FAMILY AND INDIVIDUAL PERSPECTIVES ON HEALTH AND LONG- TERM SERVICES AND SUPPORTS REFORMS

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OVERVIEW OF PRESENTATION

- Context of managed care and DD
- Involving families and individuals with DD
  - Planning
  - Implementation
  - Evaluation
- Example of Integrated Care Program Evaluation
- Lessons learned

DEMOGRAPHIC AND POLICY CONTEXT FOR PEOPLE WITH DD AND THEIR FAMILIES

- Longevity revolution
- Rebalancing from institutions to group homes and to supported living
- Increase in family support
- Increase in self-directed supports
- Broader changes in state DD service systems toward managed care

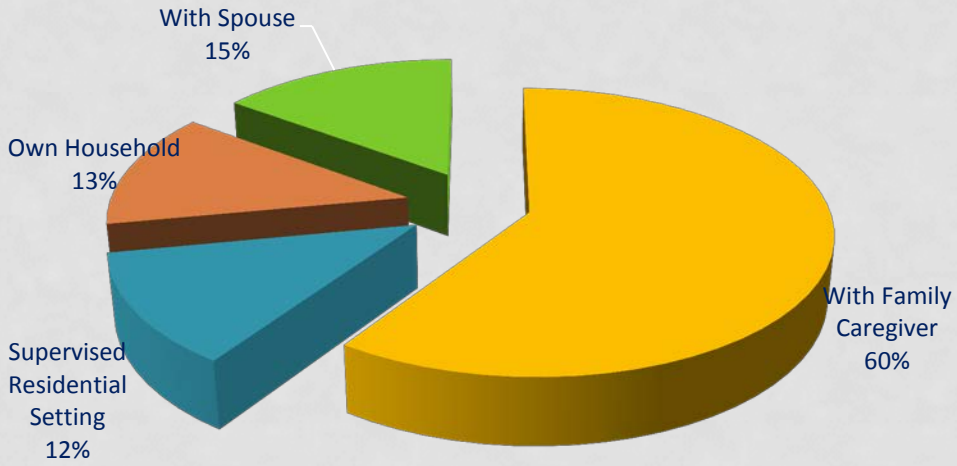
ESTIMATED NUMBER OF IDD CAREGIVING FAMILIES COMPARED TO FAMILIES SUPPORTED BY STATE IDD AGENCY FUNDS: 2011

State	Total IDD Caregiving Families	Families Supported by I/DD Agencies	% of Families Supported
UNITED STATES	3,513,224	467,958	13%

Source; Braddock et al, Coleman Institute and Department of Psychiatry, University of Colorado, 2012.

Emerging Challenges: Demographics

Where People Live: US, 2011



Source *Braddock, Hemp, & Rizzolo, 2012*

TRENDS IN POLICIES

- Shrinking of federal/state DD budgets
  - Great Recession (starting 2007) resulted in largest spending drops in 35 years
  - Weak recovery, 2013 budget lower (Braddock et al., 2012)
- Increasing residential waiting lists
  - Estimate of 115,059 (Larson et al., 2012)
- Greater use of supported and family living
  - Of 612,704 in out of home residential settings, 45% in 6 or fewer supported living

REASONS GIVEN FOR MANAGED CARE

- Under fee-for-service, poor communication and coordination leads to reduced quality of care and unnecessary costs

- Managed care can:
  - Coordinate health care and LTSS
  - Control costs
  - Rebalance

- Financial incentives for Managed Care Organizations

MANAGED CARE AND DISABILITY

- Most states include children, pregnant women and adults without disabilities in Medicaid Managed Care
- Slow to include people with disabilities (10% of managed care enrollees)
  - Resistance from disability service providers
  - Resistance from advocates
  - Health plans not familiar with complex needs of people with disabilities
  - Difficult to set rates and assess risks

MANAGED CARE AND MLTSS

47 states implemented managed care covering 71% of Medicaid enrollees [2010]

28 states using MLTSS

Only 9 states include IDD in MLTSS;
11 new states in next 2 years

FIGURE 4: Types of Contractors in MLTSS Programs Enrolling Individuals with ID/DD

Program	*Managed Care Entity*
AZ Long Term Care System	State Agency (Division of Developmental Disabilities)
DE Diamond State Health Plan-Plus	2 National Health Plans
HI QUEST Expanded Acess	2 National Health Plans
MI Managed Specialty Support & Services	18 County-Based Entities (1 per service area)
NC MH/DD/SAS Health Plan Waiver	3+ Local Management Entities (1 per service area)
PA Adult Community Autism Program	1 Provider Organization (Keystone Autism Services)
WA Medicaid Integration Partnership	1 National Health Plans
WI Family Care Partnership	9 County-Based or Non-Profit Entities (1 per service area)
WI Family Care	4 Local Health Plans

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

TRUVEN HEALTH ANALYTICS

BENEFITS AND CONCERNS OF MLTSS

Potential Benefits

- Improved Coordination
- Reduced Health Disparities
- More Prevention
- Training for Health Providers
- Rebalancing
- More Options for Self-Direction
- Reduced Waiting Lists and Unmet Needs
- Reinvestment of Savings in Added Benefits

Concerns

- Reduced Access
- Limits Consumer Choice
- Medicalization of LTSS
- Knowledge of Plans Related to Disability Issues
- State Capacity/Infrastructure to Oversee Programs
- Complexities of Rate Setting
- Concern to Replace Current System

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ROLE OF FAMILIES AND ADULTS WITH IDD IN MLTSS

- Engagement in stakeholder meetings throughout with feedback
- Seat at the table in policy making
- Supported decision-making for adult with IDD if needed
- Advocating for services and supports
- Serving as personal support worker (family)
- Planning for the future using person centered approaches
- Providing input in evaluation with transparency of results
- Serving as peer trainer and navigator

INTEGRATED CARE PROGRAM (ICP)EVALUATION

- UCEDD hired to evaluate impact of ICP on participants using a community based participatory approach
- Engagement of stakeholders throughout by participation in stakeholder meetings and ongoing advisory board
- Multi-method approach to obtain input of stakeholders and people with disabilities
- Challenge of getting the voice of people with IDD and their families

ICP OVERVIEW

- Impacts 40,000 in collar counties of Chicago
- Medicaid-only seniors and adults with disabilities
- Move from traditional FFS to MMC run by managed care organizations (MCO)s (Aetna or IlliniCare)
  - Establish medical homes and care coordination
  - Phase 1: Acute Health
  - Phase 2: Long-Term Supports and Services (except DD)
  - Phase 3: DD Long-Term Supports and Services

EVALUATION COMPONENTS

Advisory Board

Data Sources

- Consumer Surveys and Interviews
- Encounter Data
- Focus Groups
- MCO Data

Stakeholders

- Consumers & Families
- Advocates
- MCOs
- Providers
- State Agencies

Evaluation Types

- Process
- Outcomes
- Economic Impact

RESEARCH DESIGN

- Baseline (year before ICP) through first two years
- Comparison group design (FFS; people with similar characteristics, not living in pilot area)
- Encounter data – 40,000 in ICP & 67,000 in FFS
- Survey – longitudinal and cross-sectional with Chicago group comparison (including family survey)
- Cognitive interviews of people with DD
- Focus Groups – multiple stakeholders each year

HEALTH SERVICES APPRAISAL (HSA)

- Scale to measure person's feelings towards healthcare services received
  - Overall satisfaction with healthcare
  - Satisfaction with their primary care physician
  - Satisfaction with medical specialists
  - Satisfaction with care coordination
  - Satisfaction with the medical services received
  - Perception of the quality of care received

- HSA (α = .732)
  - ID/DD (α = .700)
  - Mental Health (α = .783)
  - Physical Disability (α = .733)

COGNITIVE INTERVIEWS

- Appraisal of overall health care over the last year
  - *They take care of all my services*
  - *My doctors tells me to take my every pills every day and sees how I am doing*
  - *– He makes you feel – and I'm not the only who has this opinion of him – he has a tendency of making you feel beneath him. He's a doctor and you're just a patient and you don't know nothing. I know my body and I know if something is wrong with me – I've been in my own body for 50 years. He thinks he's better and smarter than I am and we bump heads, we clash. He doesn't have a good bedside manner..*

COGNITIVE INTERVIEWS

- *I needed a personal assistant and it took a long time, had to have family members help and they didn't always know what to do*
- *They are helping me walk, get all medical stuff done, to feel like a person again*
- *The doctor answered all the questions that I needed to be answered and in a way I could understand*
- *I was able to receive a good psychiatrist, one that has been really helpful to me, and I was able to get my glasses.*

Cross-sectional (after Year 2) Demographics

Demographic	All Respondents		People with I/DD	
	ICP	FFS	ICP	FFS
Respondents	n=790	n=720	n=313	n=197
Gender				
- Female	59.1%	57.2%	52.9%	47.4%
- Male	40.7%	42.5%	46.5%	52.0%
Race				
- Black	31.0%	60.4%	26.5%	53.7%
- White	45.6%	15.0%	53.7%	16.8%
Hispanic Origin	8.2%	12.8%	6.7%	16.2%
Disability				
- Int/Dev Disability	39.6%	27.4%	100.0%	100.0%
- Mental Health	35.8%	33.9%	42.2%	44.7%
- Physical Disability	39.2%	43.2%	26.2%	34.5%
Age (mean)	50.2	53.5	40.3	45.4

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Cross-sectional (after Year 2) Regressions: People with I/DD

Variable	Health Services Appraisal		Unmet Medical Needs		Community Participation	
	t	Sig.	t	Sig.	t	Sig.
ICP	1.203	.230	-.673	.501	1.691	.091
Age	.084	.933	1.549	.122	-2.141	.033*
Male	.888	.375	.549	.583	.024	.981
White (v. minority)	1.369	.172	-2.384	.017*	.504	.614
Phys. Dis.	.754	.451	5.135	.000**	-3.083	.002**
Mental Health	-.919	.358	2.215	.027*	-4.025	.000**
Prev. Services	2.257	.024*			4.241	.000**
Unmet Medical Needs	-7.381	.000**			-2.873	.004**
ICPxPD	-1.856	.064				

* p < .05; ** p < .01

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Cross-sectional (after Year 2) Regressions: People with IDD

Variable	How often PCP knowledgeable about condition		How often PCP takes wishes into account	
	t	Sig.	t	Sig.
ICP	-2.131	.034*	-.024	.981
Age	-2.280	.023*	.830	.407
Male	-.837	.403	-.911	.363
White (v. minority)	.894	.372	2.458	.014*
Phys. Dis.	1.366	.173	-2.185	.029*
Mental Health	-.217	.828	-2.503	.013*

* p < .05; ** p < .01

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CONCLUSION

Among people with IDD:

1) Lower health care appraisal if have physical disability
2) More unmet needs for racial ethnic minorities, physical disability and/or mental health disabilities
3) Preventive counseling associated with higher health care appraisal and more community participation
4) Primary Care Physicians (PCP)s less knowledgeable about older people
5) PCPs less likely to take wishes of people with Mental Health disabilities into account

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IMPLICATIONS

1) Managed Care can result in better integration of services
2) However, more attention needed to people with IDD and mental health and/or physical disabilities
3) Need for more education of PCPs about aging and IDD and about respect for wishes of people with mental health needs
4) Increase preventive counseling from health professionals
5) Importance of integrating health and long term services and supports

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RECOMMENDATIONS FOR MLTSS

- **Community Living**
  - Institutional and community based in same plan
  - Savings used to expand access to HCB supports
- **Personal Control**
  - Person-centered practices, choice, and self-direction
  - Resource Allocation Decision Method, to determine effective means of providing LTSS (WI)
  - Tools and strategies to ensure person-centered and outcome-oriented planning approaches
  - Overly restrictive rules about nursing restrict choices
  - Training in managing personal support workers (e.g., *Find, Choose, Keep DSPs*)

RECOMMENDATIONS FOR MLTSS

- **Support for Family Caregivers**
  - Assistance to effectively support and advocate on behalf of people with I/DD
  - Allowed payment to family members
  - High parental satisfaction and well-being when sibling was support worker (Heller et al., 2012)
- **Stakeholder Involvement**
  - Disability advocates fully engaged in designing, implementing, and monitoring MLTSS outcomes
  - Disability Advocates Advancing Our Health Care Rights collaborated with state Medicaid agency (MA)

RECOMMENDATIONS FOR MLTSS

- **Coordination of Services and Supports**
  - Health services coordinated with LTSS
  - Service coordinators independent of the MCO—keep existing care coordinators
- **Assistive Technology and Durable Medical Equipment**
  - Access to durable medical equipment and assistive technology

RECOMMENDATIONS FOR MLTSS

- **Continuity of Care**
  - Phase in schedule with a readiness assessment
  - Provider continuity; switching care plans if want
- **Research and Evaluation**
  - Research on best practices in LTSS
  - Better health and LTSS outcome measurements
- **Education and Outreach**
  - Education and outreach campaign to families, people with IDD and providers
  - Training and education to MCOs on person centered, self-directed planning

CONTACT US

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