

## Responding to the Needs of People with Developmental Disabilities:

### Working Toward Sustainable Futures

Prepared by:

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## Topics

- This and that about Ohio
- Some honesty about our surroundings
- Facing the challenge to build a Sustainable Future
- Three things we can do
- Where does all this leave us?
- What will YOU going do about it?



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## This and That About Ohio

- Number served per 100,000 citizens
- Mix of services
- Service Capacity
- Fiscal effort
- Relative service costs

### Comparison States

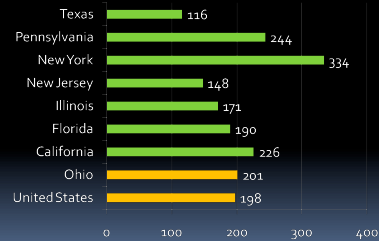
State	2007 population
California	36,553,215
Florida	18,199,526
Illinois	12,852,548
New Jersey	8,685,920
New York	19,297,729
Ohio	11,466,917
Pennsylvania	12,432,792
Texas	23,904,380

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## Number Served

Ohio provides Medicaid services to 201 people with developmental disabilities per 100,000 citizens. The national average is 198.

People Receiving Medicaid Services Per 100,000 Population



Source: Prouty & Lakin (Eds.), Residential services for persons with developmental disabilities: Status and trends through 2008. Minneapolis: University of MN, Institute on Community Integration

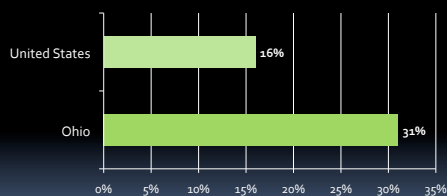
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## Mix of Services

Ohio provides residential services to 6,667 people in ICFs-MR and another 15,807 within HCBS waiver options. The number living in ICFs-MR amounts to 31% of the total, compared to 16% nationally

Percent of People Receiving Residential Services in ICFs/MR



Source: Prouty & Lakin (Eds.), Residential services for persons with developmental disabilities: Status and trends through 2008. Minneapolis: University of MN, Institute on Community Integration

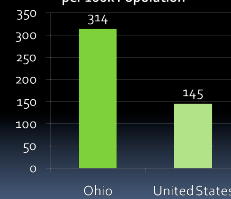
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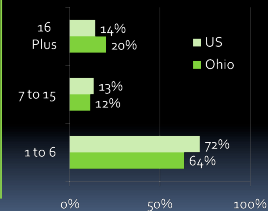
## Mix of Services

The number of people receiving residential services per 100,000 in state population is 314. Nationally, it is 145. Yet, Ohio relies more on larger facilities than the national average

People Served in Out-of-Home Residential Settings per 100k Population



People Living Out-of-Home



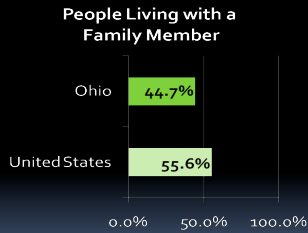
Source: Prouty & Lakin (Eds.), Residential services for persons with developmental disabilities: Status and trends through 2008. Minneapolis: University of MN, Institute on Community Integration

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## Mix of Services

44.7% of people receiving services in Ohio live with family (17,602 of 39,356 people). The national average is 55.6%.

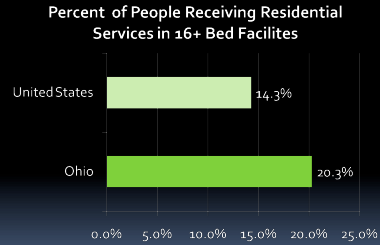


Source: Prouty & Lakin (Eds.), Residential services for persons with developmental disabilities: Status and trends through 2008. Minneapolis: University of MN, Institute on Community Integration

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## Service Mix

In 2007, in Ohio 4,409 people resided in facilities of 16+ beds. Given a total residential population of 21,754, this amounts to 20.3%. The national average is 14.3%.



Source: Prouty & Lakin (Eds.), Residential services for persons with developmental disabilities: Status and trends through 2008. Minneapolis: University of MN, Institute on Community Integration

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## Service Capacity

- From 2001 through 2007 Ohio added 9,714 people to its system. This included:
  - 10,738 added to the HCBS waiver
  - 1,024 subtracted from ICFs/MR rolls
- This amounts to 1,388 per year on average.
- Only California, New York and Florida added more people.
- Regarding HCBS, this amounts to 96 people per year per 100k population. This ranks Ohio 37th among all states.



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## Resources

### Spending Comparison

Florida	47
California	37
Georgia	50
Illinois	40
New Jersey	31
New York	2
North Carolina	25
Ohio	9
Pennsylvania	14
Texas	49

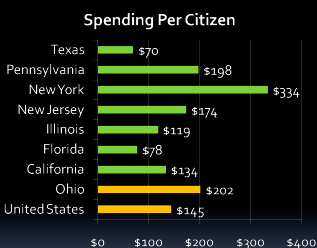
### Fiscal Effort

- This method appraises a state's level of financial effort by measuring its overall spending for developmental disabilities services relative to state personal income.
- In 2006 ranked Ohio ranked **9<sup>th</sup>** among the states with respect to its overall level of fiscal effort.
- In 2006-2007, the US Census Bureau ranked Ohio **26<sup>th</sup>** in Personal Income per Capita.

Braddock, D. et al. (2008). The State of the States in Developmental Disabilities: 2008. Boulder, Colorado: Department of Psychiatry and Coleman Institute for Cognitive Disabilities.

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## Resources



### Spending per Citizen

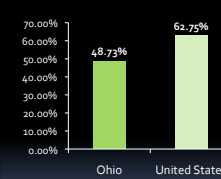
- This method measures a state's financial effort is its expenditures per citizen – that is, total DD expenditures divided by the state's population.
- In 2006, Ohio spent \$202 per citizen for developmental disabilities services.
- The nationwide average (\$144 per citizen) was 40% lower.

Braddock, D. et al. (2008). The State of the States in Developmental Disabilities: 2008. Boulder, Colorado: Department of Psychiatry and Coleman Institute for Cognitive Disabilities.

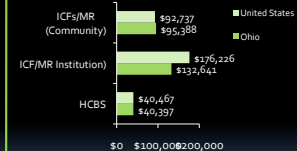
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## Relative Service Costs

### Percent Expenditures for HCBS vs. ICFs/MR Services



### Relative Annual Costs per Person of Three Service Types



Source: Prouty & Lakin (Eds.), Residential services for persons with developmental disabilities: Status and trends through 2008. Minneapolis: University of MN, Institute on Community Integration

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## Challenges Faced By Policy Makers...

- Budget stress
- Accelerating service demand
- Reliance on legacy and inefficient systems
- Workforce shortages
- Continued push for community integration, participation, contribution... self direction.



## Budget Stress?

- Iraq and Afghanistan wars continue
- Gas prices rise, then fall
- Economy Falters
- Unemployment rate moves to over 6% with job losses highest in 20 years
- States face revenue shortfalls



State	Total Budget Shortfall for FY2009	Gap as Percent of FY2009 General Fund	State	Total Budget Shortfall for FY2009	Gap as Percent of FY2009 General Fund
Alabama	\$1.2 billion	15.00%	Mississippi	\$114 million	2.20%
Arizona	\$3.1 billion	30.80%	Missouri	\$342 million	3.80%
Arkansas	\$107 million	2.40%	Nevada	\$1.4 billion	19.60%
California	\$28.8 billion	30.30%	New Hampshire	\$20 million	8.00%
Colorado	\$99 million	1.30%	New Jersey	\$3.7 billion	11.40%
Connecticut	\$542 million	3.20%	New Mexico	\$253 million	4.20%
Delaware	\$369 million	10.10%	New York	\$6.4 billion	11.40%
D.C.	\$227 million	3.60%	North Carolina	\$800 million	3.70%
Florida	\$5.5 billion	21.50%	Ohio	\$1.9 billion	6.80%
Georgia	\$2.7 billion	12.80%	Oklahoma	\$114 million	1.70%
Hawaii	\$232 million	4.00%	Oregon	\$142 million	2.10%
Idaho	\$131 million	4.40%	Pennsylvania	\$66 million	2.00%
Illinois	\$3.8 billion	13.40%	Rhode Island	\$802 million	24.50%
Iowa	\$350 million	5.50%	South Carolina	\$804 million	11.70%
Kansas	\$137 million	2.10%	South Dakota	\$27 million	2.20%
Kentucky	\$722 million	7.80%	Tennessee	\$1.2 billion	10.40%
Maine	\$265 million	8.60%	Utah	\$354 million	5.90%
Maryland	\$1.3 billion	8.80%	Vermont	\$122 million	10.00%
Mass.	\$2.6 billion	9.20%	Virginia	\$2.2 billion	12.80%
Michigan	\$472 million	4.80%	Washington	\$413 million	2.70%
Minnesota	\$1.4 billion	7.90%	Wisconsin	\$998 million	7.10%

Texas projects budget gaps in FY2010

Total Shortfall \$78 billion ...

This was reported just after the October economic downturn

## The Early Impacts Include Cuts To...

- **Public health programs:** At least 13 states have or are considering cuts affecting children's or families' eligibility for health insurance or to reduce their access to health care.
- **Programs for elders and people with disabilities:** At least 7 states are cutting medical, rehabilitative, home care, or other services, or significantly increasing their cost.
- **K-12 education:** At least 11 states are cutting or proposing to cut K-12 and early education; several of them are also reducing access to child care and early education.
- **Colleges and universities:** At least 16 states have implemented or proposed cuts to public colleges and universities.
- **State workforce:** At least 15 states have proposed or implemented reductions to their state workforce.



## Service Demand Is Going Up!

- Demand for publicly-funded developmental disabilities services is growing nationwide.
- It is increasing at a rate greater than population growth alone.
- This increase in service demand is driven by:
  - People living longer ... or surviving trauma
  - Aging baby boomers
- Turnover among individuals receiving services is reduced so that there is less capacity to absorb new demand
- There is a growing number of individuals who live in households with primary caregivers who are themselves aging.

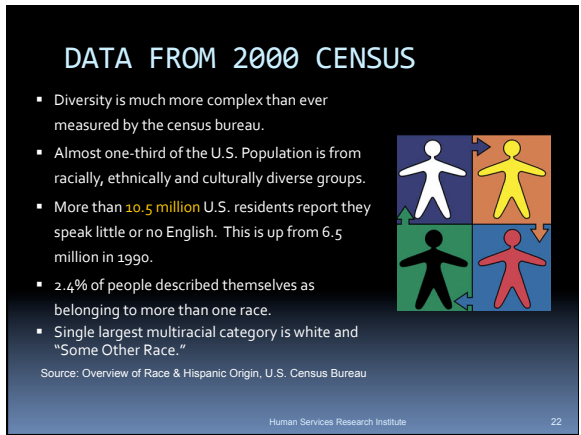
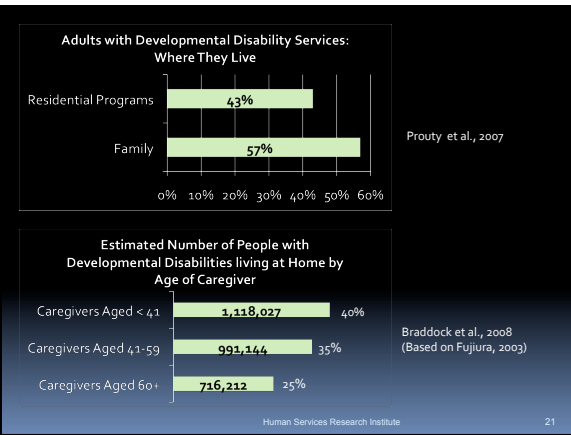
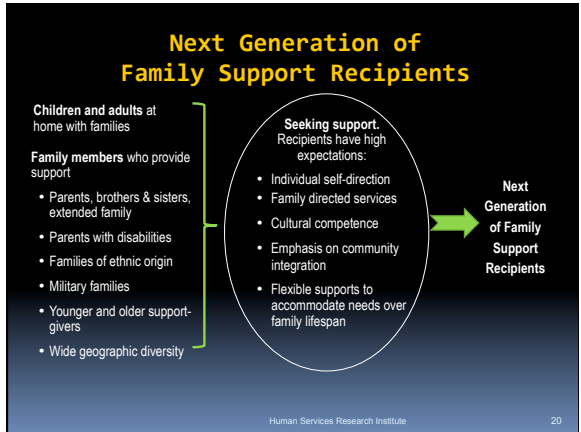
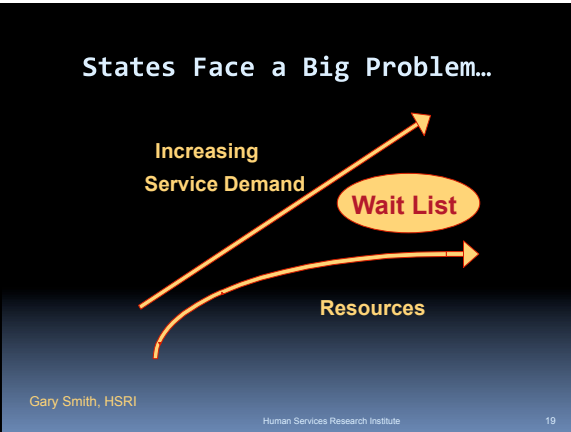
## Waiting for Residential Services

People Waiting	Residential Services Recipients	% of Growth Needed
88,349	437,707	20%

People with ID/DD on a waiting List for, but not receiving, residential services on June 30, 2007

Lakin Residential Services Status and Trends 2008

OHIO did not Furnish Information

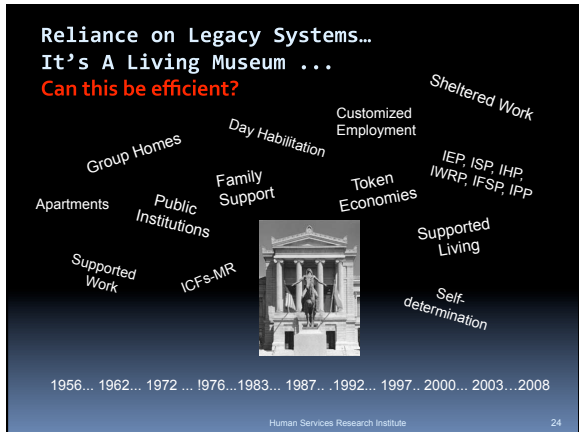


### "The Naked Truth"

- It is sometimes hard to access & apply for services.
- Agencies, staff and services are often invisible to us.
- Agencies may think that they are doing a "great job" of "outreach." The reality is often different.
- Each minority group is different, requiring differing approaches... Translation from English is often easier said than done.
- Immigration policies pose a formidable barrier for children.
- Agency staff from various agencies don't talk... And don't work together.
- There are some terrific agency workers who want to help. But there are others who aren't so helpful at all.
- Agency decisions are sometimes hard to understand and agency mistakes sometimes seem to penalize families.
- Services are not always "culturally competent."
- The US Territories and Indian Nations pose unique problems.
- When things "change"... For low income people and people with disabilities, things don't change. Yet we are ALL Americans.

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**Helping Hands Workshop**

"We offer our consumers choice and self-determination in the least restrictive environment. They can package plastic forks, knives, and spoons **OR** sort nuts and bolts."

"Don't buy it."


"Professionals know what words to say but they keep doin' the same old thing. He's not foolin' me!"

Jazzy \*

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### Work Force Shortages Are Real

- Providers have trouble hiring and keeping staff.
- Families have trouble hiring respite workers.
- Pay is low. Benefits are not always the greatest.
- There are often issues to overcome related to culture and staff.
- We imagine systems that are well staffed by well trained people.
- We compensate with a mountain of rules, pre-scripted routines and paperwork.



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### Changing Expectations...



"In the 1960's and earlier we were treated like plants. You fed us, clothed us, kept us warm, and wheeled us out to feel the sun.

In the 1970s and 80s you discovered we could be taught -- 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 plants. We are not your pets.

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

Dirk Wasano -- Hawaii Planning Council on Developmental Disabilities

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### Heading for a crash!





**Budget Shortfalls**

- Weighty Legacy Services & Structures
- Rising Demand
- Workforce Shortages
- Fragmentation
- Quality Problems
- Antiquated Technologies

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### What To Do???

We can't stay on this spot

We need to rethink what we do – affirm our values but resolutely search for “value”

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### Sustainable Futures ...

An action agenda anchored in **values** and committed to making the **changes** necessary to secure the best **outcomes** possible for people with developmental disabilities and families.

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### 3 Things We Can We Do To Develop a Sustainable Future

1. Hear self –advocates
2. Make our services systems efficient
3. Rediscover ourselves and our communities.



**It can't ALL be about Medicaid!**

### 1. Hear Self-Advocates

People want to live the life they want in the community with the support they need. Just like anyone else.



### Self-Advocates Say...

That Self-Determination means that...

- I am a person like all people.
- I make my own choices.
- I am the boss of my own life.
- I make my decisions in my own life.
- I do for myself... and not depend on others so much.



### About "Self Determination"

"Before self determination there is self-esteem. A person has to love themselves. A person has to be proud of who they are."



*Rebecca Hare  
National Consortium on Leadership and Disability  
Institute for Educational Leadership*

### Here's a Thought...

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*

### What's With These Silly Rules!!!



## Some Examples

- Won't let me be home by myself.
- Say we are supposed to eat brown bread.
- Make us go to bed at 9pm
- Lights out at 10pm on weekends, and we can't sleep in
- Won't let me out on a date or let us have a boyfriend or girlfriend.
- Make me go bowling just because the others are going.
- Say I can't smoke, even during free time.
- Won't let us eat popcorn in the TV room even when we are watching movies.
- Say we can't stare at each other during meals
- Say we can't watch scary or X-rated movies
- Can't make or receive phone calls.
- Won't let us cuss, even though staff do.
- We can't wear makeup



www.theriotrocks.org

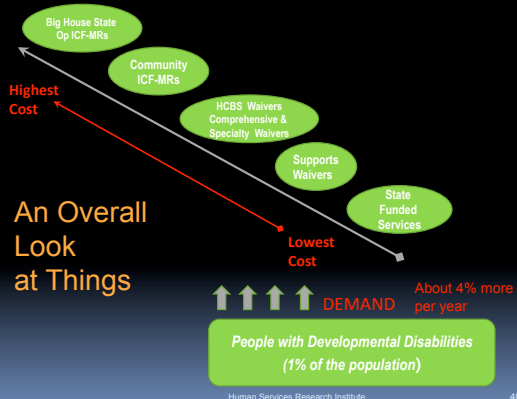
It's Free... but contributions are most welcome

## 2. Make Our Service Systems More Efficient

- Promote person-centered system architecture
- Disinvest from low value/high cost services
- Make systems fair and more efficient
- Encourage providers to be agile and utilize "Non-traditional" providers
- Invest in "in-home supports."



An Overall Look at Things



## Would You Buy These Cars?

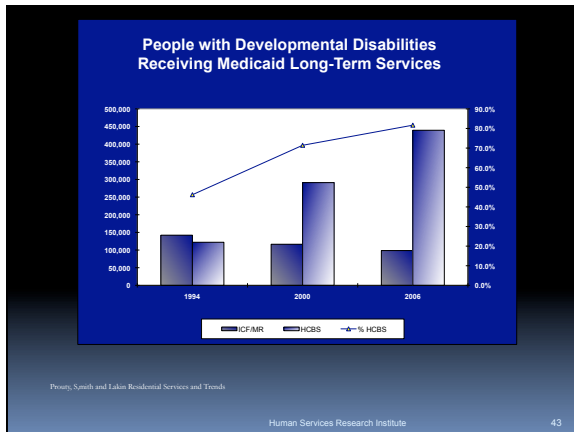


But we run our service system just as inefficiently as these cars burn gas. Maybe more so...

## We've Already Taken Some First Steps...

- Fewer than 37,000 in institutions; 10 states with no institutions
- Residential options are getting smaller
- ICF-MD/DDs are "out"; Waiver services are "in"
- States are investing in "in-home supports" through supports waivers.
- States are looking at how they allocate resources to individuals.





### Working To Get Personal Allocations Right

- Do we really know what it costs to serve a person?
- Why are some people allocated more than others, even though they have similar needs?
- Is the way we allocate funds fair? Is it based on support needs?
- Is this efficient?
- Several states are working to assess needs systematically and allocate accordingly.

Person-Centered Budget Allocations  
Adjusted Service Reimbursement Rates

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### Focus on In-Home Supports

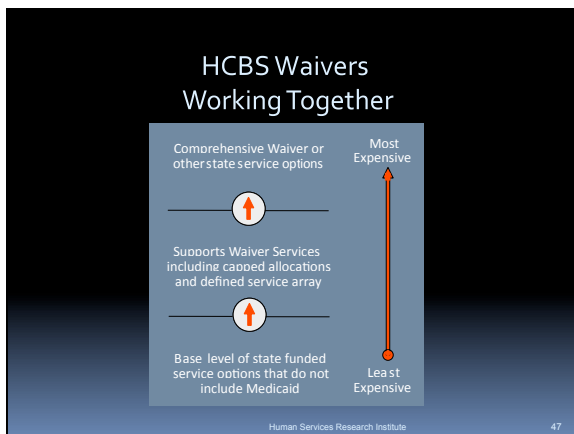
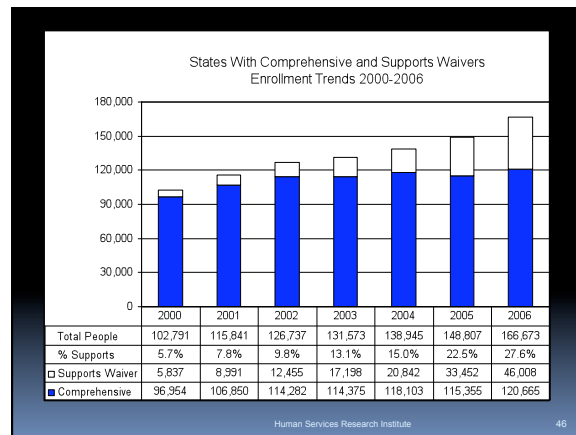
Providing supports to individuals living at home with family members

- 55% of those receiving services nationally live at home (44% in OH).
- Involves non-residential supports... so it is typically less expensive
- Encourages use of "non-traditional service providers"

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- Raises issues pertaining to the individual's preferences for where s/he wants to live
- Creates numerous issues regarding infrastructure
- Calls for new means for managing risk
- What about paying family members as service providers?

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### Family Support 360s...

21 Implementation Grants	9 Planning Grants
Alaska	Connecticut
Colorado	Delaware
District of Columbia	Illinois
Hawaii	Iowa
Idaho	Mississippi
Maryland	New Jersey
Massachusetts	North Dakota
Michigan	Ohio
Minnesota	Tennessee
Missouri	
New Hampshire	
New Mexico	
North Carolina	
Northern Mariana Islands	
Oklahoma	
Oregon	
Rhode Island	
South Dakota	
Utah	
Vermont	
Wisconsin	

- Funded by the US Administration on Developmental Disabilities since 2003
- Receive no state or Medicaid Funding
- Designed initially as "One Stop Centers"

[www.addfamilysupport360.org](http://www.addfamilysupport360.org)

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## Family Support 360s...

- Develop staff as "family navigators,"
- Find that families and individuals often have support needs that fall outside of what traditional developmental disability systems address.
- Assist families to apply for and receive services from a variety of public service agencies,
- Utilize resources available outside the public service system, including faith-based and other community serving organizations, and businesses
- Develop effective opportunities for families to provide support to one another.



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## Family Support 360s...

### Numbers of Families Served by Service Type (Unduplicated Counts)

(20 of 21 Centers responding) (July 07 through July 08)

1,426 families	Comprehensive Assistance
2,766 families	Casual Assistance
1,915 families	Participated in Center Activities

**5,499 families served**

At a cost of (based on a budget of \$4,140,000):

**\$752/family overall**

**\$2,903/family (counting Comprehensive Assistance only)**

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## Issues related to "self-direction"

### When We Ask Self-Advocates...

(In New Hampshire, Alabama, Mississippi, Texas, Oregon, Colorado, North Carolina, Arizona, Idaho, Montana, Virginia, Missouri, Montana ...)



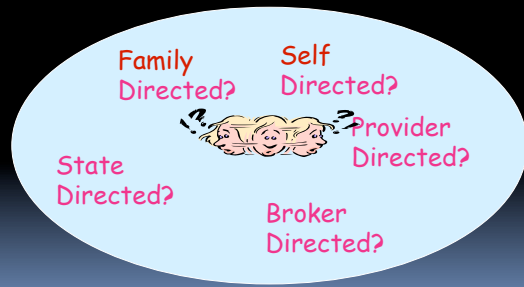
- What or who helps you to be in control of your life?  
Very quickly someone will say... "My Parents." And many will agree.
- What or who keeps you from being in control of your life?  
Very quickly someone will say... "My Parents." And many will agree.

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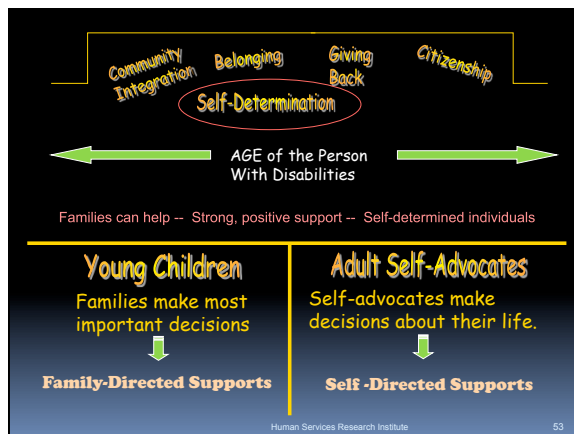
## Considering the "Rub"...

### Who Is "The Self" In Self-Determination?



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## Managing Risk



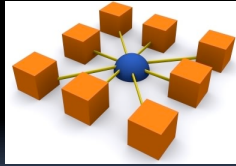
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## Infrastructure and In-Home Supports

Infrastructure can be defined as the underpinning physical and organizational structures needed for the operation or enterprise to succeed.

Human services infrastructure may include:

- system administration,
- rules or regulations,
- paperwork requirements,
- service coordination,
- training for system participants,
- technical assistance,
- crisis response,
- information management,
- quality monitoring and assurance.



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## Are In-Home Workers Independent Contractors or Not?



The general rule is that an individual is an independent contractor if [the individual or family], the person for whom the services are performed, has the right to control or direct only the result of the work and not the means and methods of accomplishing the result.

Under common-law rules, anyone who performs services for you is your employee if you can control what will be done and how it will be done.

<http://www.irs.gov/businesses/small/>

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## Paying Family Members

In many instances, family members can be a most appropriate provider.

- Relatives who are willing to work provide an additional pool of workers
- Relatives know and care about the person
- Individually contracted services are typically less expensive than those offered through a traditional agency.



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## Paying Family Members

When using family members the following factors are reviewed:

- The lack of available providers
- A finding that the family member is qualified to provide support.
- A determination that that the family member will not undermine the individual's goals and preferences.



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## Paying Family Members

- CMS policy is that payments for personal care or similar services delivered by legally responsible individuals (typically a parent of a minor child or a spouse) are not eligible for federal financial participation.
- Legally responsible individuals do not include the parent of an adult beneficiary or other types of relatives
- FFP for payments are prohibited to legally responsible individuals for State plan personal care services.
- **But... Through a waiver**, states can make payments for personal care or similar services when such services are for extraordinary care (i.e., beyond the care a person would ordinarily perform in a household). States need to specify the governing criteria...
- States may impose other limitations
- **Providing for payments to legally responsible individuals is a state option, not a federal mandate.**

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## Paying Family Members



- The waiver must specify the types of legally responsible individuals who can be paid, and the types of services.
- The service must meet all waiver criteria required of customary providers.
- Family members must meet provider qualifications.
- State must conduct monitoring and implement other safeguards (pay review procedures, limits on hours, assuring that it is in the best interest of the beneficiary)
- Note... unless a state uses rules to disregard family income for a child waiver participant, the pay provided could affect the child's eligibility for Medicaid

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## But Here Is Some Truth About Medicaid

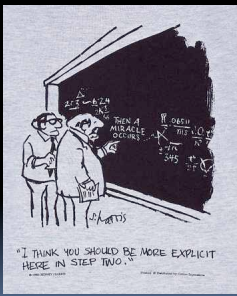


- States use state funds to earn Medicaid Match (50%-75%)
- 78% of \$43.83 Billion in services are in the Medicaid programs**
- Medicaid can only serve the "beneficiary"
- Not everyone is eligible for a Medicaid waiver
- Not everyone can get into a waiver even if they are eligible
- Not everyone knows about applying for Medicaid waivers
- Medicaid doesn't meet every need a person/family has
- Medicaid can over-serve people
- No matter how much money we have, it will never be enough**

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## Our Reality

- We can't afford to pay for 24 hr. residential services for everyone.
- We can't staff 24 hr. residential services even if we could afford to.
- If we could, would we want to?
- How will we support people?
- Is it all really about that Medicaid waiver slot?
- Just exactly what ARE we going to tell this next generation of individuals and their families?**



Thanks Nancy!

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## 3. Rediscover Ourselves and Our Communities

**A Three Legged Approach!**




**Individuals**

**Community**      **Government**

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## Assumptions

- It's about children and adults at home, not just children.
- Government's role will be... important...essential... yet modest.
- Medicaid funding is essential, but let's not define "support" by what is "Medicaid reimbursable"
- We must look to each other and our communities to promote a culture of mutual aid... mutual support...



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 **1<sup>st</sup> leg... Government**

- A need to settle on a direction...
- A need for greater efficiency...



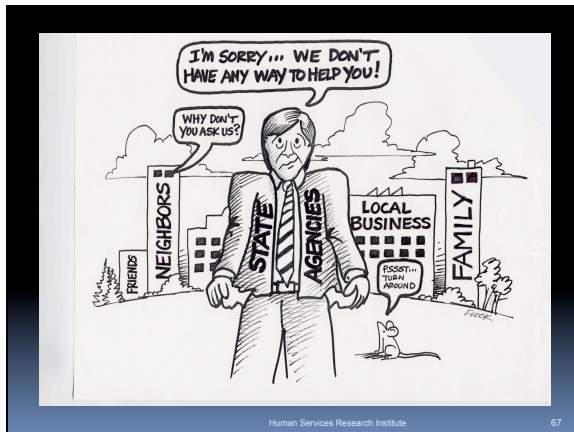
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 **2<sup>nd</sup> leg... Community**

- Enlisting community businesses
- Enlisting faith-based organizations
- Enlisting community serving organizations



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3<sup>rd</sup> leg...  
People Helping People

**Me + Me + Me = We**

### People Helping People

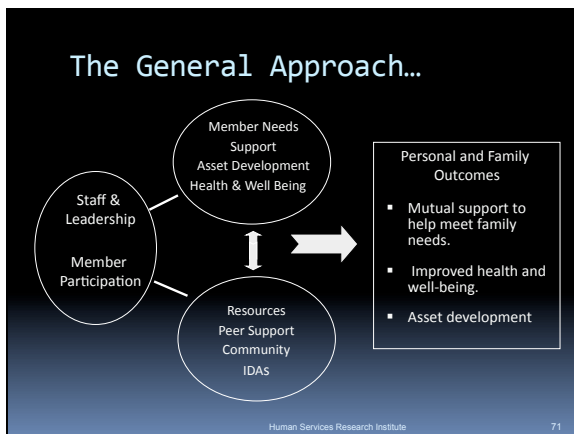
- Toy Exchanges... Equipment Exchanges
- Exchange Networks
- Peer Support Networks
- Mentoring
- Micro-Loans

Talk about Match! States match state dollars for Medicaid reimbursement.

For the price of running a peer cooperative, consider the "match" returned as people help one another!

### Yeah... So... What About... Family and Peer Cooperatives?

In a cooperative participants unite to address common or individual needs through mutual support and/or joint action.

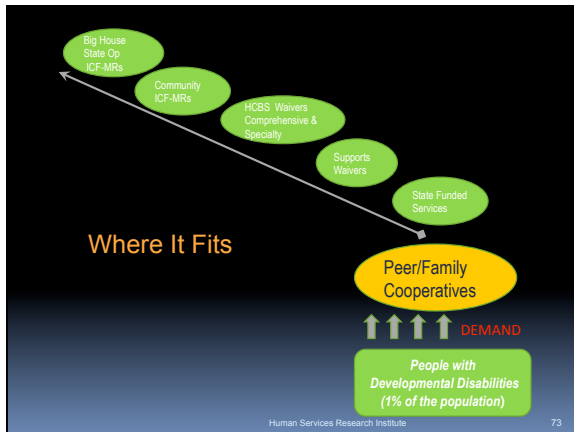


### An Added Twist... Individual Development Accounts

**Individual Development Accounts (IDAs)** are matched savings accounts that enable low-income American families to save, build assets, and enter the financial mainstream.

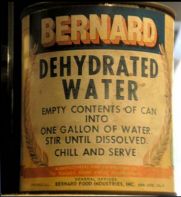
**Key Concepts:**  
Low income Americans  
Asset development  
Matched savings accounts

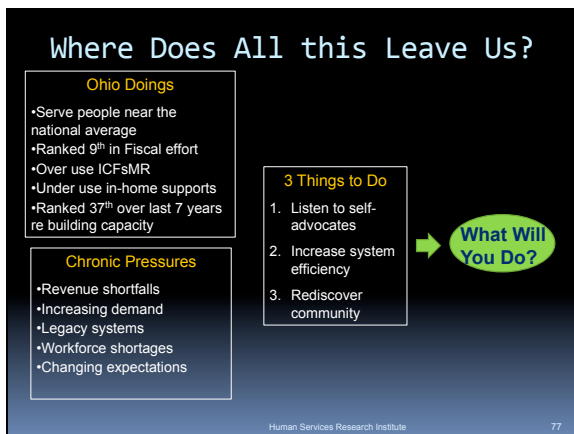
<http://www.cfed.org/>  
<http://www.vidaoregon.org/>



- ## Federated Human Service Coops
- HSC® Companies are recognized by the Federated Human Service Cooperative
  - The goal is to "assist in the creation of Human Service Cooperatives and other self directed companies. (See <http://www.federatedhsc.coop/>)
  - This entity develops and certifies local cooperatives directed by individuals and families who use disability services .
  - Once certified, a cooperative operates as a provider .
  - This type of cooperative is built on partnerships developed between agencies and community-service organizations in the public and private sector.
  - These partnerships create a responsive network to offer self-directed services addressing member needs.
- Human Services Research Institute 74

- ## Federated Human Service Coops
- Several local HSC Companies have been successfully implemented
- Arizona Autism United, (AZA United) Phoenix Arizona <http://www.azaunited.org>
- Arizona Service Co-op Enterprise, (ASCENT, HSC®), Flagstaff Arizona <http://www.ascenthsc.org>
- Inspire, HSC®, Phoenix, AZ, <http://inspirehsc.org>
- Freedom Co-op, Memphis TN
- Keep Marin Green Cooperative; San Rafael, California
- Total Link 2 Community Cooperative, (Total Link 2); Northbrook Illinois
- Community Choices Cooperative, Champaign, Illinois
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- ## And So... In the End... We Must...
- Listen to what self-advocates are telling us.
  - Make our service systems much more efficient. Let's stop throwing good money after bad.
  - Rediscover the assets within ourselves and our communities
- 
- Human Services Research Institute 76



- ## What Are You Going To Do About It?
- What traditions, commitments and vision define us?
  - What assets can we count on and leverage?
  - What alliances can we forge?
  - What opportunities will we create?
- If I am only for myself, who is for me?  
And if I am only for myself, what am I?  
And if not now, when?



Rabbi Hillel
- Human Services Research Institute 78

## The Challenge Is To Find Ways To ...

- Encourage, model and support an "action bias" consistent with retooling...
- Encourage, nurture and support alliances that work to mobilize energy to act...

Anyone who has never made a mistake has never tried anything new.

Albert Einstein



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## The Fundamental Issues to Overcome Are:



- **Technical**  
Can we figure out ways to make the structure work in a technical sense?
- **Political**  
Do we have the will to make changes to the flow of money?  
Can we abandon program (slot) driven approaches?  
Can we move from supply centered to demand centered systems?

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## Concluding Thoughts

### Let's Agree to Change.

- Change imposes choice.
- Choice imposes ambiguity.
- Ambiguity promotes discussion.
- Discussion promotes deliberation.
- Deliberation forms opinion.
- Opinion leads to action.

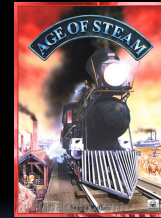


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## Need and Opportunity

A service system for [people with disabilities] and others in need of support will have to be a system in constant change. It has to be continuously developed, if the 'customers' are not to be left behind and to become hostages of an outdated way of doing things."



Alfred Dam (undated)  
Denmark

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