THE FUTURE IS NOW
(OR WHY STAYING IN THE SAME PLACE IS NOT AN OPTION)
“In the 1960s you treated us like plants. You fed us, clothed us, kept us warm, and wheeled us out to feel the sun.

In the ‘70s & ‘80s you discovered we could learn - and we were treated like pets. You taught us all types of tricks and we stood by your side.

But now it is the 1990s. We are not your plants. We are not your pets.

We are people like you and we want to be treated as people. We want the same opportunities as anybody.”

Dirk Wasano -- Hawaii Planning Council on Developmental Disabilities, from John Agosta
I did then what I knew how to do.

Now that I know better, I do better.

~ Maya Angelou
WE STILL VIEW PEOPLE WITH DISABILITIES AS:

- VULNERABLE

- DEPENDENT

- IN NEED OF “FIXING”
And We Accept:

• SEGREGATION

• EXCLUSION

• ISOLATION
Why

do we

need to change?
REASON ONE: People don’t want what we’re offering ...

Most people don’t want congregate services.

A recent survey of progressive service providers found that, almost without exception, when offered options, no one chose to live in a group home or work in day programs/sheltered environments.
Our Rights Are Restricted When:

• Activities or the freedom to come and go are limited to what the provider will allow,

• Our ability to have friends or see family is limited by the agency in any way,

• We have to do what we are told and staff watch our every move,

• Rules are about what works for the agency or the staff,

Our Rights Are Restricted When:

• We are restricted or even punished for expressing our sexuality,

• People make decisions for us, limiting choices about where to live, food, clothing, health care, or how we spend our money.

Joint Report: ASAN, SABE, NYLN, ‘Keeping the Promise of Community’, 2011
REASON TWO: We Can’t Afford It ....

UNITED STATES

TOTAL PUBLIC I/DD SPENDING FOR SERVICES: FY 1977-2013

Billions of 2013 Dollars

Fiscal Year
Medicare and Medicaid

[Image: Graph showing Medicare and Medicaid expected to rise rapidly, other programs (except Social Security) to shrink. Spending and revenues as a share of GDP from 1980 to 2050.]

Source: CBPP projections based on CBO data.

Center on Budget and Policy Priorities | cbpp.org

NASDDDS
National Association of State Directors of Developmental Disabilities Services
Annual Cost of Care ($1,000s)

- Supported Living: $26,708
  - 293,956 Participants
- Private ICF/ID 15 or fewer: $95,506
  - 39,103 Participants
- Private ICF/ID 16+: $98,851
  - 18,027 Participants
- Public ICF/ID 15 or fewer: $133,003
  - 1,575 Participants
- State-Operated Institution: $255,692
  - 24,675 Participants

# Cost of Long Term Supports – IDD in North Carolina

<table>
<thead>
<tr>
<th>Type of Service</th>
<th>Cost per Person</th>
<th>20 yrs. Cost</th>
<th>30 yrs. Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>State Institution</td>
<td>$208,808</td>
<td>$4,176,160</td>
<td>$6,264,240</td>
</tr>
<tr>
<td>Group Home: 24 hr. staffed Residential</td>
<td>$49,440</td>
<td>$988,800</td>
<td>$1,483,200</td>
</tr>
<tr>
<td>Supported Living</td>
<td>$26,708</td>
<td>$534,160</td>
<td>$801,240</td>
</tr>
</tbody>
</table>

Data Source: Lakin, K.C.  MSIS and NCI data from 4 states (1,240 Individuals)
[https://www.ncd.gov/publications/2012/DIToolkit/Costs/inDetail](https://www.ncd.gov/publications/2012/DIToolkit/Costs/inDetail);

NASDDDS

National Association of State Directors of Developmental Disabilities Services
### REASON THREE: Some People are Over-Served While Others Get Nothing

<table>
<thead>
<tr>
<th>Facility/Service Type</th>
<th># of People Statewide</th>
<th>Average Cost Per Person/Per Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>State-operated DD Centers</td>
<td>927</td>
<td>$208,807.76</td>
</tr>
<tr>
<td>Community-based ICF-ID</td>
<td>2,555</td>
<td>$98,119.97</td>
</tr>
<tr>
<td>Innovations</td>
<td>11,813</td>
<td>$63,589.20</td>
</tr>
<tr>
<td>- Residential Supports</td>
<td>3,525</td>
<td>$49,440.60</td>
</tr>
<tr>
<td>- Family/own home</td>
<td>8,288</td>
<td>$29,881.72</td>
</tr>
</tbody>
</table>

**Waitlist (Registry of Unmet Needs)** 12,809
Figure 13

Medicaid § 1915(c) HCBS Waiver Waiting Lists, by Enrollment Group, 2004-2014

- Others
- Aged/Disabled
- Persons with Intellectual/Developmental Disabilities

<table>
<thead>
<tr>
<th>Year</th>
<th>Others</th>
<th>Aged/Disabled</th>
<th>Persons with Intellectual/Developmental Disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>2004</td>
<td>1%</td>
<td>53%</td>
<td>45%</td>
</tr>
<tr>
<td>2005</td>
<td>6%</td>
<td>41%</td>
<td>53%</td>
</tr>
<tr>
<td>2006</td>
<td>5%</td>
<td>42%</td>
<td>53%</td>
</tr>
<tr>
<td>2007</td>
<td>6%</td>
<td>26%</td>
<td>68%</td>
</tr>
<tr>
<td>2008</td>
<td>6%</td>
<td>30%</td>
<td>64%</td>
</tr>
<tr>
<td>2009</td>
<td>10%</td>
<td>29%</td>
<td>61%</td>
</tr>
<tr>
<td>2010</td>
<td>9%</td>
<td>28%</td>
<td>63%</td>
</tr>
<tr>
<td>2011</td>
<td>8%</td>
<td>32%</td>
<td>62%</td>
</tr>
<tr>
<td>2012</td>
<td>10%</td>
<td>29%</td>
<td>58%</td>
</tr>
<tr>
<td>2013</td>
<td>11%</td>
<td>29%</td>
<td>60%</td>
</tr>
<tr>
<td>2014</td>
<td>14%</td>
<td>26%</td>
<td>60%</td>
</tr>
</tbody>
</table>

Total: 206,427 260,916 280,176 331,689 393,096 365,553 428,571 511,174 523,710 536,464 582,066

NOTES: Percentages may not sum to 100 percent due to rounding. The “Other” enrollment group includes waiver enrollees who are people with physical disabilities, children, people with HIV/AIDS, people with mental health needs, and people with traumatic brain and spinal cord injuries.

SOURCES: KCMU and UCSF analysis of CMS Form 372 data and program surveys.

United Cerebral Palsy,
The Case for Inclusion, 2013

Disability Frontline
REASON FOUR: There Won’t Be Enough Staff

Figure 1

The 65 and Over Population Will More Than Double and the 85 and Over Population Will More Than Triple by 2050

We’ll Be Competing with Senior Services for the Same Pool of Staff

Source: U.S. Census Bureau, Population Division, Interim State Population Projections, 2005

Females aged 25-44  Individuals 65 and older
REASON FIVE: It’s Not What CMS is Going to Fund

- The person selects where he/she lives from a range of options (including types of services and different providers);
- Settings are integrated in and offer full access to the greater community;
- People have opportunities to work in competitive integrated settings, engage in community life;
- People control personal resources; and,
- Settings optimize autonomy and independence in life choices
Most Importantly: It’s the Right Thing to Do

But We’re Good People ...

And we’re only doing what we think is best for the people we support ..... 

So what’s wrong with that?
If I Was in Charge of Your Lives
We often offer lives dictated by a bunch of rules that most people wouldn’t tolerate. No pets. We all eat dinner together at 6. Everyone has to go to the day program.

Lights out by 10. Ask before using the phone. No smoking.

No snacking after dinner. TV from 7-9 only. No alcohol.

Make your bed before you go out. No sex. No Pets.

Home by 9 pm. No one of the opposite sex in your room.
We need to stop assuming that there is some relationship between the significance of your disability and where you have to live

... and stop making decisions about people’s lives based on openings or slots
Quality of life has a whole lot more to do with personal relationships and a sense of community than it does with the ability to fold laundry, balance a checkbook, or set a proper table.
Martin Luther King Jr. said:

I Have a Dream ...

He didn’t say, I have an annual plan, quarterly goals, and a big old case file to keep track of it all
"I think you should be more explicit here in step two."
Your Comfort Zone → Where the magic happens
Football Wisdom ....

In life, there are four essential needs:

- To have something to do...
- To have someone to love...
- To have something to believe in...
- To have something to hope for...

Lou Holtz addressing the Notre Dame football team, 2005
Thank you

Nancy Weiss
nweiss@udel.edu