

# What Has Medicaid Managed Care Meant to Family Caregivers?

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# Presentation Overview

Background

Why Managed Care?

Study Background

Study Results

Lessons Learned & Limitations



# Background

# Background

- o Introductions

- o Annie

- o Heather

- o Maureen



# Background

- Majority of individuals with intellectual and developmental disabilities (I/DD) live with family caregiver
- More home and community based
- Majority I/DD services supports funded through Medicaid
- States vary greatly on spending

# Background

- o Medicaid Long Term Services and Supports (LTSS)
  - o Personal assistance services
  - o Family support
  - o Home and community based services (HCBS)
  - o Intermediate care facilities
  - o Nursing homes



# Background

- o Current Study

- o Trend is towards managed care for LTSS
- o Little known about managed LTSS from family caregiver perspective

# Why Managed Care?



# Why Managed Care?

- Growth in community living
- Medicaid fee-for-service
- Improve quality
- Achieve Medicaid savings
- Reduce waiting lists

# Why Managed Care?

## Waiting Lists for Medicaid 1915(c) HCBS Waiver: 2011, ID/DD

| Location             | ID/DD | Location      | ID/DD | Location       | ID/DD | Location       | ID/DD   |
|----------------------|-------|---------------|-------|----------------|-------|----------------|---------|
| California           | 0     | Oregon        | 0     | New Mexico     | 1,141 | North Carolina | 7,000   |
| Delaware             | 0     | South Dakota  | 23    | South Carolina | 1,296 | Virginia       | 7,188   |
| District of Columbia | 0     | Nevada        | 148   | Utah           | 1,847 | Louisiana      | 8,333   |
| Hawaii               | 0     | Wyoming       | 246   | Mississippi    | 2,000 | Georgia        | 10,364  |
| Idaho                | 0     | West Virginia | 409   | Arkansas       | 2,252 | Florida        | 19,460  |
| Kentucky             | 0     | Wisconsin     | 675   | Tennessee      | 2,316 | Pennsylvania   | 20,471  |
| Massachusetts        | 0     | Montana       | 806   | Kansas         | 2,414 | Illinois       | 33,114  |
| Michigan             | 0     | Washington    | 829   | Nebraska       | 2,657 | Indiana        | 35,837  |
| New Jersey           | 0     | Alaska        | 982   | Maryland       | 3,210 | Ohio           | 48,735  |
| New York             | 0     | Maine         | 1,000 | Colorado       | 3,232 | Texas          | 91,354  |
| North Dakota         | 0     | Connecticut   | 1,106 | Oklahoma       | 6,228 | United States  | 316,673 |

Source: Kaiser Family Foundation

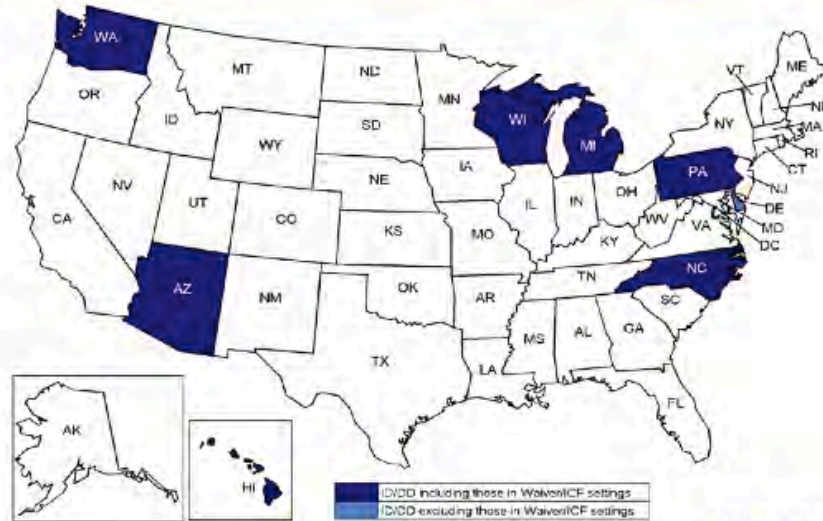


# Why Managed Care?

- o 10% enrollees in Medicaid managed-care are individuals with I/DD
- o Why so few?
  - o Resistance from disability community
  - o Health plans unfamiliar with complex needs
  - o Unsure rate settings
  - o Risks to health plans

# Why Managed Care?

**FIGURE 2: States Enrolling Individuals with Intellectual and Developmental Disabilities in MLTSS Programs, 2012**



Saucier, P., Kasten, J., Burwell, B., & Gold, L. (2012)

**TRUVEN**  
HEALTH ANALYTICS

Source: President's Committee for People with Intellectual Disabilities, 2012 Report to the President, Managed Long-Term Services and Supports

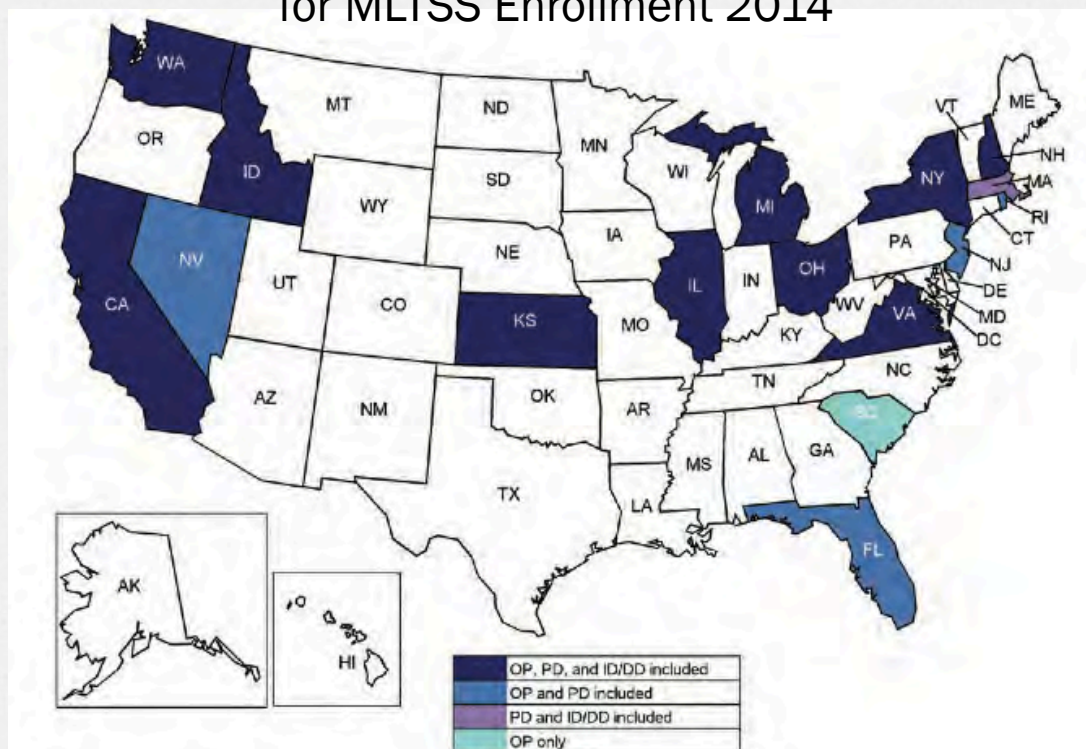


# Why Managed Care?

- More states considering managed care for LTSS
  - State budgets
  - Affordable Care Act opportunities
  - Population trends

# Why Managed Care?

## Population Groups Being Considered for MLTSS Enrollment 2014



Source: Saucier, P., Kasten, J, Burwell, B. & Gold, L. (2012). *The growth of managed long-term services and supports (MLTSS) programs: A 2012 update*. Washington, DD: Trueven Health Analytics prepared for the Centers for Medicare and Medicaid Services (CMS).



# Why Managed Care?

**FIGURE 6: Potential Benefits and Concerns in MLTSS**

**Potential Benefits:**

- Improved Coordination
- Reductions in Health Disparities
- Benefits in Prevention, Wellness, and Training of Health Providers
- Rebalancing
- Greater Options for Self-Direction
- Reduce Waiting Lists and Unmet Needs
- Reinvestment of Savings in Added Benefits

**Concerns:**

- Reduced Access
- Limits in Consumer Choice
- Medicalization of Long-Term Services and Supports
- Knowledge and Expertise of Health Plans in Disability
- State Capacity and Infrastructure to Oversee Programs
- Complexities in Rate Setting

Source: President's Committee for People with Intellectual Disabilities, 2012 Report to the President, Managed Long-Term Services and Supports

# Study Background



# Study Background

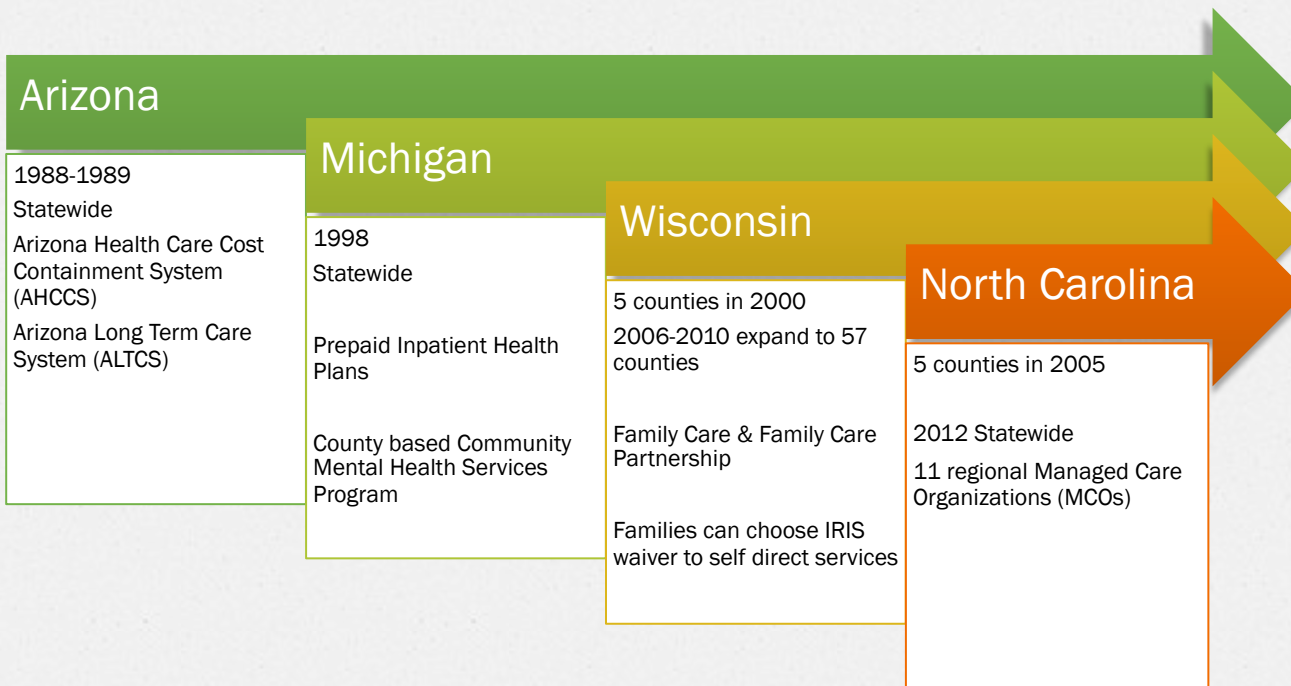
- Study Purpose: To understand how managed-care impacts families and family caregivers. Specifically, the study explores changes to support services available to family caregivers, as well as the impact-economic or other-on their family's ability to care for their family member with a disability.

# Study Background

- In-depth semi-structured telephone interviews
- Interview protocol
- Families from Arizona, North Carolina, Michigan & Wisconsin
- Inclusion criteria
- Recruited through The Arc network



# Study Background



# Study Background

## Study Sample N=16

| Family Caregiver   | Adult with I/DD   |
|--|---|
| <ul style="list-style-type: none"><li>• All female</li><li>• 1 Sibling</li><li>• Mean age 57.9 (SD=10.8)</li><li>• Age range 41-86</li><li>• 15 out of 16 live in urban area</li></ul> | <ul style="list-style-type: none"><li>• 11 female, 5 male</li><li>• Mean age 29.2 (SD=10.4)</li><li>• Age range 15-49</li></ul> |



# Study Background



# Study Background





# Study Background

## o Individuals with I/DD

- o 4 Autism (Mild to Severe ID)

- o 5 Genetic syndromes (Moderate to Severe ID)

- o 4 Down syndrome (1 Severe ID, 1 Moderate ID, 2 unknown level ID)

- o 1 Cerebral Palsy (Severe ID)

- o 2 Mild to Moderate ID

# Study Results



# Study Results

## o Study Results

- o Caregiving role: Overall experience as a family caregiver
- o Family support services: Overall experience with family support services
- o Medicaid managed care experience
- o Ideal supports and services

# Study Results

## Caregiving Role Experience

### Caregiving Advocacy

- Networking with other families is key
- Devote yourself to understanding services & supports system
- Can't rely on the system for help ■
- Different advocate roles ■
- Need for more family advocate training ■
- Quality of life of adult with I/DD will suffer without family advocacy ■



# Study Results

- o Caregiving Role: Caregiver advocacy
  - o Devote yourself to understanding
  - o Can't rely on the system for help

“What they don't realize is that you have to devote yourself to maintaining the plan, to keeping up with service definitions, to learning whole new language, to managing a staff of people”  
*NC Family Caregiver*

“I know all of the right people to call. I know how to make things happen if I need to make them happen” *AZ Family Caregiver*

# Study Results

| Caregiving Role Experience  |   |
|---|---|
| Caregiving Wellbeing  | Compound Caregivers   |
| <ul style="list-style-type: none"><li>• Experienced as a gift from God</li><li>• Experience of stress, grief, and sacrifice</li></ul> | <ul style="list-style-type: none"><li>• Family caregiver also taking care of others in the family</li></ul> |



# Study Results

- Caregiving Role: Caregiver wellbeing
  - Stress, grief, and sacrifice from caregiving

“So you know, it’s either sacrifice my life for her to have a beneficial treatment plan, or I sacrifice her completely to save myself, and that’s the dilemma that I’m in, and I’m sensing others with these complex individuals. They may not be articulating it that same way, but that’s exactly how they’re feeling.” *NC Family Caregiver*

“And stress definitely...you might have a few months of low, but your low, you always know it’s when the other shoe is going to drop you got to get into action, so whenever that happens, you got to be ready” *NC Family Caregiver*

# Study Results

## Caregiving Role Experience

### Economic Impact

- Sacrifice careers ■
- Live modestly to make ends meet
- Only income from being paid as the family caregiver
- Lack of long term family financing plan

### Future Planning

- Fear about what will happen when they are no longer around
- Uncertainty about quality of life for adult with I/DD once no longer in family home



# Study Results

## Family Support

### Experience and Meaning

- Respite
- Transportation
- Importance of flexibility
- Payment to family caregivers to provide services
- Direct support professionals (DSPs) that are long term and trustworthy
- Education
- Emotional support and encouragement from other families
- Decline or lack of services

# Study Results

## o Family Support Services: Experience & Meaning

### o Decline or lack of services

“I wish there were some. I don’t feel that I’m getting support except from other parents that I know” *MI Family Caregiver*

“I would say miniscule, that I’ve seen a substantial change over the last, oh, I’d say 6 to 7 years...from a place where family support was way at the top of the priority list for ...the main providing agency in our state, and now, it’s pretty much non-existent to the point that it’s as if it’s an entirely different agency that we’re working with” *AZ Family Caregiver*



# Study Results

## Family Support

### Caregiver Wellbeing

- Helpful if they empowered the family
- Critical for sustaining caregiving role
- Helps family caregiver have a life
- Reduce stress

# Study Results

- o Family Support Services: Caregiver Wellbeing
  - o Family support services are critical for sustaining caregiving role

“I can’t survive without them. I mean literally cannot survive without them” *NC Family Caregiver*

“I do get a lot of lot of help with her, for her, which you know to me, if I didn't get this help I probably would have placed her a long time ago. So it really, it really does help, it gives me, it gives my husband and I a life where we can do things.” *MI Family Caregiver*



# Study Results

## Family Support

### Adult with I/DD Status

- Family training and education improved outcomes
- If services are reduced then their son/daughter would spend less time in the community
- Consistency of support providers has helped their son/daughter to blossom
- Consideration of placement or resigning of guardianship without support services
- More strain on the family caregiver to individualize supports and services

# Study Results

## Family Support

Provided by family/friends vs. direct support professional

- Satisfaction with support services because only family or friends being paid to provide support services
- Low payment rates for support service providers
- If DSPs are not family members, families experience staff turnover, lack of availability, and criminal behavior by staff ■



# Study Results

## Medicaid Managed Care Experience

### Access to Services

#### North Carolina

- Assessment tool a barrier to providers
- Decrease in service provider agencies
- Reduce staff pay & increase staff turnover
- Decreased access to specialty services
- No choice of MCO provider
- 30-35% decrease in services
- Not maintained service level while on appeal

#### Michigan

- Increase in lower paying services resulting in lower staff pay
- Varying experience with respite availability
- Decreased community living supports & mileage rates limits activities for person with I/DD
- 70% reduction in community living supports seen by one family
- Kept at same service level while awaiting appeal hearing

# Study Results

## Medicaid Managed Care Experience

### Access to Services

#### Arizona

- Increased difficulty in obtaining eligibility
- Reduction in provider pay
- Reduced options for group homes
- More sheltered workshops
- Limited respite providers
- Saw respite reduced by 35%
- Don't use services (can't find providers) then you lose services
- No more back up system funded by county to cover services not qualified for through state
- The more individualized the plan, the more difficult to achieve

#### Wisconsin

- Better now than it used to be since now paying for transportation
- Happy with services



# Study Results

## ◦ Medicaid Managed Care Experience:

### ◦ Access to Services

“So you get the sense of the family that your person that you’re taking care of has to fit their box as opposed to having, shall we say, a sort of, some thoughts about what would really work well during the day for an individual, and then being able to talk to providers and have them try to create something. That’s very, very, very difficult to do now, and that did not used to be the case” *AZ Family Caregiver*

# Study Results

## Medicaid Managed Care Experience

### Care Coordination

#### North Carolina

- Care coordinator is a paperwork processor
- No more care coordinator advocacy ■
- Care coordinator works for MCO ■
- Poor communication
- Lack of respect from MCOs
- Took one person's job, case manager, and divided it into three positions

#### Michigan

- Support coordinator communicates with family periodically and handles yearly paperwork processing
- Care coordinator lacks value, rather money go into budget
- Family managed their own budget which can be complicated
- Deal with two separate paperwork systems & meetings to manage budget



# Study Results

## Medicaid Managed Care Experience

### Care Coordination

#### Arizona

- Service coordinator only attends meetings & processes paperwork
- Service coordinator caseloads too large so just putting out fires
- Used to get more personalized services from service coordinator but now just status quo
- Lost highly skilled support coordinators ■

#### Wisconsin

- Feels listened to by her MCO contact and that they are there to help
- Better quality service from care coordinator with lived experience
- Managed care puts less expectations on the family to manage services and supports ■

# Study Results

- Medicaid Managed Care: Care Coordination
- Lack of respect

“No discussion with me... They don’t listen to a word I say like I’m an idiot, even though I’ve had to live and learn and adapt and modify and seek information, and you know. My word is garbage because I’m a system sucker. That’s what they think of me as. I’m just there to suck the system out of money. So I’m completely invalid.” *NC Family Caregiver*



# Study Results

## Medicaid Managed Care Experience

### Support Staff

| North Carolina  | Michigan  | Arizona   | Wisconsin  |
|---|---|---|--|
| <ul style="list-style-type: none"><li>• Lower pay rate</li><li>• DSP has had 3 pay cuts since managed care</li><li>• Can't find staff</li><li>• More staff turnover</li></ul> | <ul style="list-style-type: none"><li>• Reduced pay rate for DSPs</li><li>• Inability to find DSPs resulted in loss of service eligibility</li><li>• No choice of fiscal intermediary</li></ul> | <ul style="list-style-type: none"><li>• Pay cut to DSPs</li><li>• More staff turnover</li><li>• Only allowed to use one company to recruit DSPs</li></ul> | <ul style="list-style-type: none"><li>• Adult with I/DD goes to an agency for all services</li><li>• Didn't see change in provider</li></ul> |

# Study Results

| Medicaid Managed Care Experience   |  |   |  |
|--|--|---|--|
| Caregiver Wellbeing  |  |   |  |
| North Carolina   | Michigan   | Arizona   | Wisconsin  |
| <ul style="list-style-type: none"><li>Feelings of being trapped, paralyzed, punished ■</li></ul> | <ul style="list-style-type: none"><li>Grateful for what they do have</li></ul> | <ul style="list-style-type: none"><li>Using limited respite to work so no break</li></ul> | <ul style="list-style-type: none"><li>Caregivers happy with services</li></ul> |



# Study Results

- Medicaid Managed Care: Caregiver Wellbeing
- Feelings of being trapped, paralyzed, punished

“They have limited services for us in the last year. They took power April 1, 2012...and by September we couldn't even breathe” *NC Family Caregiver*

“So it’s like, we aren’t living our life by any stretch of the imagination because at any given moment, I don’t know what’s going to happen, and truly, I will resign my guardianship, and the new guardian will have 30 days to figure out where my daughter is going to live because it’s not going to be here. I’m done. I’m out. I tap out. ” *NC Family Caregiver*

# Study Results

| Medicaid Managed Care Experience  |  |  |  |
|---|--|--|--|
| Economic Impact   |  |  |  |
| North Carolina  | Michigan   | Arizona  | Wisconsin  |
| <ul style="list-style-type: none"><li>Family members are paid providers so with reduction in services they can barely buy groceries</li></ul> | <ul style="list-style-type: none"><li>If family doesn't win current appeal then they will need to decrease work hours or quit job, would lose their home</li></ul> | <ul style="list-style-type: none"><li>Using limited respite to work, so reduced work hours</li></ul> | <ul style="list-style-type: none"><li>No comments related to economic impact</li></ul> |



# Study Results

## Medicaid Managed Care Experience

### Geographic Limitations

| North Carolina  | Michigan  | Arizona   | Wisconsin   |
|---|---|---|---|
| <ul style="list-style-type: none"><li>• Feelings of inability to move without losing services</li><li>• Different services available depending on where you live in the state</li></ul> | <ul style="list-style-type: none"><li>• Different services available depending on where you live in the state</li><li>• Lack of flexibility in their area</li></ul> | <ul style="list-style-type: none"><li>• No geographic limitations noted</li></ul> | <ul style="list-style-type: none"><li>• No geographic limitations noted</li></ul> |

# Study Results

## Medicaid Managed Care Experience

### Meaning of Managed Care

| North Carolina   | Michigan  |
|--|---|
| <ul style="list-style-type: none"><li>• Gestapo, lock-down and take away services</li><li>• Put everyone in a pot to save money by providing as little as possible</li><li>• Make sure nobody gets more than anyone else</li><li>• Limit</li><li>• Belittling dictatorship</li><li>• Just another term for utilization review of services offered, I/DD has always been in managed care just a new term used today</li></ul> | <ul style="list-style-type: none"><li>• Group of people who help you coordinate services</li><li>• Not personalized service</li><li>• No response</li></ul> |



# Study Results

## Medicaid Managed Care Experience

### Meaning of Managed Care

#### Arizona

- Managed care drives the system
- Bureaucracy focused on tax payers not the families
- Multiple agencies that manage different parts of our lives
- Lack of individualized and empathetic services ■
- Restriction of services ■

#### Wisconsin

- Having all of the functions you need in one place
- Helpful
- No response

# Study Results

## o Medicaid Managed Care: Meaning and Experience

### o Gestapo, lock-down and take away services

“I call them the Gestapo, they've just come in and totally wiped us out and everything positive we had, it's gone...with this managed care, it is just gone ” *NC Family Caregiver*

### o Belittling

“Managed Care to me is – Well first of all, it’s belittling...It’s a dictatorship of what you deem medically necessary for me and my family” *NC Family Caregiver*



# Study Results

- o Medicaid Managed Care: Meaning and Experience
  - o Lack of flexibility

“To me, it means that someone in an office might be making decisions without knowing my son or without knowing what kinds of services he would need, and there might not be flexibility to tweak, you know, the system as for what he might need”  
*MI Family Caregiver*

# Study Results

- o Medicaid Managed Care: Meaning and Experience
  - o Lack of individualized and empathetic services

“I don’t feel like anybody is kind of walking with me on this, which is what the whole idea was of having this system in the first place, was to kind of walk alongside of families and help them. It’s almost to the extent that I would equate the system with the food stamp system. In other words, it just feels like it’s kind of cut and dried rubber stamped. Here’s how it works, honey. You know, if you don’t like it you just have to figure something else out. You know, it’s just really, really disconcerting that it’s gotten to that point.” *AZ Family Caregiver*



# Study Results

## ◦Medicaid Managed Care: Meaning and Experience

- Multiple agencies that have manage different parts our lives

“Well, what it means for us in Arizona, in my opinion, is we end up with multiple agencies, that we have, you know, that have different parts of my daughter’s life, that they manage different parts of her life. In reality, what I think managed care should mean, is it should be, kind of one stop shopping” *AZ Family Caregiver*

# Study Results

## Ideal Support Services

- Happy with what they have now
- Son/daughter with I/DD would live on their own, have a job, access to recreational activities, to education and skill acquisition services, and medical coverage
- Increase pay to DSPs so it is more of a career
- Not being limited by availability of staff or money to pay staff
- Family caregiver training paid for
- Not using one assessment tool for all
- Stable system that doesn't change every few years so they can plan for the future ■



# Study Results

## Ideal Support Services

- True person centered planning
- Money follow the person with just some general oversight from an agency
- Having supports so they can go back to work
- System that trusts the family ■
- Community ranch for all abilities that is self-sustaining but open to the public for recreation and shopping
- Federal safety net so families in all states have similar experience (VA Family Stipend Program)

# Lessons Learned & Limitations



# Lessons Learned & Limitations

## oSummary Thoughts

- oDirect support professional availability is critical
- oFamilies feel they must advocate for what is needed and they can't rely on the system
- oDifferent experience depending on where you live
- oThe more individualized and community integrated services the harder it is too achieve with managed care
- oManaged care with LTSS can feel like it is a management of your life

# Lessons Learned & Limitations

## o Study Limitations

- o Short timeline

- o Not representative sample of all experiences

- o Recruitment through The Arc network

- o Convenience sample

- o 2 families did not fit inclusion criteria (one lived in own home and one was a teenager)



# Lessons Learned & Limitations

## oWhat's Next?

- oResults can be used as pilot data to inform policy
- oManaged care seems to have a bias towards less individualized services and supports
- oManaged care has a real impact on the caregiver as well as the adult with I/DD
- oFamily caregivers and individuals with I/DD should have more of a voice in managed care from planning to implementation and evaluation

# Lessons Learned & Limitations

o Thank you

o University of South Florida, College of Public Health, Department of Community and Family Health Student Research Award

o The Arc National office

o The Arc State Executive Directors

o The Arc Chapters





# Study Results Additional Quotes Page 1

- o Caregiving Role: Caregiver advocacy
- o Can't rely on the system for help

“So you have to have your tool kit, your boots on the ground and get moving” *NC Family Caregiver*

“I go with the question, and then she (supports coordinator) has to get the answers” *AZ Family Caregiver* ■



# Study Results Additional

## Quotes Page 2

### ◦ Caregiving Role: Caregiver advocacy

- Multiple advocate roles and need for more family advocate training

“I realized as an advocate, I play every one of those roles, depending on who I’m dealing with and what I want...I’d go downtown and meet with a Senator, I’m a victim. I’d go downtown and meet with certain people and I am a persecutor... And then some mom calls up and is all helpless and falling apart, and I’m a rescuer, and it was absolutely killing me...It’s hard. I mean even when I was a single parent, you just don’t have extra time sometimes and you have other kids demanding your attention, and you’re overwhelmed...there’s so many folks just waiting for everyone else to fix it, and well, they’re fixing it alright” NC Family Caregiver.

# Study Results Additional Quotes Page 3

- o Caregiving Role: Caregiver advocacy
  - o Quality of life of adult with I/DD will suffer without family advocacy

“I’ll be honest with you, in some ways, even though the services, I couldn’t do without them for my daughter. I wish I could. I know it sounds really bad, but it is just, I know that if something happens to me, then they cannot be managed at the same level, and her life, and the quality of her life will be impacted” *NC Family Caregiver* ■



# Study Results Additional Quotes Page 4

## o Caregiving Role: Economic Impact

### o Sacrifice careers

“My husband...He’s the primary breadwinner. We’ve made the decision long ago, and I think you’re going to find this with almost all of your calls, at least one person in the family really chose to kind of, you know, be that champion or the advocate for that person. However they chose to do that role, you will find that it’s a divide and conquer strategy because that’s the only way to really make it through” *NC Family Caregiver* ■

# Study Results Additional Quotes Page 5

- o Family Support Services: Provided by family/friends vs. direct support professional

- o If direct support staff are not family members, families experience staff turnover, lack of availability, and criminal behavior by staff

“Prior to (support staff person), we had 19 different care providers in less than 10 years, and that’s kind of an average” *NC Family Caregiver*

“In the past, I’ve had stuff stolen from me. My daughter’s been abused” *NC Family Caregiver* ■



# Study Results Additional Quotes Page 6

## o Medicaid Managed Care: Care Coordination

### o Lack of care coordinator advocacy

“The advocacy piece is completely gone and ...for most families, that is going to be the biggest loss... because they don't have someone to explain to them. I've heard stories of parents who... they don't even hear from their care coordinator... Your support, your life line to your support is gone... I mean in the past, you'd have case managers who would go to IEP meetings with you, who would go to doctor's appointments with you if necessary. You know, that's gone. If you had to...if there was some issue with services, your case manager, you know, would step up to the plate for you or with you.” *NC Family Caregiver* ■

# Study Results Additional Quotes Page 7

- o Medicaid Managed Care: Care Coordination
  - o Care coordinator works for MCO

“But your care coordinator, how do you like this? About keeping the fox with the hens. The same managed care organization that approves your services and oversees to make sure that you are receiving quality services also employs your care coordinator. So how do I go to them if I’m complaining about care coordination? Are they actually supposed to oversee themselves? We know how well that works” *NC Family Caregiver* ■



# Study Results Additional Quotes Page 8

## o Medicaid Managed Care: Care Coordination

- o Lost highly skilled support coordinators with budget cuts

“When the moneys were less, and they were house cleaning, there was mass exodus of highly-skilled, experienced people who had been in the system as support coordinators for many, many years, they all left. They retired...People just, it just drove them out, and in order to meet the requirements of the managed care system, the agency had to hire new people, and they’re pretty green. So they are young. They may have lots of energy and enthusiasm, but they basically don’t have the years of experience and knowledge... so the ability for the support coordinator to really be a social worker for that family is pretty nil, and many people told me that.” *AZ Family Caregiver* ■

# Study Results Additional Quotes Page 9

## o Medicaid Managed Care: Support Staff

### o Can't find staff or staff turnover

“Yes, so we are dealing with new people, new faces, and fill-in, and you know...a much more revolving doorway today” *NC Family Caregiver*

“Well, I had to have my ego taken down a notch or many notches, and as well as the reality that you can have the best team in the world, but if there's not enough of the right pay to really have the people feel valued, they're gone” *NC Family Caregiver* ■



# Study Results Additional Quotes Page 10

## o Medicaid Managed Care: Caregiver Wellbeing

### o Feelings of being trapped, paralyzed, punished

"It just paralyzes me because in North Carolina, we have been in a constant state of change for a decade since 2001 when they first began Medicaid reform, and they have changed, and changed, and changed, and changed every year pretty much or every couple of years. The service definitions, the rules and regulations, and they're targeting the wrong, like we're lumped into to the collective whole, and it works less and less well for the pocket, the subset that my daughter falls into, which is the most vulnerable, the most complex" *NC Family Caregiver*

"They're ruining my life. I mean that's the bottom line as I can't do anything without questioning who's trying to take away something from her. And I've actually said out loud, you know, I'd rather the kid be dead because, and how horrible that is, but it's a constant, constant stressor, and an emotional drain that has impacted my entire family" *NC Family Caregiver* ■

# Study Results Additional Quotes Page 11

## o Medicaid Managed Care: Meaning and Experience

### o Lack of individualized and empathetic services

“If you look managed care up in a dictionary I bet, or on the internet, it is going to tell you probably something like, you know, an organized set of supports and services, does in reality that happen? Not here! Not if you use multiple services and not if you want something that is a little more independent. Now, if my daughter lived in a group home, I've always said, if my daughter lived in a group home and went to a sheltered workshop it would be easier on me. Now, would it, would my daughter have quality of life, I, I don't know. Would she have the quality of life she has now? No. But it would definitely be easier on me. Because at that point the only thing that I would have to worry about would probably be her annual meeting. And then I'd probably just get a notice of when it was going to be and her annual meeting through DDD. Because I would guarantee you the service provider that was providing her residential and her day program, would make sure she remained eligible.” *AZ Family Caregiver* ■



# Study Results Additional Quotes Page 12

## o Medicaid Managed Care: Meaning and Experience

### o Restriction of services

“It just feels like the tightening of the noose over the years, little, by little, by little, by little, till the family is kind of just so squeezed that you just want to sort of give up and say okay, fine, you take my family member and you’re in-charge, and that’s not at all what I want to do, but I do think that that happens to people” AZ  
*Family Caregiver* ■

# Study Results Additional Quotes Page 13

## o Ideal Supports & Services

- o Stable system that doesn't change every few years so they can plan for the future

“It would bring a permanent situation to my daughter’s life. It would bring predictability. It would – And with that would come the ability to plan” *NC Family Caregiver* ■



# Study Results Additional Quotes Page 14

## o Ideal Supports & Services

### o System that trusts the family

“So yeah, it’s really about trusting people and then setting up a system that does have oversight” *AZ Family Caregiver* ■

# Study Results Additional Quotes Page 15

- Managed Care Experience: Care Coordination
  - Managed care puts less expectations on the family to manage services and supports

“I have a friend that her – She’s involved with, I believe it’s Family Care it’s called. It’s Community Care, Family Care, and she loves it because they take care of certain things, but she just doesn’t see anything, and she didn’t have to deal with anything, and for her, she’s very happy with that. So I mean everybody has their own, I guess, what’s best for them. Some people don’t want to do all that or they’re not able to do those things, you know, because you got to do some paperwork, and keep track of things, and sometimes, you have to pay for things and then get reimbursed, you know, for certain items or certain things, you know, so everybody doesn’t want to do all that, so you know. It was pretty simple for us to make that decision, you know.” *WI Family Caregiver* ■