

Supporting Individuals and Families to Have Full and Meaningful Lives as Members of Their Communities

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Overview



- National Trends that will have an impact on the support needs and circumstances of families and individuals
- What reforms in family support are taking place nationally?
- What do National Core Indicators data tell us about the status of family support?
- What are the challenges and opportunities?

National Trends

- Supported Decision Making
- ► HCBS Rule
- Recent Olmstead suits and ADA
- Self-Direction
- Aging parents and other demographic and support challenges
- Growth of individuals on the autism spectrum

Supported Decision-Making

- Rationale: Guardianship is overused and has become almost reflexive when an individual turns 21
- Need to find an alternative that maximizes the individual's autonomy and choice
- Federal grant to create the National Center for Supported Decision Making – www.supporteddecisionmaking.org
- Foundation funded pilot in Western MA

Respondent is Legal Guardian or Conservator

Full Guardianship • 72% 18-22

• 65% 23+

Limited Guardiansh • 6% 18-22

• 4% 23+

• 22% 18-22

• 31% 23+

None

New HCBS Settings Requirements

- Ensure people receiving long-term services and supports through Medicaid home and community based services (HCBS) programs have full access to community life
- Ensure HCBS settings provide people with disabilities control over their lives and have choices and that they are supported I the most integrated setting (ADA & Olmstead v L.C.)
- Rule published January 16, 2014. Effective March 17, 2014
- MA has 16 programs under "heightened scrutiny"



An HCBS setting is...



- Based on the individual's experience and choices
- Is integrated in and supports full access to greater community
- Ensures the individual receives services in the community with the same degree of access as individuals not receiving Medicaid home and community-based services
- Provides opportunities to seek employment and work in competitive integrated settings, engage in community life, and control personal resources

Recent Olmstead Decisions

- In addition to the recent HCBS settings rule, Olmstead enforcement also underscores importance of inclusion and freedom from isolation
- With respect to sheltered workshops, Department of Justice has brought two prominent lawsuits that require states to close those settings
- The theory is that they are isolated settings and not most integrated setting
- May pose challenges

Self Direction



- Real Lives legislation provides new impetus to the self direction option – requires:
 - Training of service coordinators
 - Orientation for families and people with disabilities
 - Development of budgets
 - Assurance that every participant is offered a self directed option
- Affordable Care Act also requires that selfdetermination is a priority for all federal agencies

People Who Self-Direct Are More Likely To:



- Live in parent/relative's home
 - ✓ Like home, less likely to want to live somewhere else
- Spend their days in community-based settings (paid or unpaid)
- Report having privacy, being allowed to be alone with visitors.
- Report their mail is read without their permission
- Have had at least some input into critical everyday and live choices
- Be able to see friends and family and less likely to feel lonely
- Have met their case manager, report that their case manager gets back to them in a timely manner, report that their staff treats them with respect, and that staff come when they're supposed to.
- Report having gone shopping, or on errands in the past month.
 More likely to report having gone on vacation in the past year
- Indicate they are not getting needed services

Aging Families (NCI – '14-'15 data)

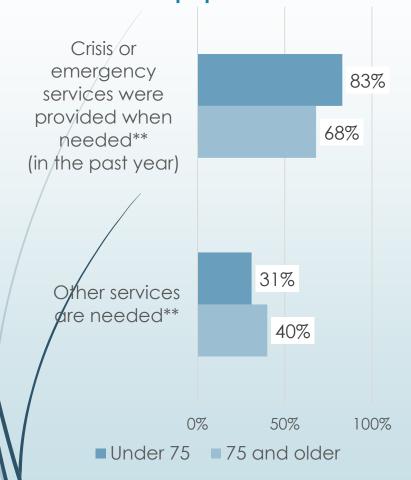
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1 in 10 primary caregivers is 75 or older

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40% of primary caregivers 75 or older are in fair or poor health

Access to Supports



Services and Support

What Other Services Are Needed

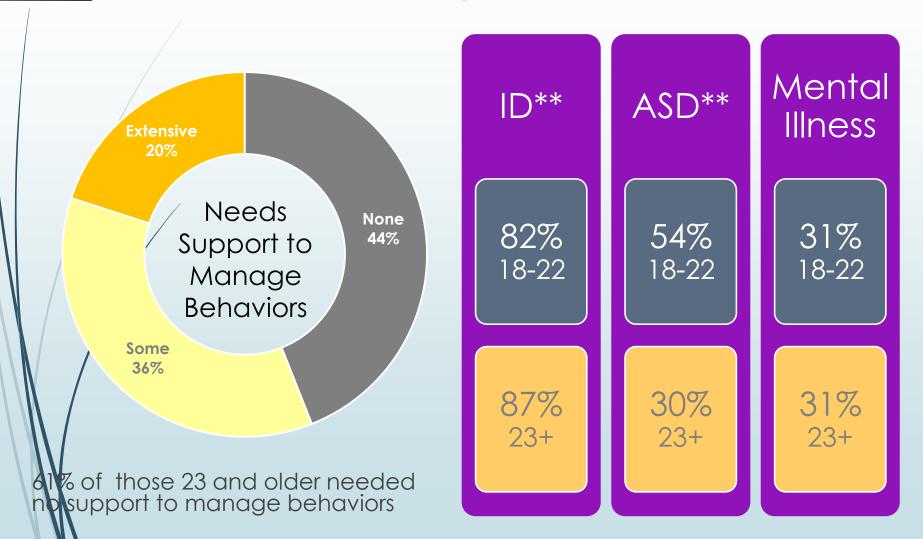
Better
transportation.
He misses a
lot of work
due to
transportation
problems

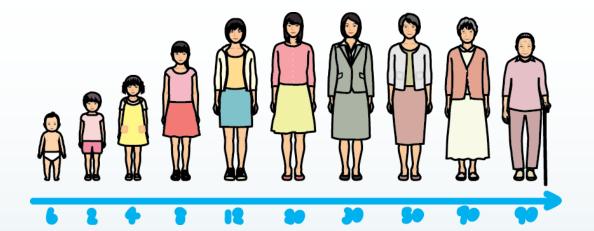
Need help for development of long term care. His care provider and father is 76 years old. Has tried to get help from state advisor to plan for his care upon death of his father.

We need more <u>respite</u>. We are glad to have what we have.

(selected comments from those 75 and older)

Transition Age Youth





National Framework to Support Families Over the Lifespan

National Initiative



Mission: "Develop and fund National Supporting the Family Initiatives that explore principles, practices, and data indicators that will inform practice and policy related to supporting families across the lifespan."

- Five-year Project of National Significance funded by the Administration on Intellectual and Developmental Disabilities (AIDD) in 2012.
- Six participating states: Connecticut, District of Columbia, Missouri, Oklahoma, Tennessee, and Washington.

Multiple Partners



National Partners

















Goal and Potential Outcomes of Family Initiative

- To build capacity through a community of practice across and within States to create policies, practices and systems to better assist and support families that include a member with I/DD across the lifespan. Hoped for outcomes include:
- State and national consensus on a framework and agenda for improving support for families with members with I/DD.
- Enhanced national and state policies, practices, and sustainable systems that result in improved supports to families.
- Enhanced capacity of states to replicate and sustain exemplary practices

Outcomes Continued...

- Systems reforms resulting in sustaining families and providing appropriate and flexible supports.
- Individuals with IDD and their families experience an integrated approach to supports across state agencies and community organizations guided by LifeCourse principles.
- Initial contact with state agencies is easy to navigate and considers both formal and informal supports that best align with needs.
- Individuals with IDD and their families are aware of and use the LifeCourse planning tools for achieving a good life with connections to community. http://supportstofamilies.org/

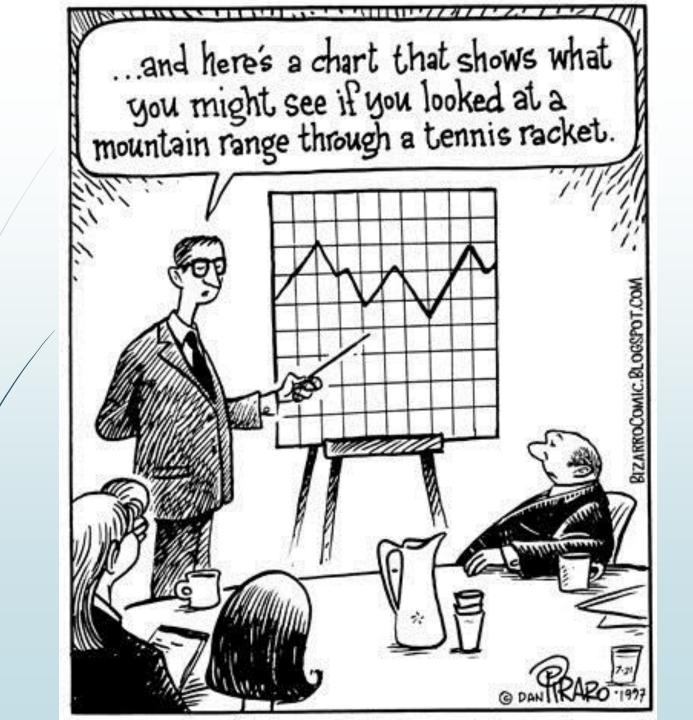


Examples of State Activities

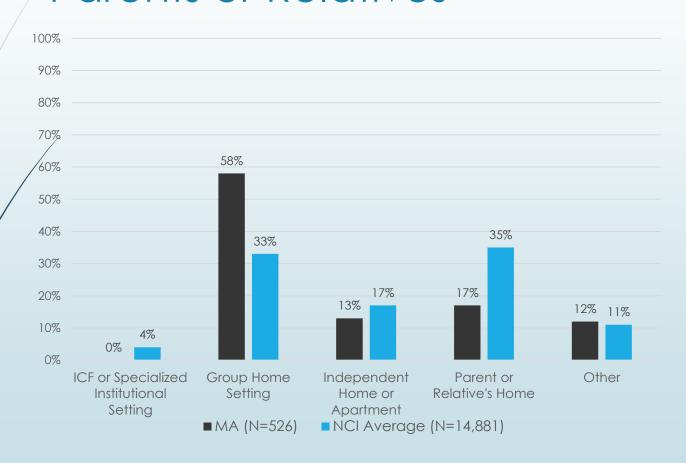
- Sharing information (resource folders, listservs, newsletters, social media, Lunch n' Learn events).
- Incorporating LifeCourse framework into Partners in Policymaking and Youth Leadership Training curriculum.
- Training family mentors on LifeCourse framework and tools.
- Modifying intake processes to improve the experience for individuals and families whether or not they are eligible for services.
- Including LifeCourse tools as part of contract with managed care organizations.
- Partnering with community organizations to host events to build relationships.



What do 2014-15 NCI National Data from the Child and Family and Adult Family Surveys Show?

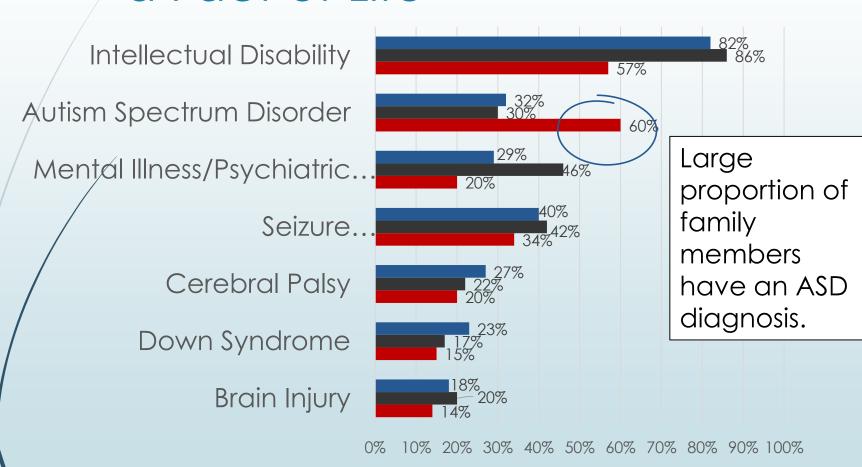


People with ID/DD in MA Are Less Likely to Live at Home with Parents or Relatives



Source: NCI Adult Consumer Survey 2013-14

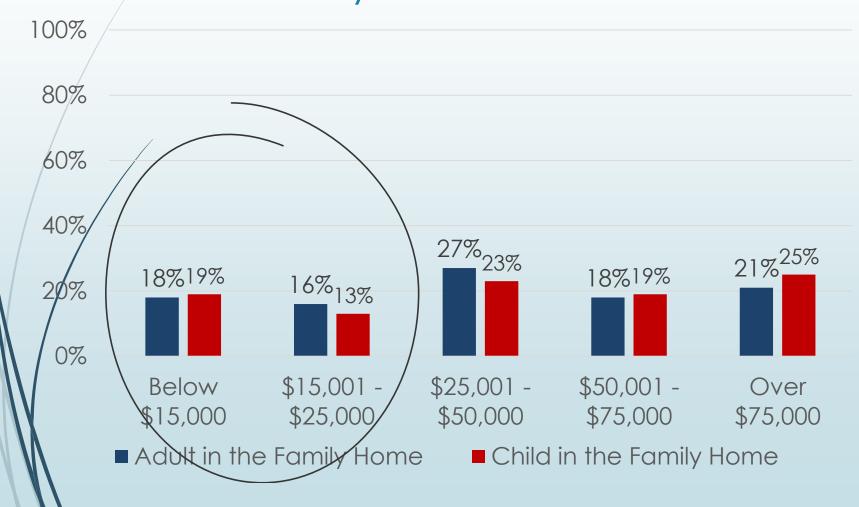
Co-Occurring diagnoses are a Fact of Life



■ Adult Outside the Family Home

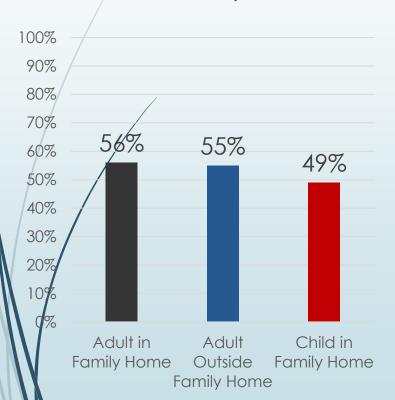
Adult in the Family Home

Many Families with Children and Adults at Home Are at or Near the Poverty Line

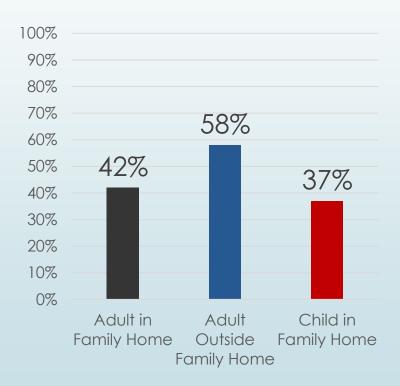


Family Satisfaction Low on Some Indicators

Support Workers Always Have the Proper Training to Meet Needs of Family Member

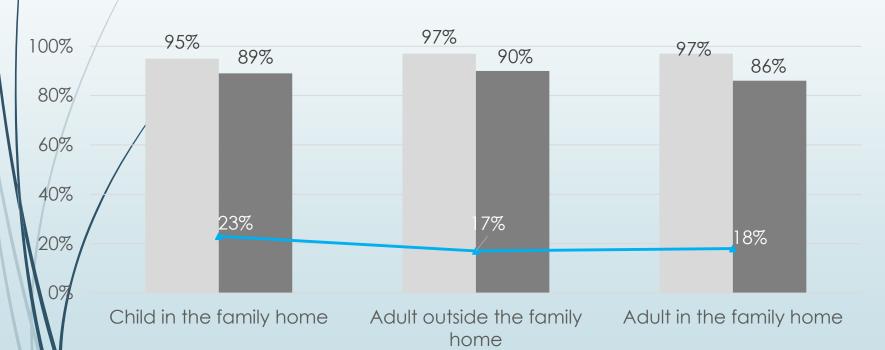


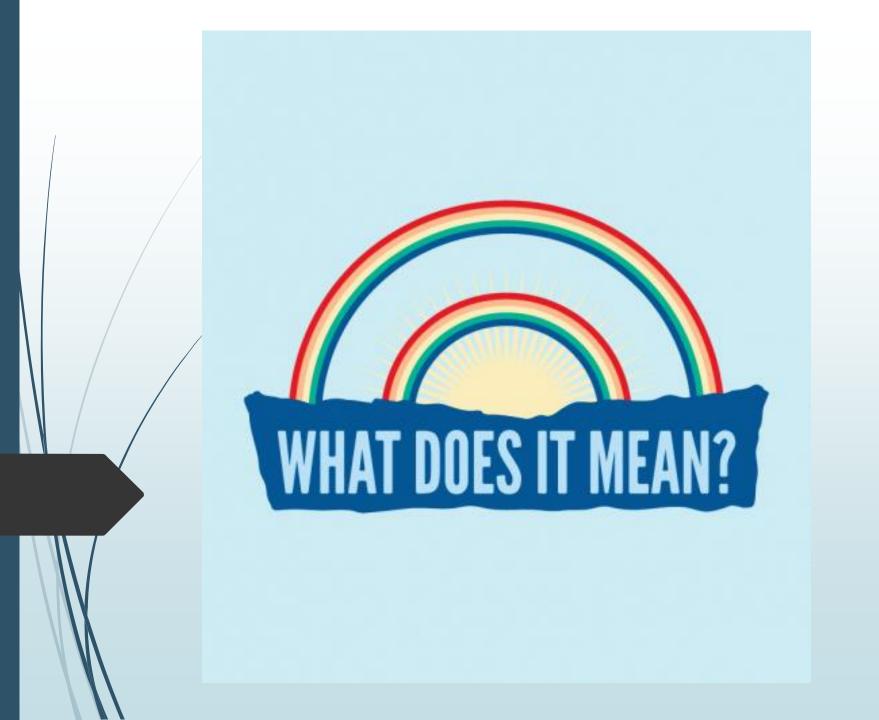
Services and Supports Change to Meet Family's Changing Needs



Impact of Services

- Services made a positive difference
- Services reduced family's out-of-pocket expenses
- Services reduced/suspended/terminated in past year





Final Thoughts



- There is a renewed interest nationally in family support across the lifespan and a framework for support more in tuned with current philosophy and resources
- The cohort of aging caregivers is growing and will present significant pressure on the system in the future
- Transition age youth have significant challenges to families and to the service system compared to their older cohort
- The reflexive use of guardianship should be reconsidered and we should begin to explore the use of supported decision-making

Further Thoughts

- Self determination is also getting a new look here in MA and across the country – offers a more personcentered approach and maximizes resources
- Federal policies and recent court orders will continue to reshape the service landscape – continually pushing us to more inclusive alternatives
- Reshaping what people do during the day will be a continuing issue requiring ingenuity, innovation, and an understanding of individual/family needs and goals.
- MA has a history of collaborating with families a relationship that will need to be continually nourished and supported

Contacts

- Valerie J. Bradley: <u>vbradley@hsri.org</u>
- NCI website: <u>www.nationalcoreindicators.org</u>
- Resources available at http://supportstofamilies.org/
- Innovations Webinar Series hosted every other month highlighting state activities.
- Archived webinars available here:
 http://supportstofamilies.org/resources/innovations/

What did she say?!!

