parent will not be able to provide practically, developmentally, or in some other way for the child (Callow, et al. 2011)."

Background

□ Research to date indicates reasons for the high rate of interaction with the CPS systems for these families and termination of parental rights.
   □ A systemic, attitudinal issue and unrelated to the availability of supports for these families (Callow, et. al, 2011).
   □ CPS system typically fails to intervene appropriately with parents with IDD, including implementing the use of developmentally sensitive intervention techniques and improved linkages with other systems outside of CPS (Azar & Read, 2009).

Parents with IDD in Washington State

□ Historical Perspective
   □ "Challenges in Providing Services to Parents with Developmental Disabilities” Conference at CHDD – October 10 & 11, 1991
   □ Kennedy Foundation Grant – 1995

□ Legislative and State Efforts:
   □ HB 2616: Dependency Proceedings and Parents with DD (2014)
   □ New Waiver: Individual Family Services (1:1 supported parenting)
   □ DDA is training public health nurses and coordinating services.
   □ Community of Practice DDC Workgroup meeting – April 2015
      □ Individuals expressed concerns that included:
         □ Fear of CPS involvement leads decision to parent
         □ Being afraid to ask for help – raises flags and brings attention to the family
Arc Trust Fund Project

- The purpose was 4-fold:
  - To provide the preliminary data needed to more accurately determine the prevalence of involvement with CPS at the birth of their child for parents with IDD.
  - To describe the self-reported issues encountered by parents with IDD, their support network (including case resource managers) and CPS investigators to parenting with intellectual disabilities.
  - To summarize the current state of the science in supporting parenting with IDD.
  - Make recommendations for improving opportunities for successful parenting by parents with IDD.

Four Research Questions

- What is the prevalence of Washington State CPS investigations of parents with IDD at the birth of their child?
- What reasons are listed for the initiation of a Washington State CPS investigation of reported abuse or neglect at the birth of the child?
- What supports are available to parents with IDD in Washington State, beginning with a pregnancy and birth of the child?
- What is the current state of the science in supporting parents with IDD beginning with a pregnancy and birth of a child?

Procedures

- Questions 1 & 2:
  - What is the prevalence of CPS investigations of parents with IDD at the birth of their child?
  - What reasons are listed for the initiation of a CPS investigation of reported abuse or neglect at the birth of the child?
- Secondary Analysis of the 2014 National Data Archive on Child Abuse and Neglect Child File Dataset, known as NCANDS.
  - Child specific data of all investigations, demographics of child and perpetrators, types of maltreatment, risk factors and services provided.
  - Risk factor for caregiver includes "mental retardation."
  - Cannot cross the NCANDS data set with other records (DDA or CPS).
Procedures

- Questions 3 & 4:
  - What supports are available to parents with IDD in Washington state, beginning with a pregnancy and birth of a child?
  - What is the current state of the science in supporting parents with IDD beginning with a pregnancy and birth of a child?
- 15 key informant interviews with CPS investigators, DDA case resource managers, parents with IDD and their family and/or members of their support network to describe their experiences.
- Review literature 2010-2016, emphasis on current best practices in supporting parents with IDD.

NCANDS Data Analysis
Findings from Washington State

CPS Involved Children in 2014

Disposition of the Investigation
Key Findings

- All 7108 records had missing data for the following items that could have been used to identify parents with IDD:
  - Caretaker – Required Special Services (disabled)
  - Caretaker – Mental Retardation*

*Term used in the NCANDS dataset
What We Learned from Interviews

Limitations: sample size too small to generalize and inability to interview CPS staff.

DDA Case Manager (1)
- They love their children, they want to do their best but don’t have the skills or resources. But if they had that extra support, they could do pretty well.
- Education is necessary and it must be long-term.
- Supports currently available are minimal and becoming less with waiver changes.
- DDA and CPS do not communicate much.

Parents (mothers) (2)
- I just want to have services in place so that there is not a disabled person that has to go through what I did.
- The thing DDA helped me with was having a service provider that came in almost every day.
- Grief related to losing custody of their child
- Confusion re: The Child Dependency process and their attorney’s role.
- Lack of necessary supports.

Recommendations
- Additional research with parents, CPS and DDA staff needed.
- Improve communication, cooperation between CPS and DDA.
- Monitor existing waivers, explore new ones to support parenting.
- Develop and provide support throughout child’s life as needed.
- Continue CLEs for attorneys on the rights of parents with IDD.
- Develop educational materials for health care staff on rights of parents with IDD.
- Develop parenting classes for K-12 students as part of life skill programs.
- Explore foster grandparent programs.
Next phase ... if funding is found

- In partnership with Partners for our Children (POC) School of Social Work program.
- They have 14 years of birth records for Washington State and are following the children through age 18 to track any CPS involvement.
- They agreed to do search for mothers with ICD-9 codes indicating ID and what CPS involvement occurred with the children.

ICD-9 Codes and Characteristics of Mothers

<table>
<thead>
<tr>
<th>ICD-9 CODE</th>
<th>DESCRIPTION</th>
<th>NUMBER MOTHERS</th>
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<tbody>
<tr>
<td>317</td>
<td>Mild ID</td>
<td>18</td>
</tr>
<tr>
<td>318</td>
<td>Moderate ID</td>
<td>3</td>
</tr>
<tr>
<td>319</td>
<td>Unspecified ID</td>
<td>39</td>
</tr>
<tr>
<td>758</td>
<td>Down Syndrome</td>
<td>14</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td></td>
<td><strong>74</strong></td>
</tr>
</tbody>
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CPS Involvement with those 74 families

- Within the first year: 29
- Within in the first five years: 44
- Analysis in progress:
  - Disposition and placement of those involved with CPS
  - Person reporting the concerns to CPS
Legal Underpinnings to the Right to Parent

- US Constitutional Right to Marry and to Parent (right to liberty).
- Limitations on the right and parameters of parental power and authority (decision-making) related to their children have been set by state law.
- All states have a CPS agency with the authority to investigate reports of child abuse and/or neglect (child maltreatment) and intervene in the child-parent relationship under certain conditions.
- CPS has the authority to 1) remove a child from parents and 2) terminate parental rights with judicial authorization.
- CPS standard is “best interest of the child.”
- All parents (including those with disabilities) are required to “parent” within the societal standards set by the laws protecting children from maltreatment.
- CPS mandatory reporting laws place ethical/professional/legal obligations on certain individuals to report when there is “a reasonable cause to believe” that a child is being maltreated.

Civil Rights of Individuals with Disabilities

- Americans with Disabilities Act (ADA) of 1990
  - Title II of the ADA covers services of state and local government – e.g., DDA, CPS, state and local courts.
  - Section 504 of the Rehabilitation Act of 1975 recipients of federal 
    - Prohibit disability based discrimination:
      - denial of opportunities to benefit from services;
      - failure to reasonably modify policies and procedures;
      - impose methods of administration that have the effect of discriminating on the basis of disability.
- State laws against discrimination:
  - RCW 49.60 Washington State Law Against Discrimination.
  - Typically mirror ADA although some provide broader coverage

DOJ and HHS Investigation and Ruling

- Massachusetts Department of Children and Families (DCF) found to have “committed extensive, ongoing violations of Title II and Section 504 by discriminating against Sara Gordon on the basis of her disability and denying her opportunities to benefit from supports and services numerous times over the past two years, including her existing family supports.”
- Sara Gordon, young woman with DD, gave birth to a daughter in 2011. Two days later DCF removed the child from the hospital. Ms. Gordon lives with her parents who intended to continue to support their daughter including parenting.
- DCF acted based on Ms. Gordon’s disability without consideration of implementing appropriate family-based support services.
- DOJ/HHS ordered DCF to immediately implement services and supports to Ms. Gordon for sufficient time for reunification to occur.

International Human Rights

  - Broad statement of rights of all individuals to have access to full panoply of rights – including rights to marry and parent.
  - Responsibility of government to provide reasonable modifications/accommodations to exercise those rights.
  - Right to supported decision making (Article 12)

- UN Declaration on the Right to Development (UNDRD) 1986
  - “Development defined as an inalienable human right by virtue of which every human person and all peoples are entitled to participate in, contribute to, and enjoy economic, social, cultural and political development, in which all human rights and fundamental freedoms can be fully realized.”

Discussion Topics

- How to balance “best interests” of children and rights of individuals with IDD to parent?
- Role of societal assumptions re: capabilities of individuals with IDD in shaping state policy?
- Questions/concerns you have that need answers re: research needed?
- Comments?

References

- Disability, N. C. a. (2012). Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children NCD.