



NASDDDS & HSRI

Sarah Taub/NCI Webinar: Friendship and Life Outcomes for Adults With Intellectual and Developmental Disabilities

November 3, 2016



Agenda



- Introductions
- NCI Data
- **Creating our Commonwealth and Widening the Circle**
 - Larry Tummino
 - Emily Lauer
 - Christine Clifford
 - Jim Ross

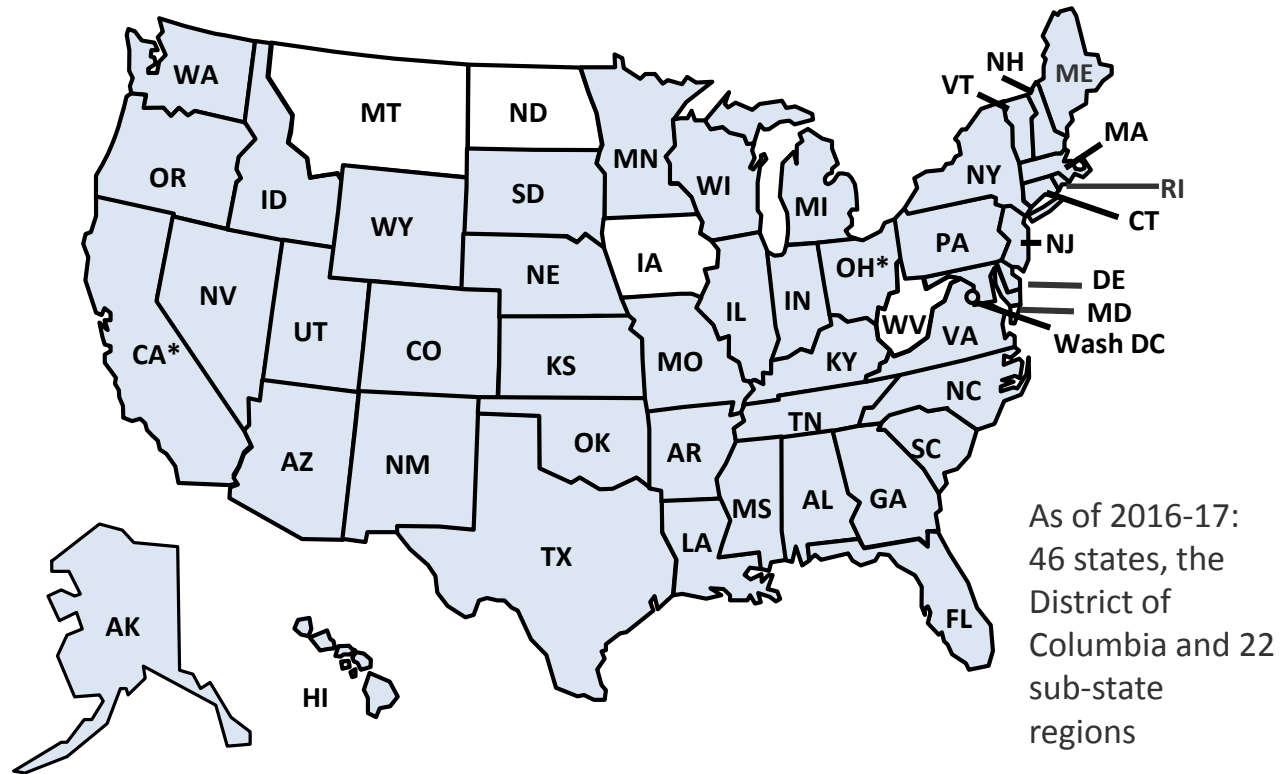


Methods: WHAT IS NATIONAL CORE INDICATORS™ (NCI)?

- Multi-state collaboration of state DD agencies
- Measures performance of public systems for people with intellectual and developmental disabilities
- Assesses performance in several areas, including: employment, community inclusion, choice, rights, and health and safety
- Launched in 1997 in 13 participating states
- Supported by participating states
- NASDDDS – HSRI Collaboration



National Core Indicators^(TM) State Participation



WHAT IS NCI?

- Adult Consumer Survey
 - ✓ In-person conversation with a sample of adults receiving services to gather information about their experiences
 - ✓ Keyed to important person-centered outcomes that measure system-level indicators related to: employment, choice, relationships, case management, inclusion, health, etc.
- Adult Family, Child Family, and Family/Guardian Surveys Mail surveys – separate sample from Adult Consumer Survey
- Other NCI state level data: Staff Stability



Types of Friendships

- Expanded friendships
 - Reported being friends with people other than staff and family
- Limited friendships
 - Those reported having no friends
 - Those who reported having friends who were all either family or staff



Sample: 2014-15 Adult Consumer Survey

- The total sample includes data from 32 states, the District of Columbia, and one regional council

“Do you have friends you like to talk to or do things with?”

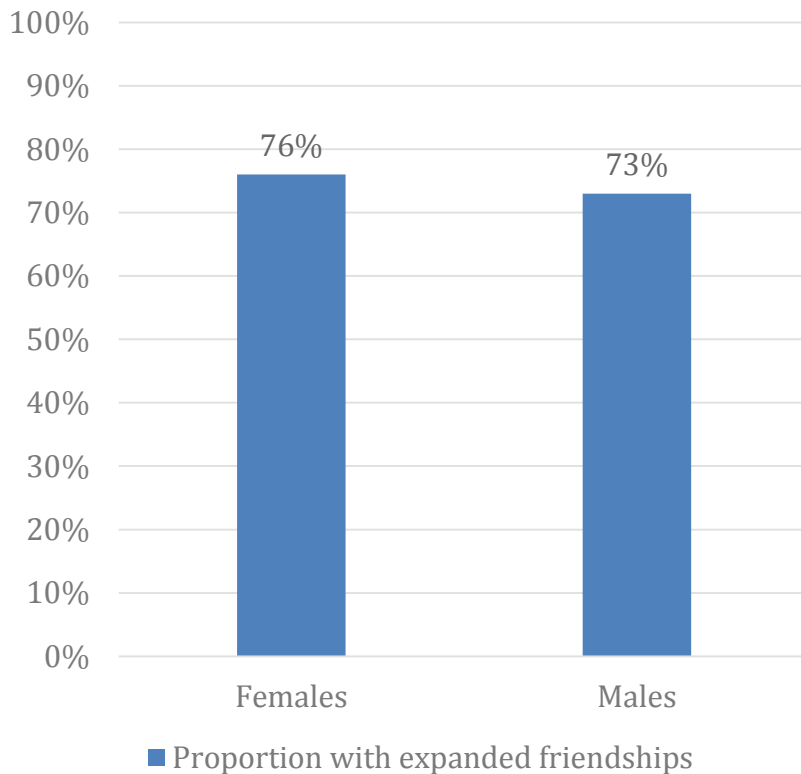
- **Yes, has friends who are not staff or family**
- **Yes, all friends are staff or family, or cannot determine**
- **No, does not have friends**
- **Don't know**
- No proxy responses permitted
- Only individuals who responded to this question were included in the sample
- Respondents for whom this question was left blank or coded as “Don't know” were excluded from the final dataset.
- The final dataset includes 16,626 people.

All relationships in this presentation are significant at the $p \leq .05$ level

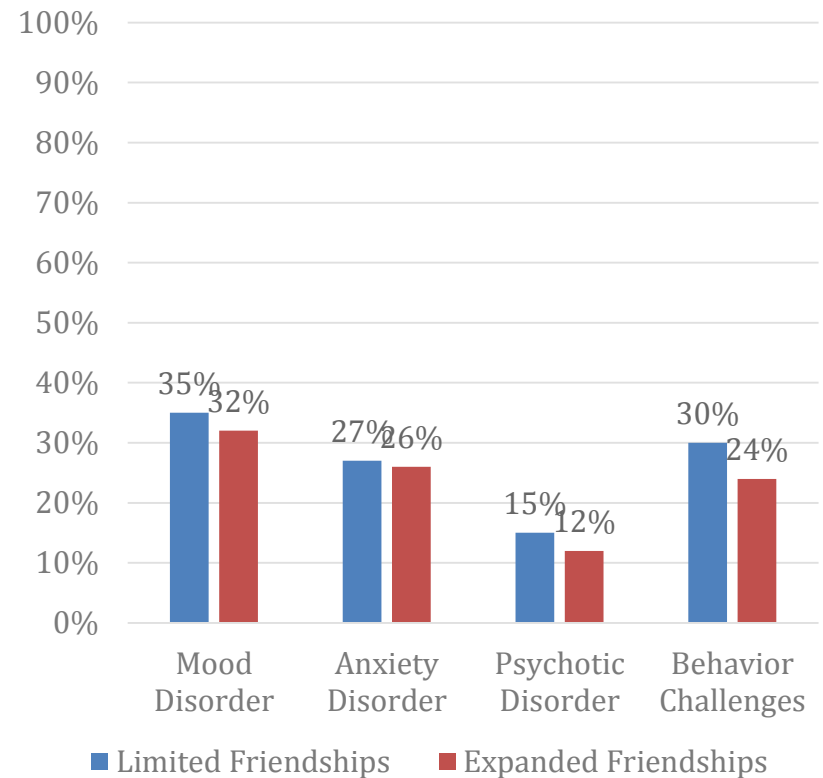


Demographics

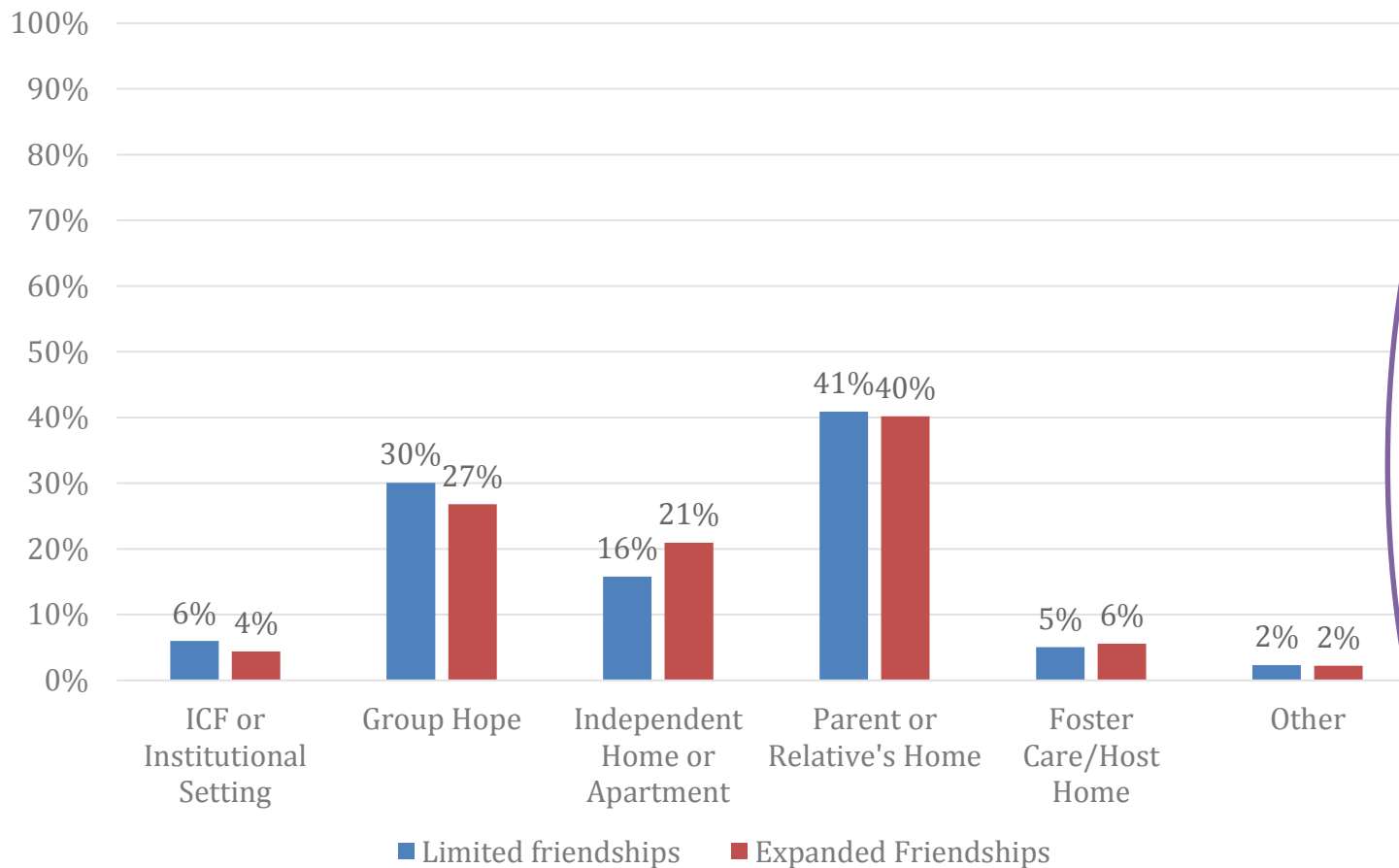
Expanded Friendships by Gender



Mental Illness/Psychiatric Diagnosis by Friendship Status



Type of Residence by Friendship Status

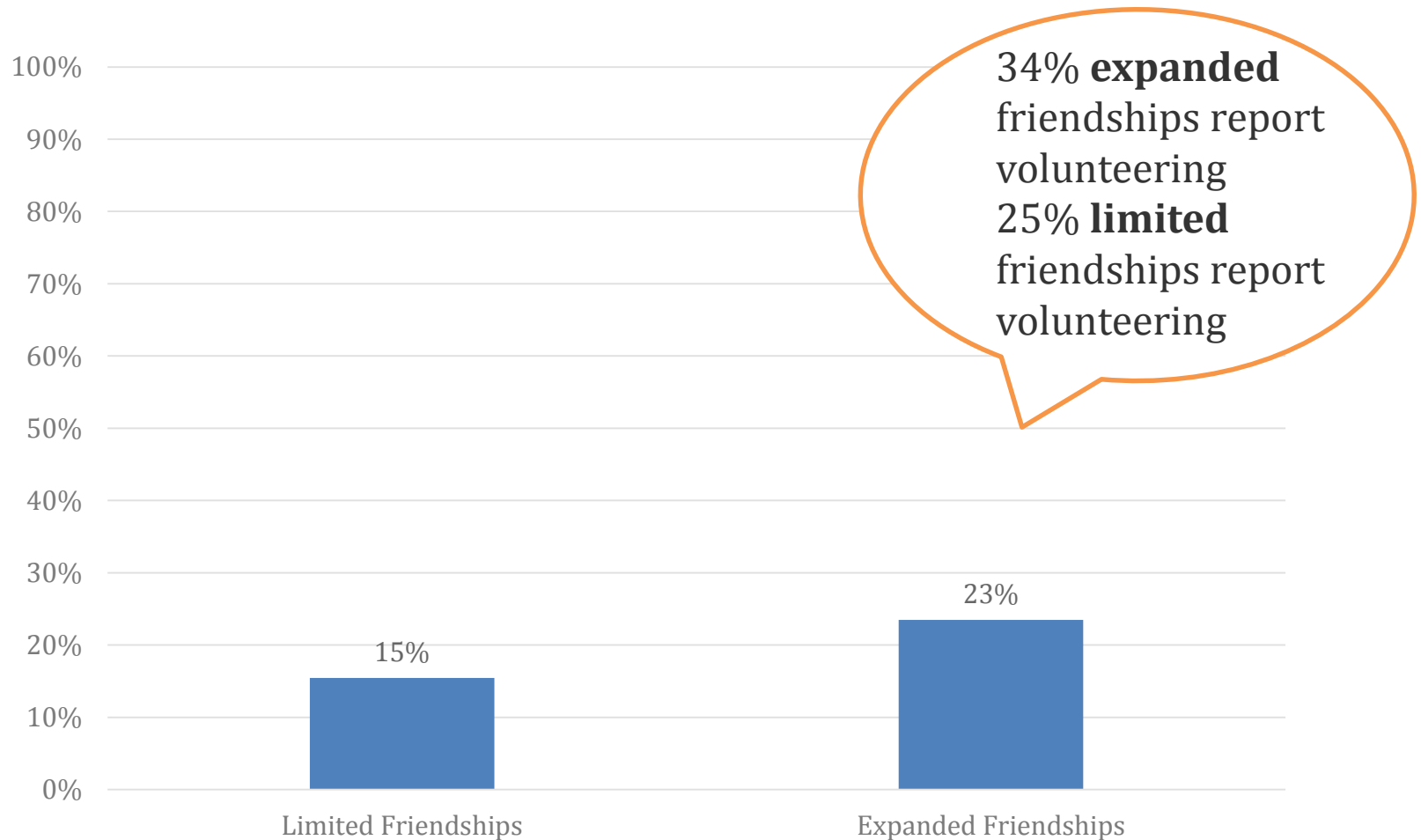


91%
expanded friendships
said they like where they live.

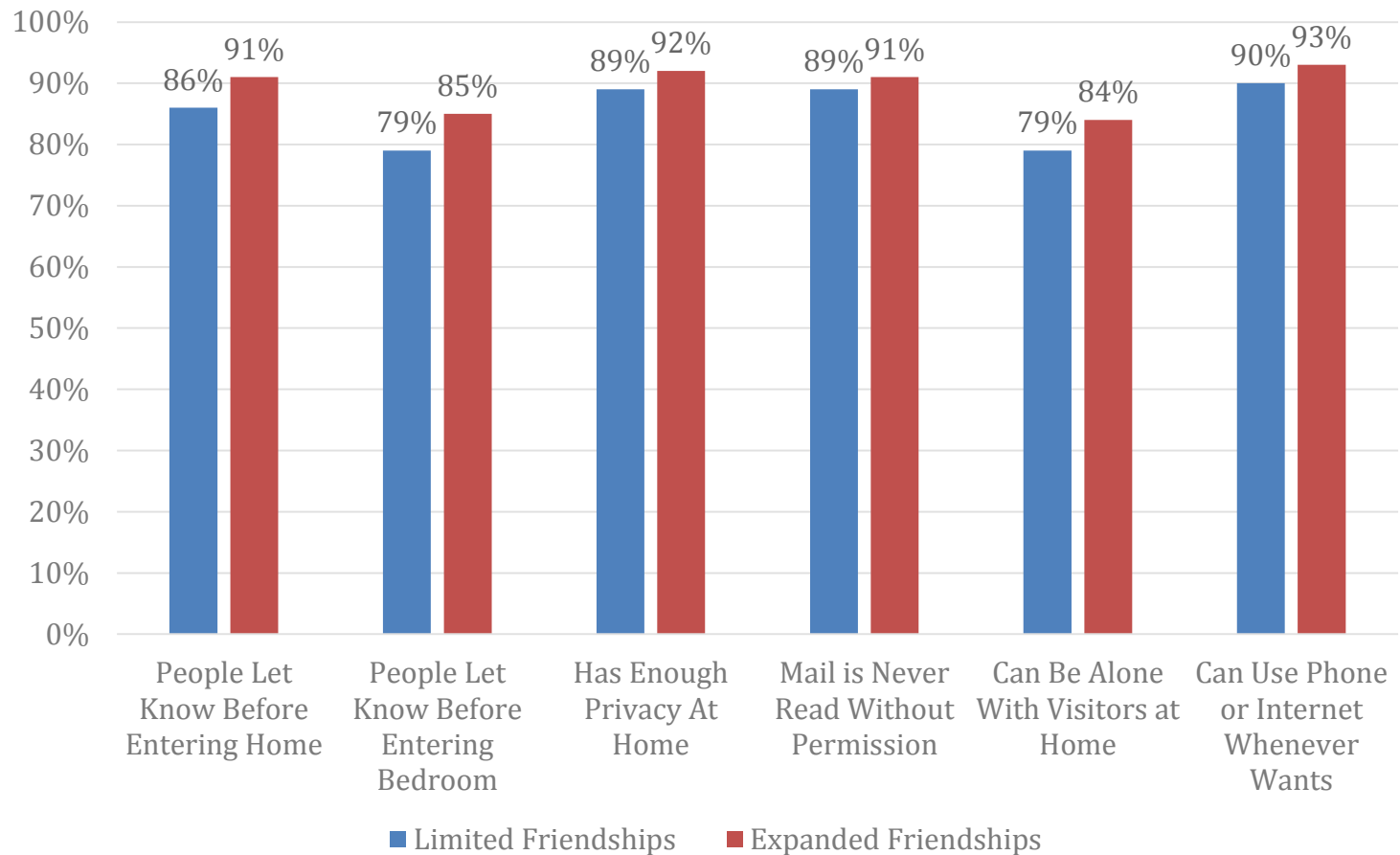
89%
limited friendships
said they like where they live.



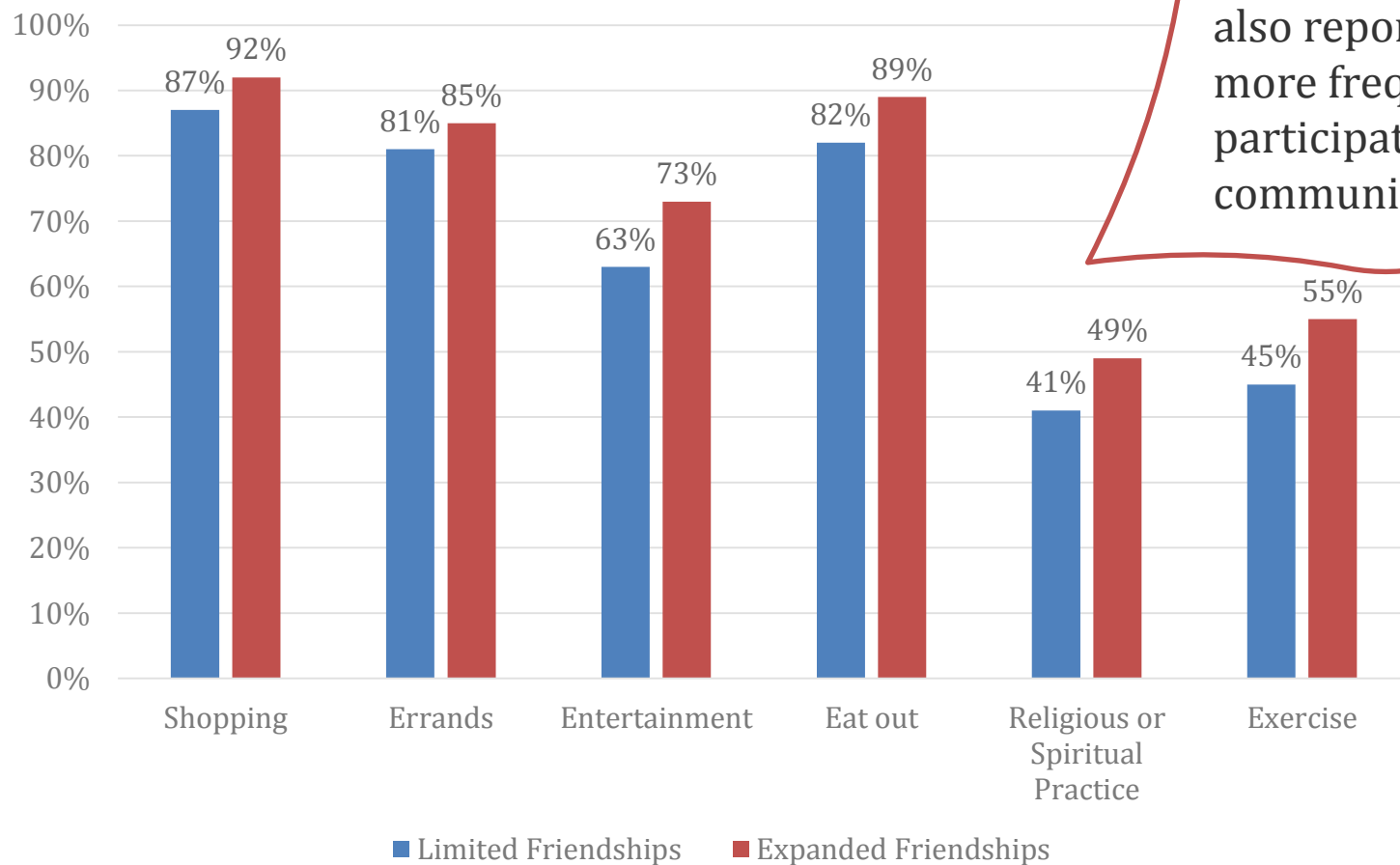
Paid Job in Community by Friendship Status



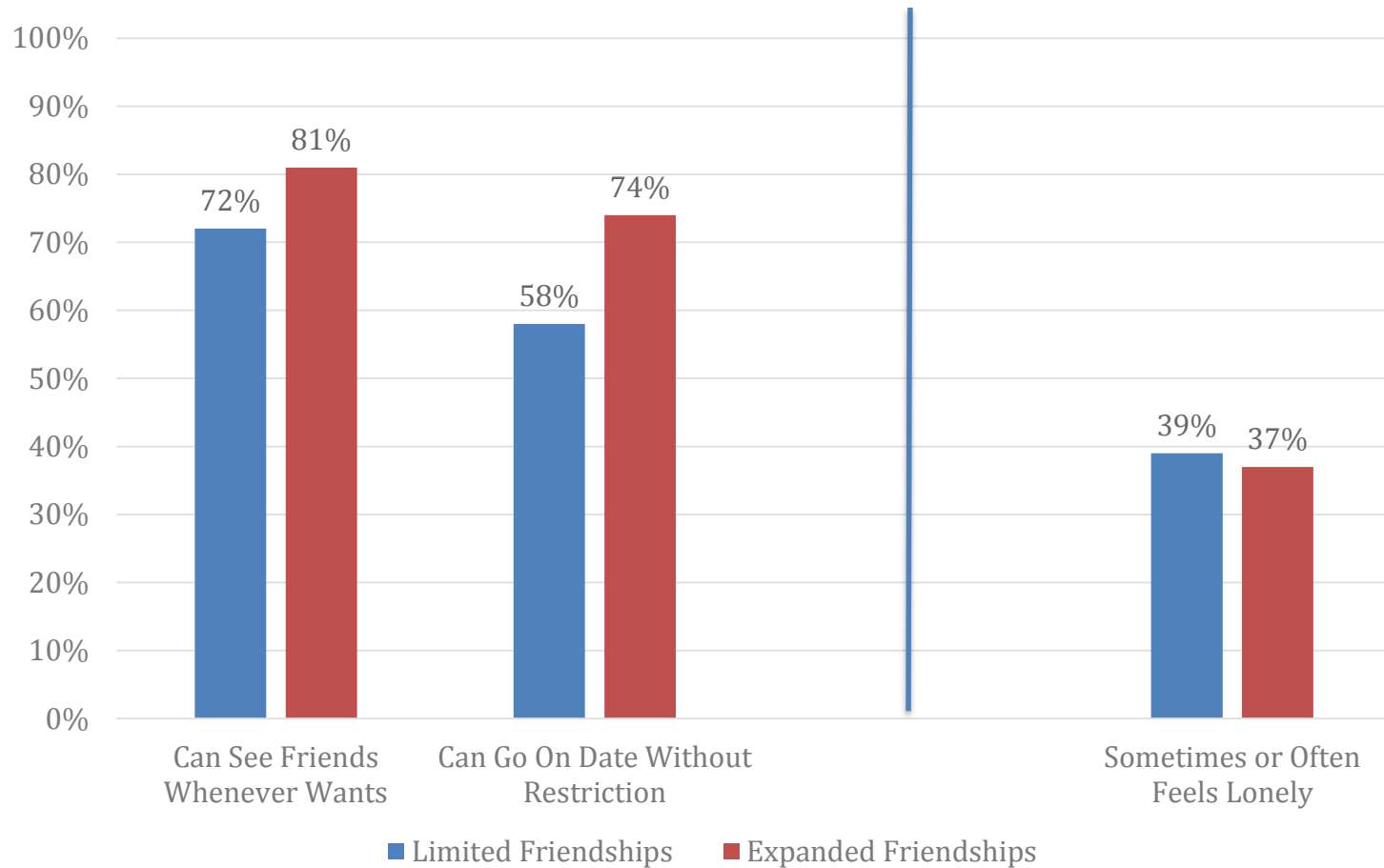
Rights and Respect by Friendship Status



Participation in Community Activities by Friendship Status



Relationships by Friendship Status



Questions?

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For questions about NCI, please
email dhiersteiner@hsri.org



*Fostering social inclusion and
community engagement:
Massachusetts's Creating Our
Common Wealth Initiative*

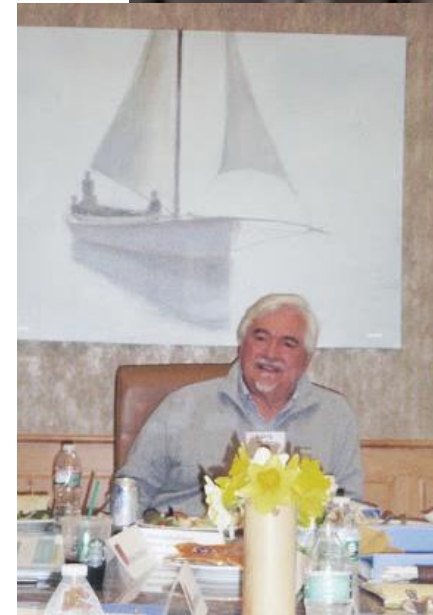
Emily Lauer, MPH, CDDER

Larry Tummino, MA DDS

Christine Clifford, MHP, CDDER

Context - Massachusetts

- Over the last 45 years, DDS has built a sophisticated community-based service system.
 - From serving >10,000 individuals in nine large institutional settings
 - To serving >35,000 individuals supported in a variety of community settings.
- DDS Mission: To provide supports that address individual needs based on a person-centered plan and that are provided in ways that draw upon a person's gifts while promoting full engagement as a contributing member of a local community.
 - Ultimate goal: To have those served feel valued, have lives that are rich in experiences and which have a bounty of friendships and relationships.



Remaining Challenges

“Isolation, one of the building blocks in the old service foundation, continues to persist in ways that often leave people lonely and disengaged from their community. Yes, individuals live in the community but too often are not yet of the community.”

– Commissioner Elin Howe

- Today:
 - Much of a person’s time is spent with paid staff and family members.
 - People often do things in groups and in ways that separate them from the community around them.
- To achieve the DDS’s “ultimate goal” steps need to be taken that will move the system into the next stage of its evolution.
 - After moving to community settings, next frontier is to bring people into the real mainstream of community life with their fellow citizens.
- Takes commitment and effort from all stakeholders!

Using Data to Assess Progress

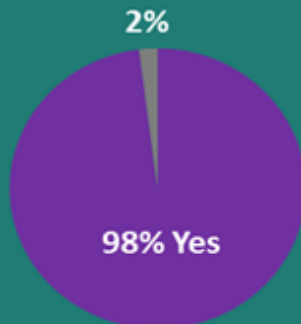
DDS utilizes data from the National Core Indicators and other sources to understand issues related to social inclusion such as friendship, community activities and participation and loneliness to assess and compare progress in these areas.

Licensure and Certification Data

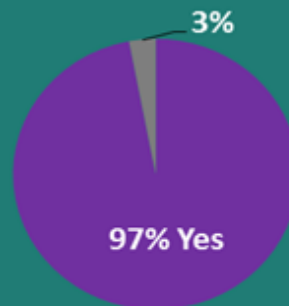
Most Recent Licensure and Certification Data FY15

Providers support people to:

Get together with family and friends
when appropriate



Develop personal
relationships and social contacts

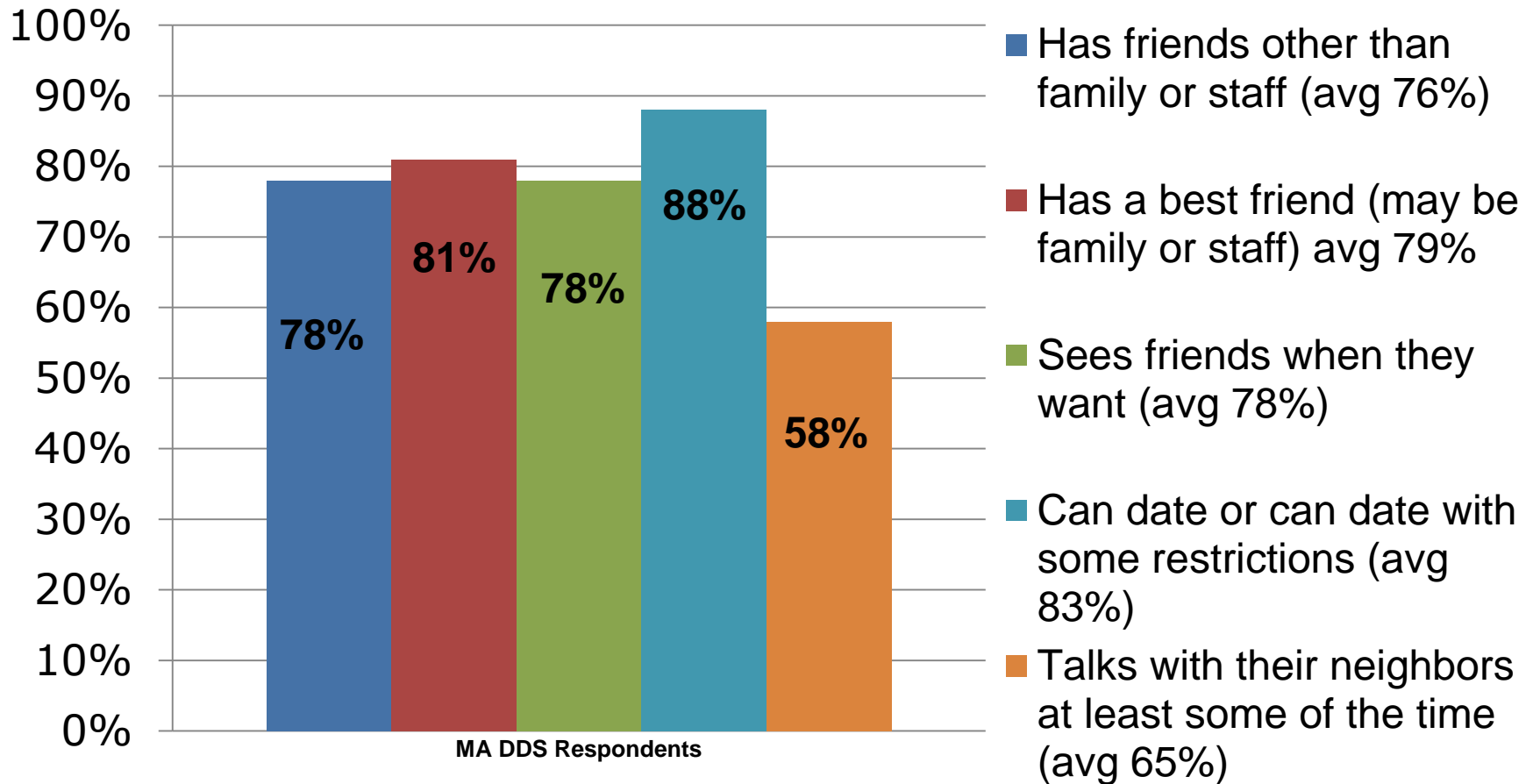


Develop appropriate social skills



Friendship Satisfaction

Percentage of people indicating 'yes'



Source: National Core Indicators
www.nationalcoreindicators.org

And yet...

**4 out of 10 people
feel lonely at least
half of the time**

(Source: NCI FY14)



— Feels lonely — Does not feel lonely

DDS Quality Council

- Consists of a variety of stakeholders who meet quarterly to review data from CDDER in order to consider how it can inform policies and practices at the Department.
- One father's story on friendship.

Creating Our Common Wealth

- Partnership between:
 - MA Department of Developmental Services (DDS)
 - Center for Developmental Disability Evaluation and Research (CDDER), University of Massachusetts Medical School
 - Involves a range of talented experts from across the country
- Leadership development initiative for 100 emerging leaders from provider and advocacy organizations, DDS Area Offices

CCW: Components of Initiative

Goals:

- To prepare participants to step into influential leadership roles.
- Ensure participants are imbued with values and strategies to address the challenges that come with meeting the community imperative of social integration and personal control.

What is “ground breaking” about today is that this is the first truly organized effort we have made to build a new foundation for our future, one we want to build with each and every one of you. You are here today because someone has seen the spark you carry within yourself that reflects passion and commitment to this work. Someone has said yes to the question, “is this a person who can become a leader, who can shape the future in ways that can build better lives with and for people with developmental disabilities?” You have been chosen to break new ground.

-- Commissioner Elin Howe

Leadership and Skill Training

- Different organizations, including provider agencies, state offices and self-advocacy and family organizations
 - Asked to identify emerging leaders
- Expectations
 - Participation in the series of leadership training events
 - An interest in fostering friendship and community inclusion

Guiding Questions

- How can we support a journey of transformation in the lives of people with disabilities, their families, support professionals, and local neighborhoods, so that people with disabilities have full membership, relationship, and belonging?
- How do we invest in the next generation of leaders to make a difference in the lives of people and local communities?
- How do we nurture personal initiative, courage, and perseverance, leading to personal, organizational and societal change?

Facilitator's Group

- Core leadership group
- Necessary component of the initiative:
 - Guide the events, content, activities
 - Local/Regional support for participants
 - Aids statewide initiative to also have local focus
 - Adapt plans as needed
 - Support each other



Initial 2 Day Event

- Dr. Beth Mount Keynote
- Day 1: Foundational Values
- Book: Mount & O'Brien, PATHFINDERS: People with Developmental Disabilities & Their Allies Building Communities That Work Better for Everybody
- Leading Ideals and Practice
- What We Need to Create, and What We're Up Against



Vision

- Explore new dimensions of person-centered supports that create fresh opportunities for people to have community jobs, homes, and self-directed supports that lead to deep membership and bountiful relationships in their local communities.
- Each participant will design their own personal development journey, bringing together passion, positive values, and skillful leadership, using frameworks provided in this beginning series of events.
- Participants will form and nurture local design teams who will participate in the following components of personal, neighborhood, and organizational development.

Transformational Practice

- The Place of Community Membership Roles in Creating Fruitful Relationships and Full Lives
- Virtual Road Trip: Mapping Membership In Your Own Community
- Portraits of Organizational Transformation
 - Real examples from local providers sand community groups
- Regional sessions to plan next steps

Regional Groups

- Regular meetings with regional liaisons with facilitation experience
 - Individual participants share the progress on projects they have developed to further social integration.
 - Receive mentorship and guidance
- Part of the local and ongoing connection to the initiative

Regional Groups – Lessons Learned

- Drop outs / New additions in a long-term initiative
- Consistent with support for families
- Variable support for projects locally
 - Local leadership support is important
- Variability in people coming up with projects, executing
 - Still working to learn how to support those who are struggling

Learning Journeys

- Exposure and ability to “try on” different models welcome by participants
- Challenges with traveling to physical locations
 - Exploring the idea of virtual journeys
 - Regional group paired journey with their regional meeting → Successful in increasing participation

Web presence

www.creatingourcommonwealth.org

- Provides a virtual “home base” for the initiative
- Includes relevant information from trainings, events, and interactive features like forums

Leadership Skills

- Deb Reidy Leadership training
- Book: “Why Not Lead?: A Primer for Families of People with Disabilities and Their Allies”
 - personal guide for people motivated to bring about positive change but who want some guidance on their journey.
 - Liberate yourself to exercise leadership whether you have a formal position or not
 - Guide for ‘ordinary people’



Members of Each Other

- John O'Brien training
 - For both CCW participants and leadership
 - Also session for DDS QI and Regional leadership
- Focused on strategies to build communities
- Combats the notions that make isolation and segregation appear natural
- Challenges the “we’re already doing this” camp
- Examples from real programs



Local projects

- Creating Our Common Wealth participants have chosen a wide variety of individual projects.
- Projects range from the levels of the individual, the program, the agency, and the larger community
- Each meant to increase the probability that, decades down the road, people with and without disabilities will view one another and act together as members of each other.
- Considering podcasts to share models/ideas

Local Projects - Examples

- A psychologist - stepped out of his professional role to encourage the likelihood of integrative relationships with people with disabilities in his son's school, by surveying student's attitudes toward their disabled classmates, and by speaking to their classes on diversity and acceptance.
- Mother of a child with a disability, successfully asked the mayor of her city to appoint her to the city's Access Committee, and she has since joined their deliberations to encourage relationship-building.

Fall 2016 Event

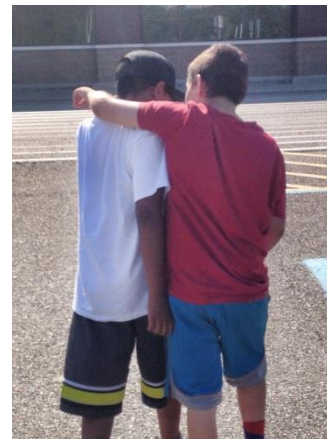
- **Understanding Social Devaluation and the Service Workers Role: A Social Role Valorization Approach**
 - Dynamic set of ideas useful for making positive change in the lives of people disadvantaged because of their status in society.
 - Basic tenet of role-valorizing efforts is the notion that the good things any society has to offer are more easily accessible to people who have valued social roles.

Upcoming Events

- 2 Leadership Training Sessions with Deb Reidy
- Individual coaching opportunities with Deb Reidy
- Spring Event with Beth Mount
 - Groups will share their work to date, experience
 - Meet across regional lines based on project themes

WIDENING THE CIRCLE

November 3, 2016



WIDENING THE CIRCLE

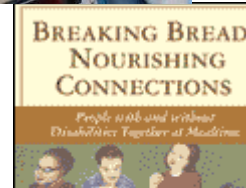
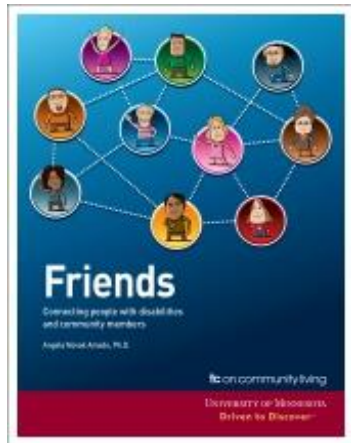
Expanding opportunities for friendships between people with and without disabilities

<http://thearcofmass.org/programs/widening-the-circle/>

Since 2012 Widening the Circle has been encouraging the development of friendships between people with and without disabilities.



RESEARCH!



**THIS
AMERICAN
LIFE**
FROM WBEZ



TASH
Webinar

SHARING RESOURCES

WIDENING THE CIRCLE

[http://www.arcofmass.org/ProgramsatTheArc/Widening the Circle.aspx](http://www.arcofmass.org/ProgramsatTheArc/Widening%20the%20Circle.aspx)



Everyone needs friends!



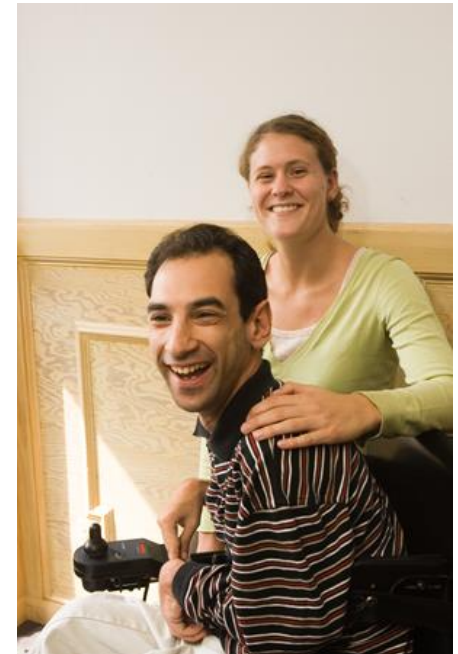
“INTRODUCTION TO FRIENDS”

TRAININGS

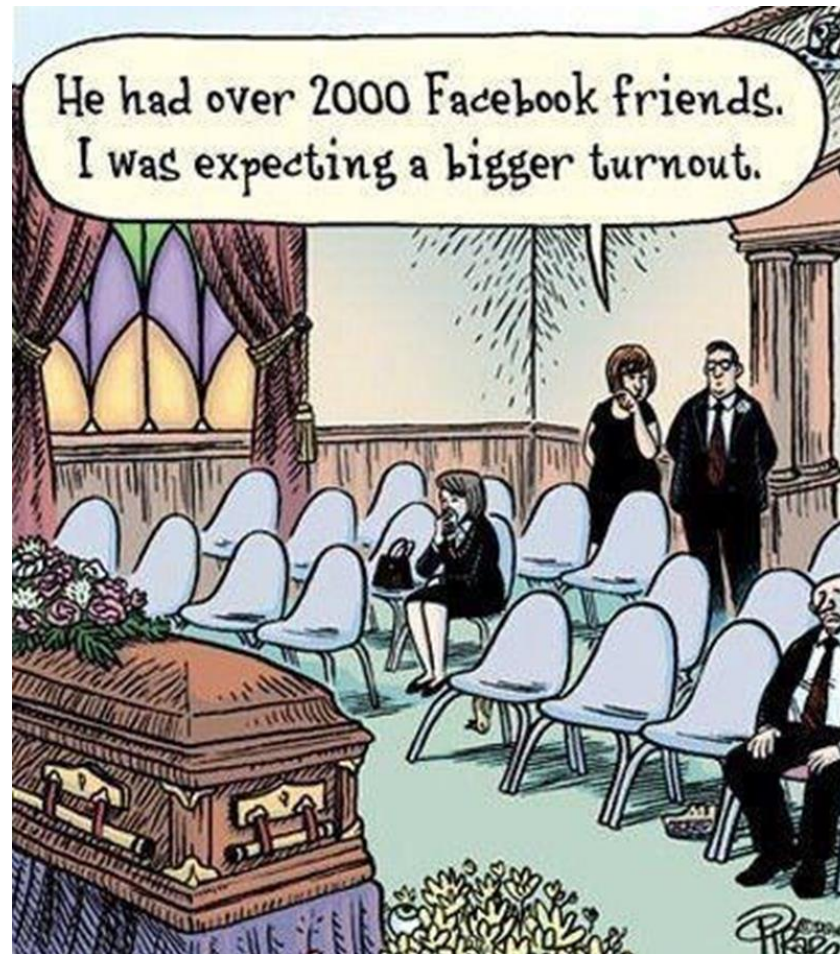
What Does “Friend” Mean to You?

Over 200 Presentations to over 5,500 people including:

- **Parents (SEPACs, MFOFC Family Leadership, etc.)**
- **People with Disabilities (SA Conferences, etc.)**
- **High School & College Students**
- **DDS Staff (SC Institutes, Orientations, etc.)**
- **Provider Staff (Conferences, Leadership events, Community Colleges, etc.)**



This is Not What We Mean



This is Not What We Mean, Either!



TRAIN-THE-TRAINERS

**We trained over 150 people across the state,
with and without disabilities,
to present the “Introduction to Friends” training.**



DEMONSTRATION PROJECTS



BUILDING FRIENDSHIPS AT WORK

A TOOLKIT FOR EMPLOYMENT SPECIALISTS, JOB DEVELOPERS AND JOB COACHES



<u>Job/Career Planning & Relationships</u> Person-centered planning can help focus attention on relationships.	<u>Job Development & Relationships</u> Paying careful attention to workplace culture can better ensure that helpful relationships will develop at work.	<u>Supporting Relationships in the Early Stages of Employment</u> A number of strategies can help job coaches facilitate relationships amongst co-workers from the get-go.	<u>Supporting Relationships from Work Over Time</u> True friendships cross over from the workplace into the community as relationships grow
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FUTURE TOOLKITS

- **Making Friends at School (K-College)**
- **Making Friends Where You Live**
 - At Home with Family
 - 24-hour Group Home
 - <24 hour Individual Supports in Own Home
 - Shared Living
- **Making Friends Where you Play**

What We Can Do For You



Please visit our website or contact us directly. You are welcome to use any material that we've developed. We will consider consulting with you as well on any activities with which we are familiar.

WIDENING THE CIRCLE

Expanding opportunities for friendships between people with and without disabilities

<http://thearcofmass.org/programs/widening-the-circle/>

Multi-Initiative Approach to Social Inclusion

Multi-pronged effort of leadership and stakeholders to create conditions for people to have better lives as fully engaged members of their community.

- **The Employment Blueprint**
- Family Support Enhancement
- **The Campaign for Shared Living**
- Self Determination
- Compliance with Social Integration Rules
- **Creating Our Common Wealth**
- **Widening The Circle**
- Positive Behavioral Supports
- **Development of formal Policy on Social Inclusion**
- Provision of services to individuals who meet new eligibility standards
- Addressing the needs of people aged 50 and older

The Employment Blueprint

- Having a full or part time job creates a feeling of self worth for everyone
- Jobs creates a valued role that can lead to:
 - a better sense of one's own identity
 - Can create a pathway to developing friendships with co-workers
- Aug. 2014 – DDS worked with Association of Developmental Disability Providers (ADDP) and The ARC of Massachusetts to laying out a plan to transform day and employment services in a way that would better address the Employment First Policy
<http://www.mass.gov/eohhs/gov/laws-regs/dds/policies/s-employment-first-policy-2010-2.html>

The Employment Blueprint

- Nov. 2014 - Employment Blueprint with goals over 4 years
<http://www.mass.gov/eohhs/docs/dmr/blueprint-for-success.pdf>
 - 1) Close the “front door” to sheltered workshops by halting any new referrals – **Achieved!**
 - 2) Close segregated sheltered workshops – **Achieved!**
 - UMass Institute for Community Inclusion provided training and consultation so that providers had resources to guide needed changes in their programs.
 - 3) Transition participants in sheltered workshops to integrated individual or group employment at minimum wage or higher and/or Community-Based Day Services (CBDS). – **Partially Achieved & In progress**
 - 4) Continue to transition individuals from CBDS to integrated work opportunities that pay minimum wage or higher based on person-centered career plans. – **Partially Achieved & In progress**
 - 5) Gradually phase out group employment settings that pay less than minimum wage. – **Partially Achieved & In progress** (end of FY18)

The Campaign for Shared Living

- Residential model – a person lives in home of community member who provides on-going support (per ISP). An agency recruits, screens, trains and matches community members, and monitors/support the match.
 - Benefits: individually tailored support, gateway to social inclusion
- Challenge: MA's reliance on group homes for provision of 24 hour residential support & projected shrinking pool of workers for these homes
- Jan 2015 – DDS and stakeholders sought ways to better educate individuals, family members, and DDS staff to promote the expanded use of this model.
- Campaign for Shared Living – Goal: increase shared living use over 4 years
<http://www.addp.org/sites/default/files/Shared%20Living%20Brochure%20Inside%201.pdf>
 - Part of larger efforts to reconfigure existing residential support system to promote more person centered and cost efficient approaches to supporting people in their communities.

Widening The Circle

- Goal: Reduce the loneliness and isolation reported by individuals and families
 - Friendship:
 - Is important for one's health and overall happiness.
 - Provides natural safeguards by watching out for and assisting individuals during difficult times.
- ARC of Massachusetts
 - provides consultation, training and informational materials in order to help create conditions that will lead to individuals developing and maintaining friendships outside of their usual circle of peers, staff and family members.
 - "Toolkit" on how to make friends on the job:
[http://thearcofmass.org/wp-content/uploads/2015/12/FRIENDSHIPS-AT-WORK-TOOLKIT -Final 1-5-2016.pdf](http://thearcofmass.org/wp-content/uploads/2015/12/FRIENDSHIPS-AT-WORK-TOOLKIT-Final-1-5-2016.pdf)
 - *New set of toolkits under development: Friends at School; Friends where you happen to live*

HCBS Settings Final Rule

- Used as foundation to support desired change within the state
- Basis for budget request to legislature to fund changes needed to comply with rule to preserve federal support of services.
- Review/revise/strengthen licensure and certification indicators
- Focus areas:
 - Increase staff ratios, transportation availability
 - Preserve individual choice and stability of supports
 - Increase progress in community inclusion & integration

Questions?

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