



SHIFT TOWARDS COMMUNITY SERVICES

- **DRAMATIC SHIFT AWAY FROM INSTITUTIONAL CARE TOWARDS COMMUNITY SERVICES**
 - 53% OF SPENDING NATIONALLY ON COMMUNITY SERVICES
- **MOST PEOPLE NOW LIVE IN SMALL COMMUNITY SETTINGS (FROM IDD DATASET)**
 - IN FAMILY HOME (56%), OWN HOME (11%), HOST HOME (5%) OR GROUP HOME WITH LESS THAN 3 OTHERS (5%)
 - BUT STILL MANY IN LARGER CONGREGATE SETTINGS: 4-6 PERSON (12%), 7-15 PERSON (5%) AND, 16+ PEOPLE (6%)
- **COMMUNITY BASED SERVICES ARE OPTIONAL WHILE INSTITUTIONAL CARE IS MANDATORY**

MEDICAID AND CHILDREN WITH SPECIAL HEALTH CARE NEEDS

- 46% OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS HAVE DIFFICULTY WITH 4 OR MORE AREAS OF DAILY LIVING
- NEARLY 3 IN 5 ARE WHITE AND 4 IN 4 ARE AGE 6 OR OLDER
- NEARLY 3 IN 4 LIVE IN LOW OR MIDDLE INCOME FAMILIES WITH INCOMES BELOW 400% OF THE FEDERAL POVERTY LEVEL
- 44% OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS HAVE MEDICAID OR OTHER PUBLIC INSURANCE

OPPORTUNITIES CREATED BY THE HCBS SETTINGS RULE

- THE HCBS SETTINGS RULE PROVIDES AN UNPRECEDENTED OPPORTUNITY TO:
 - EXPAND CAPACITY OF MORE INTEGRATED AND INDIVIDUALIZED SERVICES
 - MOVE STATE SYSTEMS AWAY FROM OUTDATED, SEGREGATED SERVICE MODELS
 - HELP STATE COMPLY WITH THEIR OBLIGATIONS UNDER *OLMSTEAD*

CHARACTERISTICS OF HOME AND COMMUNITY BASED SETTINGS

AN OUTCOME ORIENTED DEFINITION THAT FOCUSES ON THE NATURE AND QUALITY OF INDIVIDUALS' EXPERIENCES, INCLUDING THAT THE SETTING:

1. IS INTEGRATED IN AND SUPPORTS ACCESS TO THE GREATER COMMUNITY;
2. PROVIDES OPPORTUNITIES TO SEEK EMPLOYMENT AND WORK IN COMPETITIVE INTEGRATED SETTINGS, ENGAGE IN COMMUNITY LIFE, AND CONTROL PERSONAL RESOURCES
3. IS SELECTED BY THE INDIVIDUAL FROM AMONG SETTING OPTIONS, INCLUDING NON-DISABILITY SPECIFIC SETTINGS

HCBS SETTING CHARACTERISTICS (CONT'D)

4. ENSURES THE INDIVIDUAL RECEIVES SERVICES IN THE COMMUNITY TO THE SAME DEGREE OF ACCESS AS INDIVIDUALS NOT RECEIVING MEDICAID HCBS
5. ENSURES AN INDIVIDUAL'S RIGHTS OF PRIVACY, DIGNITY, RESPECT, AND FREEDOM FROM COERCION AND RESTRAINT
6. OPTIMIZES INDIVIDUAL INITIATIVE, AUTONOMY, AND INDEPENDENCE IN MAKING LIFE CHOICES
7. FACILITATES INDIVIDUAL CHOICE REGARDING SERVICES AND SUPPORTS, AND WHO PROVIDES THEM

ADDITIONAL REQUIREMENTS FOR PROVIDER-OWNED RESIDENTIAL SETTINGS

FUNDING CAPS: PER CAPITA CAPS (PCCS)

- FEDERAL GOV'T PAYS A **SET AMOUNT PER MEDICAID ENROLLEE** INSTEAD OF PAYING FOR STATE'S ACTUAL SERVICE COSTS SAME BASIC PROBLEM WITH STARTING RATE AND WITH ANNUAL GROWTH
- UNLIKE BLOCK GRANT, IT ACCOUNTS FOR CHANGES IN ENROLLMENT
- DOES NOT ACCOUNT FOR NEW TECHNOLOGIES, AGING POPULATION, CHANGING HEALTH NEEDS, ETC.

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    graph LR
      A[Per Capita Cap] --> B[Cost shift to states]
      B --> C[Budget Pressure]
      C --> D[Service Cuts  
Lower Provider Rates  
Wait Lists  
Enrollment Cuts]
  
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CURRENT FINANCING V. BLOCK GRANTS & PER CAPITA CAPS (IN THEORY)*

If your state wants to...	Do you get more federal \$?		
	Current Structure	Block Grant	Per Capita Cap
add more enrollees	✓	✗	✓
add more services	✓	✗	✗
cover new Rx	✓	✗	✗
increase provider reimbursement	✓	✗	✗

*This is theoretical since any proposal can alter a state's ability to add more enrollees or other features of the Medicaid program.

IMPACT OF BUDGET SHORTFALLS ON PEOPLE WITH DISABILITIES

AS STATE MEDICAID BUDGET SHORTFALLS GROW, STATES MAY:

- CUT SERVICES** (PARTICULARLY "OPTIONAL" SERVICES LIKE WAIVERS)
- TOTALLY ELIMINATE OPTIONAL SERVICES** (AGAIN LIKE WAIVERS)
- INCREASE WAITLISTS FOR SERVICES** (MANY STATES ALREADY HAVE THOUSANDS OF PEOPLE ON WAITLISTS FOR HCBS)
- DECREASE PROVIDER RATES**
- STATES THAT SPEND LESS PER CAPITA ON MEDICAID WILL BE PARTICULARLY HARMED
- PCCS BASED ON STATES' 2016 SPENDING



WHY ADVOCACY WORKS

- WE HAVE SHOWN THAT ADVOCACY WORKS.
- WE HAVE SHOWN THAT THE DISABILITY COMMUNITY IS A FORCE TO BE RECKONED WITH.
- WE HAVE INVIGORATED OUR DISABILITY RIGHTS MOVEMENT AND BUILT STRONG CROSS-DISABILITY COALITIONS.
- WE HAVE EDUCATED MEMBERS OF CONGRESS AND THE PUBLIC ABOUT MEDICAID AND DISABILITY RIGHTS.
- WE HAVE BUILT RELATIONSHIPS WITH BROAD GRASSROOTS GROUPS
- WE HAVE SEEN SEVERAL MEMBERS OF CONGRESS EMERGE AS MAJOR DISABILITY RIGHTS CHAMPIONS



WE ARE STRONG, FIERCE
ACTIVISTS FIGHTING FOR OUR
RIGHTS AND FIGHTING FOR OUR
LIVES. WE KNOW THAT WE HAVE
TO PUT OURSELVES AND OUR
BODIES ON THE LINE. WE KNOW
WHAT WE'RE DOING. WE MADE
THAT DECISION





**Healthcare Protesters Have Been Arrested On The Hill
500 Times Over The Past Two Months**



WHAT YOU CAN DO DURING THE RECESS

Thank them for their vote if they voted the way you wanted them to (or take the opportunity to say again why Medicaid and the protections in the ACA are so important)

- Ask for bi-partisan hearings on the topics of health care, Medicaid, and community-based long-term services and supports
- Tell them that improving the ACA and improving health care for the country is the goal; pre-empt the message to let the ACA implode and to harm millions of Americans
- And get ready for attacks on Medicaid, SSI, and SSDI—they are coming and we'll need to be ready to protect them.

HOW MEDICAID BENEFITS HELP JOSHUA PROFFITT ACHIEVE HIS DREAM

RESOURCES

- WWW.PROTECTOURMEDICAID.ORG
- **FAMILIES USA LIST OF QUESTIONS:**
[HTTP://FAMILIESUSA.ORG/SITES/DEFAULT/FILES/DOCUMENTS/AUGUST_RECESS_2017_QUESTIONS_TO_ASK.PDF](http://FAMILIESUSA.ORG/SITES/DEFAULT/FILES/DOCUMENTS/AUGUST_RECESS_2017_QUESTIONS_TO_ASK.PDF)
- [HTTPS://TOWNHALLPROJECT.COM/](https://TOWNHALLPROJECT.COM/)

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