THE INTERSECTION OF AGING AND INTELLECTUAL & DEVELOPMENTAL DISABILITIES

PRESENTED BY
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INTELLECTUAL & DEVELOPMENTAL DISABILITIES

Developmental Disability (DD):
- Occurs before age 22, persists indefinitely
- Chronic mental or physical impairment resulting delay or failure to achieve normal developmental milestones.
- Causes significant functional impairment in areas of independent living, self care, receptive and expressive language, learning, and economic self sufficiency.

Intellectual Disability (ID):
- Broad term that refers to mental capacity below normal
- Limitations both in intellectual functioning (reasoning, learning, problem solving) and adaptive behavior (covering many social & practical skills)
- Due to any cause, before age 18
- Replaces “Mental Retardation”

by Dr. Jenny Roraback-Carson of UW/Harborview Medical center
I/D DISABILITIES & AGING

- Defining intellectual/developmental disabilities
- I/DD and aging
## Developmental Disability Administration Eligible Conditions Specific to Age and Type of Evidence

<table>
<thead>
<tr>
<th>Condition</th>
<th>0-3</th>
<th>4-9</th>
<th>10-17</th>
<th>18 and older</th>
</tr>
</thead>
<tbody>
<tr>
<td>Developmental Delays</td>
<td>X</td>
<td></td>
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<td></td>
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<tr>
<td>Medically Intensive Home Care Program</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
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<tr>
<td>Intellectual Disability (ID)</td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
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<tr>
<td>Cerebral Palsy</td>
<td>X</td>
<td>X</td>
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<td>X</td>
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<td>Epilepsy</td>
<td>X</td>
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<td>X</td>
<td>X</td>
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<tr>
<td>Autism</td>
<td>X</td>
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<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Another neurological or other condition similar to Intellectual Disability</td>
<td>X</td>
<td></td>
<td>X</td>
<td>X</td>
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</tbody>
</table>
HISTORICAL CONTEXT

Institutionalization vs Community Based Services
WHO WE SERVE

CULTURALLY & LINGUISTICALLY DIVERSE FAMILIES WHO HAVE LOVED ONES WITH DEVELOPMENTAL/INTELLECTUAL DISABILITIES & SPECIAL HEALTH CARE NEEDS

MISSION

EQUAL ACCESS TO CULTURALLY AND LINGUISTICALLY APPROPRIATE INFORMATION, RESOURCES & SERVICES
SERVICES FOR CLD FAMILIES

FAMILY SUPPORT SERVICES

**Individualized family support**
- Language & cultural support
- Interpreters provided if we don’t have FSS who speaks that family's language at ODMF
- Special Education & systems navigation
- Disability related resources

**Parent support groups**
- Korean, Cantonese, Mandarin, Somali, Spanish, Cambodian, African American, Vietnamese & Arabic
- Family-to-Family support
- Information chosen by families & sessions facilitated by families

**Parent training workshops**
- Collaboration with school
- Collaboration with professionals in community
- Commonly identified topics by parents

* Both parent support groups & workshops provide language support, childcare, transportation stipends, & food for free
CURRENT PROGRAMS

**Advocacy Programs**
- **Target**: Self-advocates & Parents
- System Advocacy
- Language Access

**Youth Program**
- **Ages**: 16-24
- Pre Employment Training
- Leadership & Advocacy Training
- Pathway to Graduation & Beyond
- After School Activity

**Youth Transition Program**
- **Ages**: 16-24
- Transition Information & Resources
- Professional Cultural Competency Training

**Adult & Senior**
- **Ages**: 18+
- Community Living Connection
- Senior Caregiver Program

**Early Learning**
- **Ages**: 0-6
- Parent training workshops
- Play and Learn sessions

**Homelessness Prevention**
- Flexible funding to meet needs
- Case management
MISSION

THE ARC OF KING COUNTY PROMOTES AND PROTECTS THE HUMAN AND CIVIL RIGHTS OF PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES PROMOTING THEIR FULL INCLUSION TO LIVE, LEARN, WORK, AND PLAY IN THE COMMUNITY – IMPROVING THE QUALITY OF LIFE FOR US ALL.
The Arc
King County

Contact Us:
English: 206-829-7053
Ask@arcofkingcounty.org

Spanish: 206-829-7030
Preguntas@arcofkingcounty.org

Website: www.arcofkingcounty.org
Supporting the Individual  Supporting their Parents/Caregivers
SUPPORTING THE INDIVIDUAL

**Considerations**

- Where does the person live now? How long will they live there?
- What kind of care or support do they need right now?
  - Who provides their care now? How long can they continue providing care?
- How might their care needs change as they age? How might their support need to change to meet their needs?
- Are there signs of dementia or Alzheimer’s?
  - ~50% of people with Down syndrome develop dementia/Alzheimer’s. Symptoms tend to develop in their 50s or 60s, earlier than the general community.
SUPPORTING THE INDIVIDUAL

Strategies

- Assume competence
- “Work with me not on me”
- Dignity of Risk
- Focus on strengths
- Recognize and engage with their communication strategies
- Use combination of communication modalities (e.g. speaking, writing, pictures, videos, use of check lists, etc.)
- Be direct. Avoid euphemisms, slang, etc.
- Break things into smaller steps
- Expect repetition
SUPPORTING THE INDIVIDUAL

Resources & Services

- Developmental Disabilities Administration (DDA)
- Home & Community Services (HCS)
- Aging & Long Term Care (ALTSA)
- Division of Vocational Rehabilitation (DVR)
- Representative Payee
- Guardianship or DPOA
- “Letting Grow” Grief Support for People with I/DD at Providence Hospice
Considerations & Strategies

- “All I have to do is outlive my child…”
  - Kindly remind them that parents are not supposed to outlive their children. Validate their fears, and encourage them to create a plan for when they are gone. Pay attention to any signs that may suggest harm to the individual with I/DD.

- “No one can take care of my child better than I can…”
  - Validate this feeling. Encourage them to think about what will happen if they are not there anymore. Remind them that it is better to start planning early so that they can ensure whoever does provide care can learn from them.
Considerations & Strategies (continued)

- “My primary income is from providing care for my child…”
  - Acknowledge this tension. Focus on the individual with I/DD’s needs to have a plan and predictability rather than have too many changes happen at once. Support parents to explore resources for their own financial security.

- “Their siblings will just take them in…”
  - Is this what the person with I/DD wants? Is this what the siblings want? Is everyone on board with the succession plan?
SUPPORTING AGING PARENTS/CAREGIVERS

Resources

- Alzheimer’s Association of WA has caregiver support groups for caregivers of individual with I/DD experiencing dementia
- LifeSPAN (Lifetime Secure Personal Assistance Network)
- The Arc of King County’s closed Facebook Group: “Aging Parents of Sons and Daughters with Disabilities”
- The Arc of King County’s “Future Planning Organizer”
- The Arc and Open Doors provide individualized future planning support and group workshops.
**CONTACT US**

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www.multiculturalfamilies.org

To refer a family, please visit our website home page and fill out a referral form.