HEALTH ADVOCACY
It’s everyone’s responsibility!

David A. Ervin, BSc, MA, FAAID
The Resource Exchange
Developmental Disabilities Health Center
• 4.71 million humans in the US have an IDD
• $65.2 billion in total public spending in LTSS for IDD
  – $39.2 billion Medicaid waiver and related
  – $10.4 billion in ICF/IID
  – $15.6 billion non-Medicaid
Cost of healthcare for Americans with IDD

- $4.24 billion
  - 39% medication ($1.7 billion)
Context

National LTSS Spending

- $65.2 billion IDD services (19-20%)
- 12 million ppl total 2010
- 27 million ppl total by 2050
Context

- 741,285 HCBS Waiver participants
- Nearly 900,000 living with aging caregivers

![Health Chart]

The proportion of people described as having poor health.

<table>
<thead>
<tr>
<th>Year</th>
<th>Excellent or Very Good</th>
<th>Fairly Good</th>
<th>Poor</th>
<th>Don't Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>2008-09</td>
<td>53%</td>
<td>40%</td>
<td>4%</td>
<td>2%</td>
</tr>
<tr>
<td>2009-10</td>
<td>53%</td>
<td>40%</td>
<td>5%</td>
<td>2%</td>
</tr>
<tr>
<td>2010-11</td>
<td>53%</td>
<td>41%</td>
<td>5%</td>
<td>1%</td>
</tr>
<tr>
<td>2011-12</td>
<td>54%</td>
<td>40%</td>
<td>5%</td>
<td>1%</td>
</tr>
<tr>
<td>2012-13</td>
<td>56%</td>
<td>38%</td>
<td>4%</td>
<td>1%</td>
</tr>
<tr>
<td>2013-14</td>
<td>56%</td>
<td>39%</td>
<td>4%</td>
<td>1%</td>
</tr>
<tr>
<td>2014-15</td>
<td>56%</td>
<td>38%</td>
<td>4%</td>
<td>3%</td>
</tr>
</tbody>
</table>
BMl - Body Mass Index

The proportion of people who maintain healthy habits in such areas as smoking, weight, and exercise.

<table>
<thead>
<tr>
<th>Year</th>
<th>Underweight</th>
<th>Normal Weight</th>
<th>Overweight</th>
<th>Obese</th>
</tr>
</thead>
<tbody>
<tr>
<td>2008-09</td>
<td>6%</td>
<td>32%</td>
<td>33%</td>
<td>29%</td>
</tr>
<tr>
<td>2009-10</td>
<td>5%</td>
<td>34%</td>
<td>30%</td>
<td>31%</td>
</tr>
<tr>
<td>2010-11</td>
<td>5%</td>
<td>32%</td>
<td>34%</td>
<td>28%</td>
</tr>
<tr>
<td>2011-12</td>
<td>9%</td>
<td>30%</td>
<td>33%</td>
<td>28%</td>
</tr>
<tr>
<td>2012-13</td>
<td>6%</td>
<td>31%</td>
<td>29%</td>
<td>12%</td>
</tr>
<tr>
<td>2013-14</td>
<td>5%</td>
<td>33%</td>
<td>33%</td>
<td>29%</td>
</tr>
<tr>
<td>2014-15</td>
<td>6%</td>
<td>32%</td>
<td>34%</td>
<td>12%</td>
</tr>
</tbody>
</table>

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Hitting Close to Home...

- Obesity Costs
  - heart disease, hypertension, diabetes, hyperlipidemia

<table>
<thead>
<tr>
<th>Model-adjusted median and mean health care expenditures by BMI status.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neither Overweight nor Obese (BMI &lt; 25)</td>
</tr>
<tr>
<td>Median</td>
</tr>
<tr>
<td>----------</td>
</tr>
<tr>
<td>Non-IDD Overall</td>
</tr>
<tr>
<td>Non-IDD Per user</td>
</tr>
<tr>
<td>IDD Overall</td>
</tr>
<tr>
<td>IDD Per user</td>
</tr>
</tbody>
</table>

Note: “Overall” includes expenditures that are zero, whereas “per user” only includes non-zero expenditures.

67-73% higher! 43-45%
### Prevalence of mental ill health in the populations with and without intellectual disabilities

<table>
<thead>
<tr>
<th>Age group</th>
<th>Intellectual disabilities, n/N (%)</th>
<th>Other people, n/N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male N=15 149</td>
<td>Female N=11 200</td>
</tr>
<tr>
<td>0–15</td>
<td>450/3253 (13.8)</td>
<td>218/1981 (11.0)</td>
</tr>
<tr>
<td>16–24</td>
<td>492/2501 (19.7)</td>
<td>281/1661 (16.9)</td>
</tr>
<tr>
<td>25–34</td>
<td>436/2025 (21.5)</td>
<td>286/1450 (19.7)</td>
</tr>
<tr>
<td>35–44</td>
<td>529/2209 (23.9)</td>
<td>398/1650 (24.1)</td>
</tr>
<tr>
<td>45–54</td>
<td>653/2456 (26.6)</td>
<td>490/1845 (26.6)</td>
</tr>
<tr>
<td>55–64</td>
<td>442/1539 (28.7)</td>
<td>363/1324 (27.4)</td>
</tr>
<tr>
<td>65–74</td>
<td>212/805 (26.3)</td>
<td>208/762 (27.3)</td>
</tr>
<tr>
<td>75+</td>
<td>111/361 (30.7)</td>
<td>137/527 (25.9)</td>
</tr>
<tr>
<td>All ages</td>
<td>3325/15 149 (21.9)</td>
<td>2381/11 200 (21.3)</td>
</tr>
</tbody>
</table>
Mental Health

[Bar chart showing the percentage of females and males with mental health issues by age group and intellectual disabilities status.]

- Females
  - 75+:
  - 64-74:
  - 55-64:
  - 45-54:
  - 35-44:
  - 25-34:
  - 16-24:
  - 0-15:

- Males
  - 75+:
  - 65-74:
  - 55-64:
  - 45-54:
  - 35-44:
  - 25-34:
  - 16-24:
  - 0-15:

Legend:
- No intellectual disabilities
- Intellectual disabilities
Takes medications to treat mood disorders anxiety and/or psychotic disorders 2014-15

The proportion of people who currently take medications to treat mood disorders, anxiety and/or psychotic disorders

2014-15

Percent

51%

49%

No  Yes
Polypharmacy

People with polypharmacy are more likely to die than people without.
Culturally competent health home for people with IDD.

<table>
<thead>
<tr>
<th>FQHC</th>
<th>Mental Health Center</th>
<th>RCCO/ACC</th>
<th>IDD Provider</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical</td>
<td>Mental health/Psych</td>
<td>Care Coordination</td>
<td>Care Int., Behavioral</td>
</tr>
<tr>
<td>Cost-based reimb.</td>
<td>Medicaid state plan</td>
<td>Medicaid pm/pm</td>
<td>GF, FFS, Med Waiver</td>
</tr>
</tbody>
</table>
DDHC Patients

Sample = 576

- 66.3% high or very high risk
- 0.64 ED visits
- $42,188 tot. Medicaid
  - Polypharm (data as of 2/28/2017)

Non-DDHC

Sample = 1077

- 34.1% high or very high risk
- 0.30 ED visits
- $54,065 tot. Medicaid (+28%)

<table>
<thead>
<tr>
<th></th>
<th>2015</th>
<th>2016</th>
<th>2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>DDHC</td>
<td>$2114</td>
<td>$2448</td>
<td>$2418</td>
</tr>
<tr>
<td>Non-DDHC</td>
<td>$2675</td>
<td>$3019</td>
<td>$3222</td>
</tr>
<tr>
<td><strong>dif</strong></td>
<td>&lt;21.0%</td>
<td>&lt;18.9%</td>
<td>&lt;25.0%</td>
</tr>
</tbody>
</table>

Data are as of 12/31/2017 unless noted.
Weight Loss

POWERSforID¹

- Avg. weight loss = 5.6 (control = +2.2)

HRQoL

MFP Q: “Are you happy with the way you live your life?”

<table>
<thead>
<tr>
<th>DDHC ≥ 6 mos.</th>
<th>DDHC 0-6 mos.</th>
</tr>
</thead>
<tbody>
<tr>
<td>76.4%</td>
<td>59.2%</td>
</tr>
</tbody>
</table>

p=0.088

¹ Rehabilitation Research and Training Center on Developmental Disabilities and Health (RRTCDD), funded by the United States Department of Health and Human Services, Administration for Community Living (ACL), National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) Grant # 90RT5020-03
Cross sectional view of the DDHC Population 2013-2017 (Jan 1 thru Dec 31)
Oh. My. Gawd.
• It’s as bad as we have always known!

• Culturally competent care more likely to deliver better health outcomes
  • Different, less expensive healthcare utilization
  • Improved clinical/bio-markers
  • Health related quality of life

• Interdisciplinary, integrated health neighborhoods
WHAT DO WE WANT?  HEALTH EQUITY

WHEN DO WE WANT IT?  NOW!
Barriers

• Financing Systems
  – High costs (disproportionality)
  – Conveyor Belt medicine
  – Disincentives to integration
  – Bi- and Tri-furcated systems of care

• System Capacity
  – Physicians, dentists and other health science practitioners not trained in Developmental Medicine
    • Transitions to adult med a big deal!
Barriers

- **Policy Threats**
  - Healthcare Reform
    - Block-granting Medicaid
    - Pre-existing conditions
    - Medicaid Managed Care
    - Why is MUP so hard?
  - LTSS Reform
    - Work requirements
    - Block-granting Medicaid

- **Attitudinal Barriers**
  - “Oh, that’s just the Autism actin’ up!”
Barriers

- Others?
Health Advocacy

EQUALITY

EQUITY
Health Advocacy

A deliberate attempt to influence decision makers and other stakeholders to support or implement policies that contribute to improving health equity using evidence.

Individual, community and systems
Health Advocacy

Clinical Care
Med Education
Policy
Med Education
Policy
Clinical Care
Clinical Care
Health Advocacy

• Policy
• Clinical Care
• Health/Medical Education

• And, don’t forget the evidence?
  – What are your data?
  – What data are you collecting
  – To what purpose?
Policy

• Financing Systems
  – High costs (disproportionality)
  – Conveyor Belt medicine
  – Disincentives to integration
  – Bi- and Tri-furcated systems of care

• Healthcare Reform
  – Block-granting Medicaid
  – Pre-existing conditions
  – Medicaid Managed Care
  – Why is MUP so hard?

• LTSS Reform
  – Work requirements
  – Block-granting Medicaid
Clinical Care

- **Attitudinal Barriers**
  - “Oh, that’s just the Autism actin’ up!”
  - Pediatricians and 53 year-olds
  - Absence of options (Medicaid panels ‘closed’)

- **Healthcare Reform**
  - Pre-existing conditions
  - Medicaid Managed Care
  - Why is MUP so hard?
Education

- Developmental Med curriculum
  - Boards—specialty or subspecialty
  - Practical training opportunities

“Because of limited formal training in medical school and residency, few physicians have the clinical competence and comfort level required to treat people with disabilities. A survey commissioned by Special Olympics found that only 25% of medical schools include content regarding people with intellectual/developmental disabilities in their curricula.”

(Woodard, Havercamp, Zvygart & Perkins, 2012)
What Else?
Action Plan

• What are our priorities?
  – Top three
• Who or what can help us?
  – DDNA? AADMD? AAIDD?
  – Your organization?
• Self-Advocates, families & professionals
• What do we need to do?
• By when-ish should these things be done?
• How will we know if we are successful?
• How do we stay connected and engaged?
<table>
<thead>
<tr>
<th></th>
<th>Goal / Action Steps</th>
<th>Description / Desired Outcome</th>
<th>Party/Department Responsible</th>
<th>Date to Begin</th>
<th>Date Due</th>
<th>% Complete</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td><strong>Goal 1</strong></td>
<td>Policy: Change financing</td>
<td>The Resource Exchange</td>
<td>04/02/18</td>
<td>06/30/19</td>
<td>0%</td>
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<tr>
<td>2</td>
<td>Analyze DDHC data on health outcomes</td>
<td>Lower high-cost utilization</td>
<td>TRE Research Center</td>
<td>02/25/18</td>
<td>03/25/18</td>
<td>100%</td>
</tr>
<tr>
<td>3</td>
<td>Analyze DDHC data on health outcomes</td>
<td>Lower bio-maker: Cholesterol</td>
<td>DDHC</td>
<td>02/25/18</td>
<td>03/25/18</td>
<td>100%</td>
</tr>
<tr>
<td>4</td>
<td>Analyze DDHC data on health outcomes</td>
<td>Improve HRQoL</td>
<td>DDHC/TRE Research</td>
<td>02/25/18</td>
<td>03/25/18</td>
<td>100%</td>
</tr>
<tr>
<td>5</td>
<td>Present outcomes data to Health Care Po</td>
<td>Funding innovation pilot</td>
<td>David</td>
<td>07/02/18</td>
<td>09/01/18</td>
<td>25%</td>
</tr>
<tr>
<td>6</td>
<td><strong>Goal 2</strong></td>
<td>Write your goal 2 statement here</td>
<td>Department 2</td>
<td>01/02/17</td>
<td>03/31/17</td>
<td>44%</td>
</tr>
<tr>
<td>7</td>
<td>Action step 1</td>
<td>Desired outcome</td>
<td>Employee 5</td>
<td>01/02/17</td>
<td>03/31/17</td>
<td>25%</td>
</tr>
<tr>
<td>8</td>
<td>Action step 2</td>
<td>Desired outcome</td>
<td>Employee 6</td>
<td>01/02/17</td>
<td>03/31/17</td>
<td>25%</td>
</tr>
<tr>
<td>9</td>
<td>Action step 3</td>
<td>Desired outcome</td>
<td>Employee 7</td>
<td>01/02/17</td>
<td>03/31/17</td>
<td>75%</td>
</tr>
<tr>
<td>10</td>
<td>Action step 4</td>
<td>Desired outcome</td>
<td>Employee 8</td>
<td>01/02/17</td>
<td>03/31/17</td>
<td>50%</td>
</tr>
</tbody>
</table>
Outcome
Neglected for Too Long: Dental Care for People with Intellectual and Developmental Disabilities

Fall 2017

This policy brief is designed to provide insight concerning the lack of dental care many people with intellectual and developmental disabilities (IDD) continue to experience due to a shortage of properly trained dental care providers and, consequently, a lack of dental care providers willing to provide that care.

The brief will provide recommendations regarding how to begin to rectify the problem, including modifying dental school accreditation and professional ethics requirements. It will also recommend that Congress amend the Public Health Service Act, thereby providing more public funding and student loan debt forgiveness to improve dental care.

Introduction

Unfortunately, interactions with patients who have disabilities may become uncomfortable when the care providers themselves are unfamiliar with their disabilities. This may lead to a lack of care and, accordingly, a lack of preventive care. Adults with disabilities are four times more likely to report their health to be only fair or poor than people without disabilities. More specifically, studies have shown that adults with developmental disabilities are at risk for multiple disorders due to poor oral health. 

Source: https://www.ncd.gov/sites/default/files/NCD_Dental%20Brief%202017_508.pdf
Resources

www.aadmd.org/policy-statements

http://aaidd.org/news-policy/policy#.WpMnlkxFyUk

https://www.thearc.org/what-we-do/public-policy


Resources

http://www.stateofthestates.org/

https://www.kff.org/

https://ddna.org/forums/


https://withfoundation.org/blog/
Resources

https://www.nationalcoreindicators.org/

https://www.ncd.gov/policy/health-care

https://www.aahd.us/


http://www.adhce.org/
Contact

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Developmental Disabilities Health Center
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Colorado Springs, CO 80919
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The task is not yours to complete, but neither are you free to desist from it.

Pirke Avot 2:21


References

