FRIENDSHIP MATTERS!

IMPROVING HEALTH AND WELL-BEING BY SUPPORTING RELATIONSHIPS

AAIDD National Conference June 2015

Angela Novak Amado Institute on Community Integration, University of MN

Kim Zoeller Ray Graham Associates, Lisle, IL

Elizabeth Pell HSRI, Cambridge, MA



ELIZABETH PELL, M.S.W.

Policy Associate Human Services Research Institute Cambridge, MA

epell@hsri.org

Topics

- 1. General population research on how friendship impacts health
- 2. National Core Indicators data differences by friendship status
- Lessons learned from a provider's 20 year commitment to increasing friendships and valued social roles. Provider uses CQL's Personal Outcome Measures.
- 4. Collaborating with states on provider-level and statewide initiatives to increase valued social roles and relationships. Factors that lead to success.

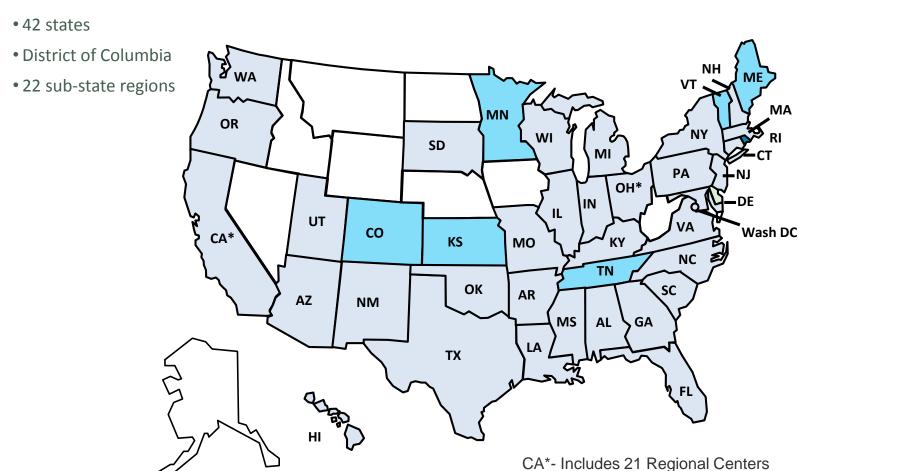
General Population Research: Loneliness Impacts Health & Friendship Types Matter

All studies found loneliness impacts health, even reducing mortality. Who your friends are matters too! In terms of health impact, all friendships are not the same.

- University of Chicago Friendships benefit health by helping people develop their resilience and ability to bounce back after adversity; to gain strength from stress rather than be diminished by it.
- Australia Friendships that protected against mortality did not include those with children or relatives.
- U.S. Nurses Women with breast cancers (stage 1 through 4) without close friends were 4 times as likely to die from cancer as women with many friends. Friends did not need to be close by. Survival rates related to not feeling socially isolated and having friendships beyond one's spouse.

National Core Indicators (NCI)

State Members 2014-15



OH*- Also includes the Mid-East Ohio Regional Council

NCI Comparison Groups 2013-14 Data

Limited Friendships

- Adults with I/DD receiving publicly-funded services
- People who do not have a friend or best friend
- Friends are family members and/or paid staff
- 17% of adults receiving services

Expanded Friendships

- Adults with I/DD receiving publicly-funded services
- Friends or best friend are neither family members or paid staff (includes friends with disabilities)
- 76% of adults receiving services

Loneliness & Connections

| NATIONAL CORE INDICATORS™ | Feels lonely sometimes or all the time | If afraid, has someone to go to | Opportunity to participate in self advocacy meeting or event | Can see friends whenever want to | |
|---------------------------------|---|--|--|---|--|
| Limited friendships | 40% | 88% | 30% | 69% | |
| Expanded friendships | 38% | 94% | 37% | 80% | |

Work & Volunteer

| NATIONAL CORE INDICATORS™ | Had community job in past 2 weeks | Volunteers in community | Chose job or had some input |
|---------------------------------|---|-------------------------|-----------------------------|
| Limited friendships | 15% | 25% | 80% |
| Expanded friendships | 22% | 32% | 85% |

Rights & Respect

| NATIONAL CORE INDICATORS™ | Use phone or internet on demand | Can be alone with visitors in home | Chooses or input into what to buy with own money | Has enough privacy at home |
|---------------------------------|---------------------------------|------------------------------------|--|----------------------------|
| Limited friendships | 86% | 74% | 90% | 89% |
| Expanded friendships | 91% | 80% | 96% | 92% |

Choice: Chose or had input into decisions

| NATIONAL CORE INDICATORS™ | Case Manager | Staff (residential & day/work) | Roommate* | Where to live |
|---------------------------------|-----------------|--------------------------------------|-----------|---------------|
| Limited friendships | 62% | 64% | 46% | 55% |
| Expanded friendships | 68% | 70% | 56% | 65% |

^{*}Excludes those who live with family or relatives

Community Inclusion

| NATIONAL CORE INDICATORS™ | Entartainment ()ut to eat | | Religious service | Exercise | |
|---------------------------------|---------------------------|-----|----------------------|----------|--|
| Limited friendships | 67% | 83% | 46% | 55% | |
| Expanded friendships | 75% | 88% | 54% | 63% | |

Co-occurring: Communication & Mobility

| | Primary Means of Expression | | Mobility | | | |
|---------------------------------|--------------------------------|-------------------------------|--------------------------|--|---|--|
| NATIONAL CORE INDICATORS™ | Spoken | Gestures/ body language | Moves without aids | Moves with aids or uses wheelchair independently | Always needs assistance to move about | |
| Limited friendships 85% | | 11% | 78% | 15% | 7% | |
| Expanded friendships | 93% | 5% | 82% | 14% | 4% | |

Data shows characteristics occur at same time but NCI does not show that the characteristics are *the cause* of any difference between groups.

Co-occurring: Home Type

| NATIONAL CORE INDICATORS™ | Parent or relative's home | Independent home or apartment, or shared with roommate | Group home 1-3 people* or agency- operated apartment | Group home 4-6 people* | Group home 7-15 people* | ICF/DD; public & private; all sizes |
|---------------------------------|---------------------------|--|--|---------------------------------|----------------------------------|--|
| Limited friendships | 36% | 19% | 14% | 15% | 4% | 2% |
| Expanded friendships | 37% | 22% | 11% | 14% | 5% | 1% |

^{*} Indicates number of people with disabilities living together

Data shows characteristics occur at same time but NCI does not show that the characteristics are *the cause* of any difference between groups.

Co-occurring: Intellectual Disability (ID)

| NATIONAL CORE INDICATORS™ | Mild ID | Moderate ID | Severe ID | Profound ID |
|---------------------------------|------------|----------------|--------------|----------------|
| Limited friendships | 39% | 33% | 12% | 5% |
| Expanded friendships | 45% | 32% | 8% | 2% |

Data shows characteristics occur at same time but NCI does not show that the characteristics are *the cause* of any difference between groups.

KIM ZOELLER, M.P.A.

President and CEO Ray Graham Association Lisle, IL

kimz@raygraham.org

Provider Values Alignment

- Core values of provider organizations drive whether or not relationships and friendship flourish.
- Understand that people have personal definitions for "friendship". (Acquaintance vs. Friend)
- Relationships and friends must be central to the Person-Centered Planning process.
- Realize that regulations and rules can be unintended barriers.

- Actively listen and learn from people. Never assume you know what people want.
- Create an environment that encourages creativity and empowerment.

CQL- Personal Outcome Measures ©

Relationships and Social Capital

Using POMs©

- Central to conversations with people and person-centered planning.
- Focus on the "outcome" and the "support".
- Personalized for each person.
- Data used on an individual and aggregate level.

Key POMs_©

- People have friends.
- People have intimate relationships.
- People are connected to natural support networks.
- People interact with other members of the community.
- People perform social roles.
- People participate in the life of the community.
- People feel respected.

Meet Angelo...sometimes we get out of the way!

- Angelo lives in a group home setting with 24 hour support.
- Long-term employee for Red Lobster.
- Prefers work life and friends from work to be separate from other supported activities.
- Friends from work pick him up to go out to sports bars, etc...
- Some hoops to jump through...accessibility, medications, support with decision making.



Being the matchmaker...Denise and Eddie

- Denise expressed interest in an intimate relationship, but needed help finding someone.
- She had clear criteria!
- Support to participate in community activities to socialize, volunteer, and work.
- Hosted a "meet and greet" and she met Eddie.
- Started dating, but now their relationship is flourishing.
- Support for privacy, arranging dates, transportation, etc...



Raymond...supporting old friends, too!

- Moved from another residential provider.
- As part of the PCP process, discussed relationships to understand priorities.
- Susan was a great longtime friend. Started as a volunteer and became a friend.
- Susan takes Raymond out and about all the time!
- Gardening, making dinner...
- A welcoming environment is key!



Raymond with another important person in his life...his girlfriend, Marilyn.

ANGELA NOVAK AMADO, PH.D.

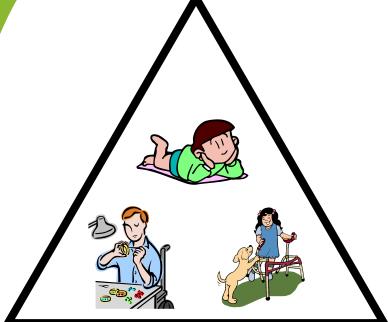
Research/Project Manager, University of Minnesota, Institute on Community Integration

Executive Director, Human Services Research & Development Center

amado003@umn.edu



Critical Boundary



"PERSON-CENTERED PLANNING"

The term "Person-Centered Planning" refers to:

A family of approaches to organizing and guiding community change in alliance with people with disabilities and their families and friends.

-- John O'Brien & Herb Lovett

IMPORTANT DIFFERENCE

Important to distinguish between:

PHYSICAL integration, and

SOCIAL integration

COMMUNITY PARTICIPATION

- "Community Participation"
- "Most integrated setting"
- "Engage in community life"
 - > go beyond "Activities" to "Relationships"
 - from "Inclusion" to "Belonging"

WHAT

WORKS?

KEY BEGINNING FACTOR

Regular, ongoing social contact, such as:

- 1. Schools
- 2. Jobs
- 3. Faith communities
- 4. Community associations and groups

Shift thinking from "Activities" to "People":

Who are they going to get to know there?

EFFORTS/PROJECTS OVER TIME

State-wide efforts:

- New Mexico
- Louisiana
- Kentucky

Regional: New Hampshire

Long-term efforts, agency-wide: Minnesota, North Dakota

STRATEGIES HAVE BEEN USED IN OTHER STATES!

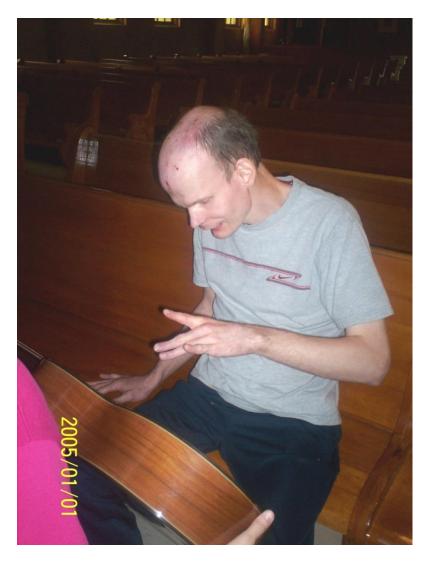
3 AREAS OF OUTCOMES

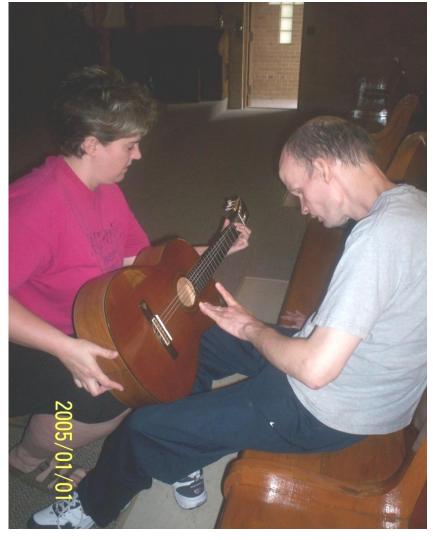
Friendships with community members

Joining community groups/associations

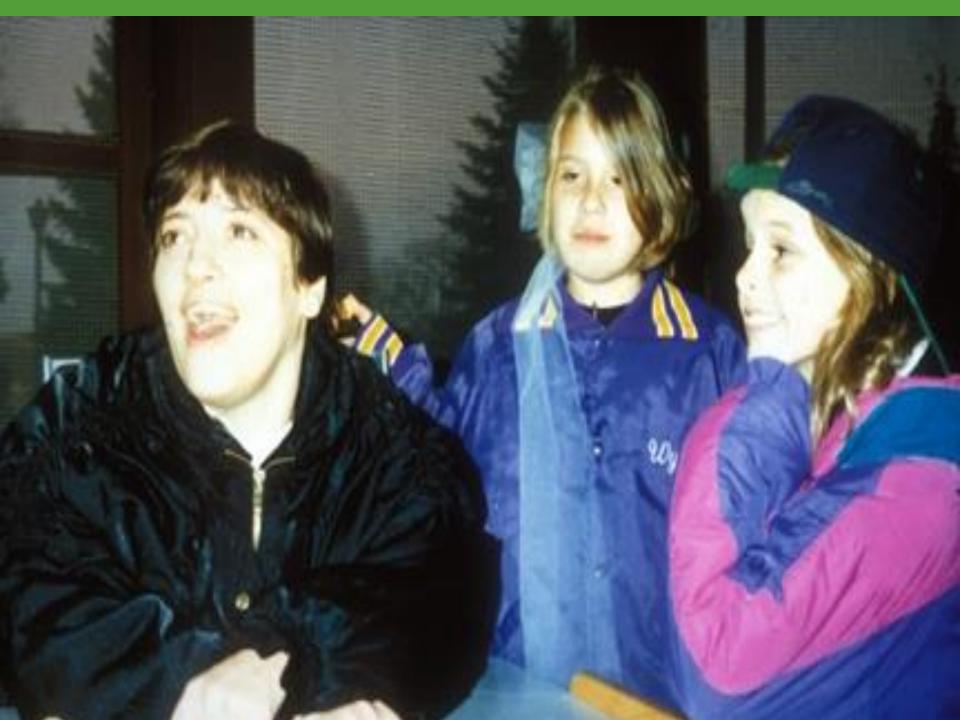
 New community social roles (e.g., church greeter)

Karen and Joel

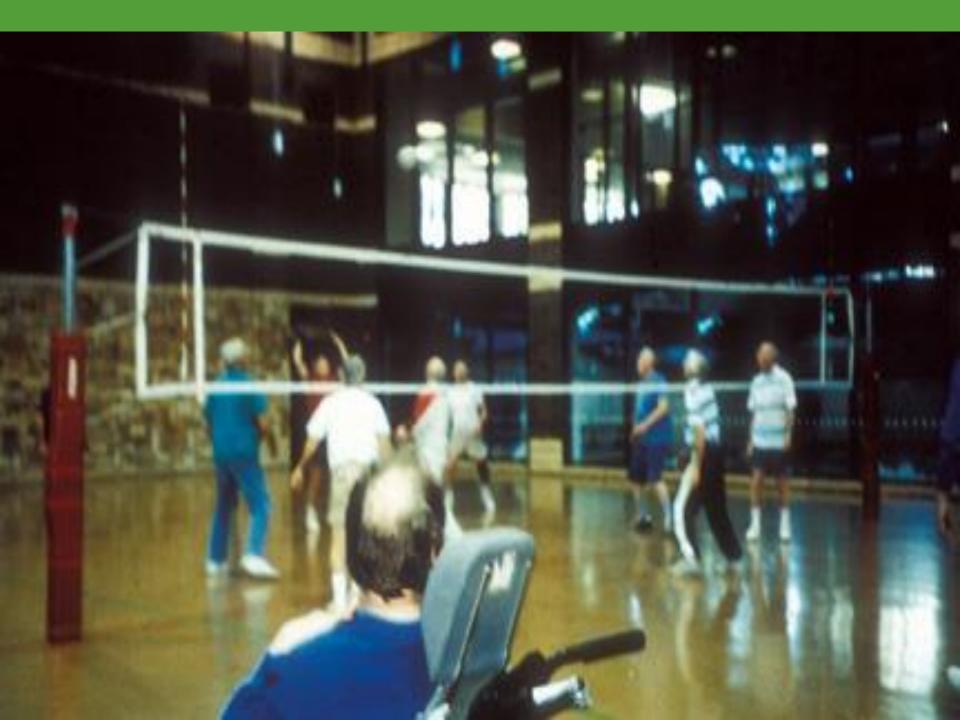
















The children ask if Kyle is coming so they can read to him each week!

- The children love to show their new reading skills to Kyle and Kyle loves listening to them as they read their stories.
- Kyle volunteered several years in this classroom.

St. Francis School appreciates its volunteers



St. Francis School greatly appreciates the many volunteers it has. One of our volunteers is Kyle, and he visits the kindergarten classrooms every Wednesday to see the students. Kyle listens to stories the children have written and loves to see their artwork. He also loves to hear about all the things the children have

been doing at school and at home. Kyle has a smile on his face for the children every time he sees them. The St. Francis kindergarteners are always excited when Wednesday comes because they know Kyle will be visiting. Every time Kyle comes to visit, he never leaves the school without all the cards, pictures, and stories the kindergarteners

have made for him. The students have grown very attached to him.

Clint is another great volunteer in Mrs. Titus's kindergarten class.

Lana Helgeson also volunteers her time in Mr. Koman's kindergarten classroom.

7 APPROACHES TO CONNECTING

OVERALL QUESTION:

Where are the Opportunities for Relationships? Who will they get to know there?

A. CONNECTING THROUGH GIFTS AND INTERESTS

- 1. Where are people who would appreciate receiving this person's gifts?
- Where are all the community places where people engage in one of this person's interests? Who are the people who share this interest?

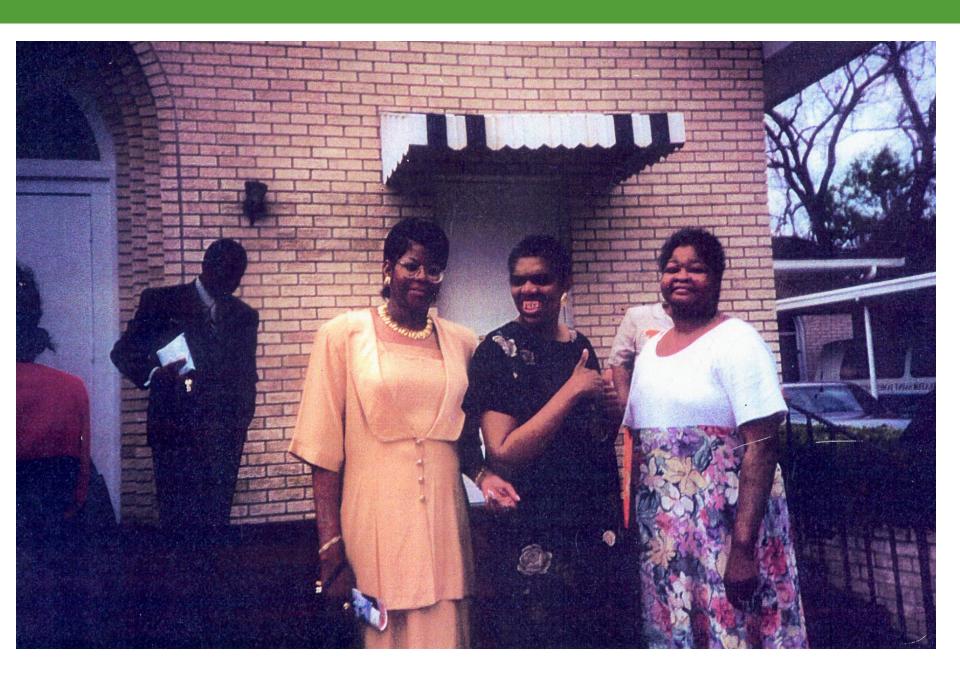
B. CONNECTING WITH INDIVIDUAL COMMUNITY MEMBERS

- 3. Who are the people who are already acquaintances, who could be asked to get to know the person better?
- 4. Who might be/where could we find an interested person who could be asked to get to know the person better?

7 APPROACHES TO CONNECTING

C. COMMUNITY MEMBERSHIP

- 5. Where are the associations, clubs, and groups?
 - formal
 - informal
- 6. Where are there community places that are hospitable and welcoming?
- 7. Where are there community places the person can fit in, just the way they are?





AGENCY LEVEL – What Makes a Difference?

- Commitment of Executive Director/ agency values
- Shift focus to PEOPLE not activities
- It takes ASKING community members
- Incorporate into job description, expectations, etc.
- Ongoing training and problem-solving
- Perseverance (We tried this, this, and this and...)

PRACTICE IMPLICATIONS

- 1. At executive level: define the role of the agency in relation to community
- 2. Identify staff roles as community-builders
- 3. Make ISP goals about relationship building, not just community activities
- 4. Figure out one-to-one support
- 5. Put tracking/evaluation systems in place
- 6. Generate community-wide efforts

POLICY RECOMMENDATIONS

 "Community Participation" is more than "activities"

 Address conflict between "promotion of natural supports" and "community participation/integration" versus "confidentiality, data privacy" and "HIPAA"

POLICY RECOMMENDATIONS

- 3. The more individualized the support, the greater the opportunity for relationships with community members.
- 4. But also recognize that individuals in their own apartments/homes need support for relationships, not just grocery-shopping, banking, etc.

POLICY RECOMMENDATIONS

Group situations: sufficient staff is required for one-to-one support for relationships

6. Transition planning from school: address not just jobs but also continuity in relationships

7. State-wide efforts are possible: focus, definitions, context, resources

Life is nothing without friendship

Resources: General Population Research on Health Impact of Friendships

- Effect of Social Networks on 10 Year Survival in Very Old Australians: The Australian
 Longitudinal Study of Aging. Lynne Giles, Gary Glonek, Mary Luszcz, Gary Andrews, Journal
 of Epidemiological Community Health, 2005; 59:574-579 Source:
 <a href="http://jech.bmj.com/content/59/7/574.abstract?maxtoshow=&HITS=10&hits=10&RESULTFORMAT=&fulltext=friends&andorexactfulltext=and&searchid=1&FIRSTINDEX=0&sortspec=date
 &resourcetype=HWCIT
- Rewarding Social Connections Promote Successful Ageing, Professor John Cacioppo. Reported by The Guardian online newspaper. Source: http://www.theguardian.com/commentisfree/2014/feb/17/loneliness-report-bigger-killer-obesity-lonely-people
- Social Networks, Social Support, and Survival After Breast Cancer Diagnosis. Candyce H. Kroenke, Laura D. Kubzansky, Eva S. Schernhammer, Michelle D. Holmes and Ichiro Kawachi, *Journal of Clincial Oncology*. Source: http://jco.ascopubs.org/content/24/7/1105.full
- The Spread of Obesity in a Large Social Network over 32 Years, Nicholas A. Christakis, M.D., Ph.D., M.P.H., and James H. Fowler, Ph.D., New England Journal of Medicine. July 26, 2007; 357:370-379. Source: http://www.nejm.org/doi/full/10.1056/NEJMsa066082
- The Health Benefits of Strong Relationships, Harvard Health Publications, Harvard Medical School, December 2010. Source: http://www.health.harvard.edu/newsletters/Harvard_Womens_Health_Watch/2010/December/the-health-benefits-of-strong-relationships

Additional Resources:

- Angela Novak Amado, "Friends: Connecting People with Disabilities and Community Members." (Free Friends Manual & Activity Worksheets): www.rtc.umn.edu/friends
- Friendship and Community Connections Between People with and without Developmental Disabilities, by Angela Novak Amado, www.amazon.com
- CQL (Council on Quality & Leadership), Performance Outcome Measures®: http://www.c-q-l.org/the-cql-difference/personal-outcome-measures
- National Core Indicators® (NCI) website: www.nationalcoreindicators.org
- National Core Indicators contact, Alixe Bonardi, HSRI NCI Director, abonardi@hsri.org

Contact Us!

Angela Novak Amado, Ph.D.

Research/Project Manager, University of Minnesota, Institute on Community Integration

Executive Director, Human Services Research & Development Center

amado003@umn.edu

Kim Zoeller, M.P.A., President and CEO Ray Graham Association

kimz@raygraham.org

Elizabeth Pell, M.S.W., Policy Associate Human Services Research Institute (HSRI) epell@hsri.org