



## What Do NCI Data Show About Friendship and Life Outcomes for Adults With Intellectual and Developmental Disabilities?

*By Stephanie Giordano, Dorothy Hiersteiner, and Elizabeth Pell*

### Overview

Friendships enrich the lives of people with intellectual and developmental disabilities (I/DD) just as they enrich the lives of people without disabilities. Research has shown that friendships have a positive impact on health, habits and well-being, and contribute to overall quality of life.<sup>1</sup> However, studies have shown that people with I/DD often live with few social connections and friendships outside those with family and staff.<sup>2</sup>

For adults with I/DD, National Core Indicators<sup>™</sup> (NCI<sup>™</sup>) data show significant differences in many areas of life, between those whose friendships are limited to family or paid staff and those with more extensive friendship networks that include other people with disabilities and people in the general population.

This NCI data brief examines those differences and identifies some resources for supporting people with I/DD to develop their relationship networks.

## Background

Recent studies have shown that, in the general population, having a network of close friendships and relationships is central to a person's well-being.<sup>3</sup> The benefits of friendship extend beyond combatting feelings of sadness, loneliness, and isolation; having friends may also contribute to a healthier lifestyle (getting regular exercise or being less likely to smoke) and a longer life<sup>4</sup> (for example, socio-emotional support has been associated with lower rates of mortality from certain chronic diseases<sup>5</sup>).

We examined NCI data to see if friendships relate to outcomes in areas such as employment, choice, and community inclusion for adults with intellectual and developmental disabilities. For the purposes of this data brief, we differentiate between two types of friendship networks:

- **Expanded** friendships extend beyond a person's immediate circle of paid staff or family to include other people with disabilities and people within the general community.
- **Limited** friendships do not extend beyond paid staff or family; this category also includes those who reported having no friends.

Data from the 2014-15 NCI Adult Consumer Survey reveal that nearly three-quarters of individuals had expanded friendship networks (74%); 26% reported having limited friendship networks. This data brief compares differences in people's experiences based on their friendship network type.

NCI data show more positive outcomes for individuals with I/DD who report having expanded friendships—namely that they are more likely to be employed in a community job, have their rights and privacy respected, have more autonomy and choice, and engage in community activities. Interestingly though, there were few significant findings showing more positive health outcomes for individuals with expanded friendships in terms of long-term conditions (e.g., cardiovascular disease, diabetes), overall wellness (e.g., BMI, tobacco use), and preventive screenings.

These comparisons can help inform state officials, providers, and advocates as they design and implement programs and policies for individuals to expand and maintain their relationships with individuals outside their immediate circle of family and staff.



## Description and Demographics of Sample

The data in this brief are from the 2014-2015 administration of the National Core Indicators (NCI) Adult Consumer Survey (ACS). All individuals surveyed were aged 18 or over and receiving at least one service beyond case management. The total sample includes data from 32 states, the District of Columbia, and one regional council.<sup>6</sup>

The questions analyzed for this data brief come from the Background Information Section and from Sections I and II of the NCI Adult Consumer Survey. The Background Information Section contains data that would most likely be found in agency records or information systems. In most states, this section is completed prior to a face-to-face interview with the person receiving services. Section I of the survey solicits information about individual satisfaction with a range of services and situations and can only be completed by the individual during the interview. Section II questions can be answered by a proxy who knows the person well, such as a family member or a staff person, if the individual is unable to respond. (Case managers or service coordinators are *not* allowed to respond on the individual's behalf.)

The survey question that pertains to friendship, **“Do you have friends you like to talk to or do things with?”** is included in Section I of the survey, and can only be answered by the individuals themselves, not by proxy respondents. The response options are coded as:

- 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

For the purposes of these analyses, 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.

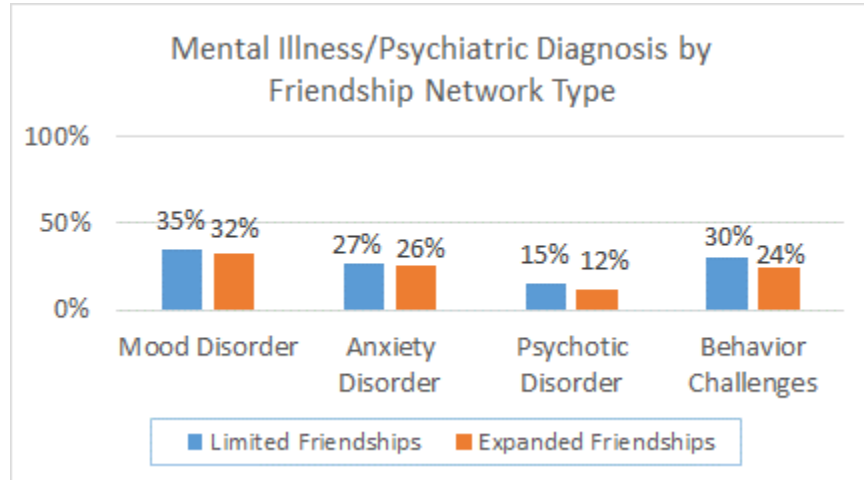
*For the purpose of this Data Brief, only group differences that were significant at the  $p < .05$  level are reported.*

## Results

### Demographics & Personal Characteristics

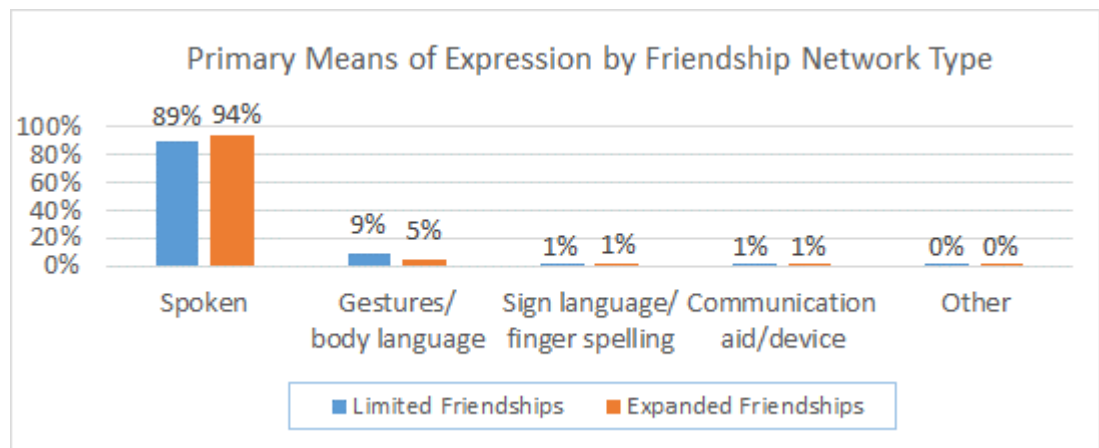
A significantly higher proportion of females reported having friends compared to males (76% compared to 73%). Further, a higher proportion of individuals with limited friendship networks reported being in limited or full guardianship relationships (41% vs. 36%).

Higher proportions of individuals with limited friendship networks were diagnosed with mood disorders, anxiety disorders, or psychotic disorders, or reported as having behavior challenges:



### Communication and Mobility

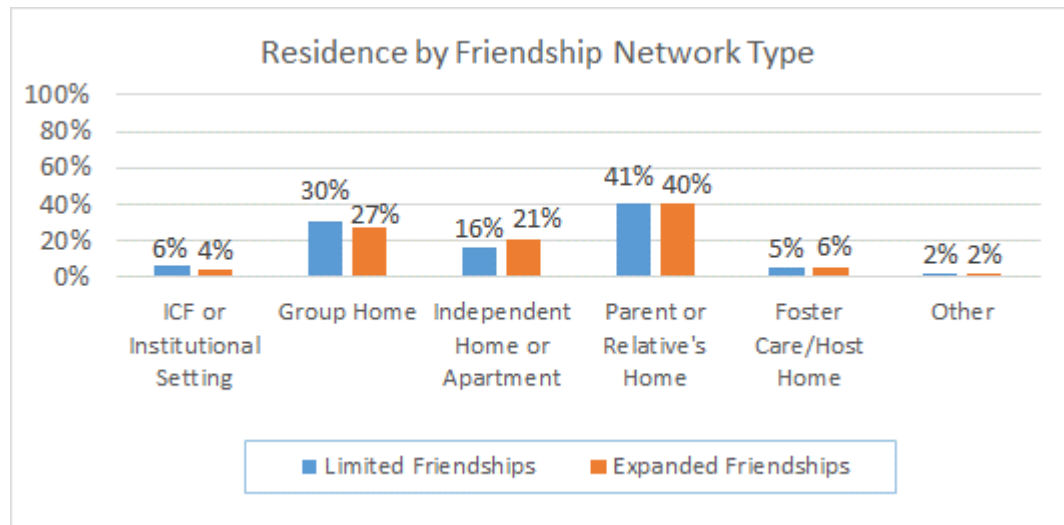
NCI data also reveal a relationship between primary means of communication and friendship. Individuals with expanded friendship networks were more likely to use spoken expression compared with those with limited friendship networks (94% vs. 89%).



In addition, respondents with limited friendship networks were more likely than respondents with expanded friendship networks to be non-ambulatory and to always need assistance moving around their environment (6% vs. 4%).

## Home

Residence type varied significantly by friendship status. Individuals with expanded friendship networks were significantly more likely to live in an independent home or apartment than those with limited friendship networks (21% vs. 16%), while those with limited friendships were more likely to live in the home of a parent or relative, a group home, or an ICF/institutional setting.



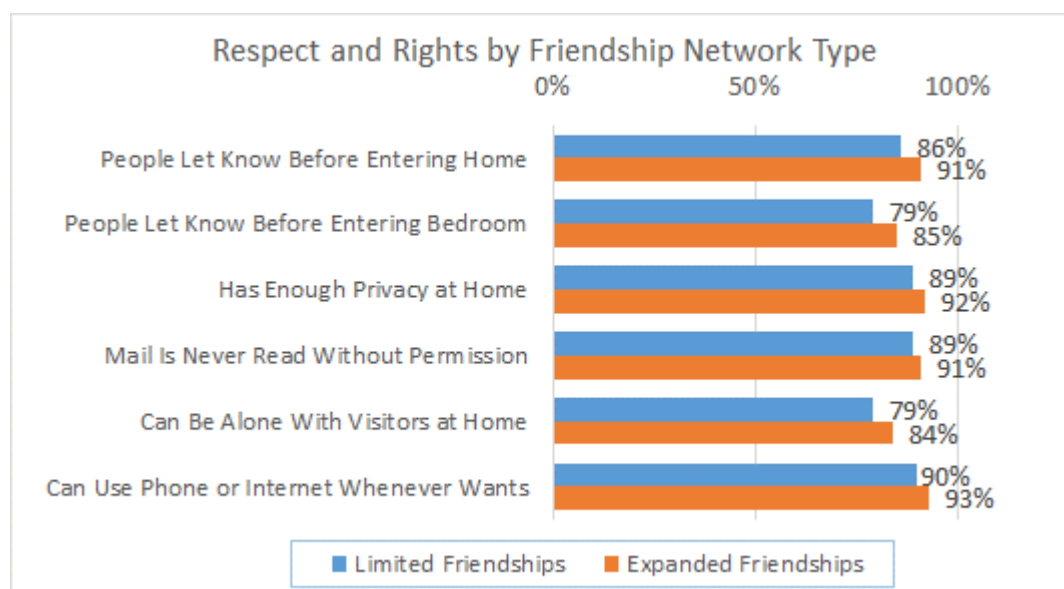
Also of note, 91% of those who reported having expanded friendship networks said they like where they live, compared to 89% among those with limited friendship networks.

## Employment

A greater proportion of people with expanded friendships reported having a paid job in the community (23% compared to 15% among those with limited friendships). In addition, 34% of people with expanded friendship networks reported that they volunteered, compared to 25% among those with limited friendship networks.

## Rights & Privacy

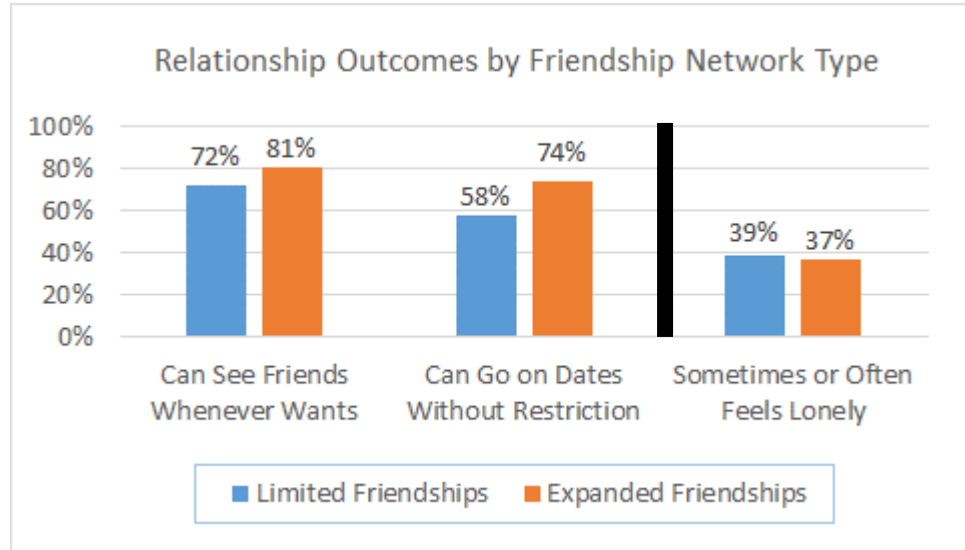
Individuals with expanded friendship networks reported having their rights and privacy respected at higher rates than those with limited friendship networks: A greater proportion reported that people always let them know before entering their home (91% vs. 86%) and their bedroom (85% vs. 79%), and they were significantly more likely to report that they have enough privacy at home (92% vs. 89%) and could be alone at home with visitors (84% vs. 79%).



A significantly higher proportion of individuals with expanded friendships reported that others do not read their mail or email without asking (91% vs. 89%) and that they could use the phone or Internet whenever they wanted (93% vs. 90%).

### Relationships

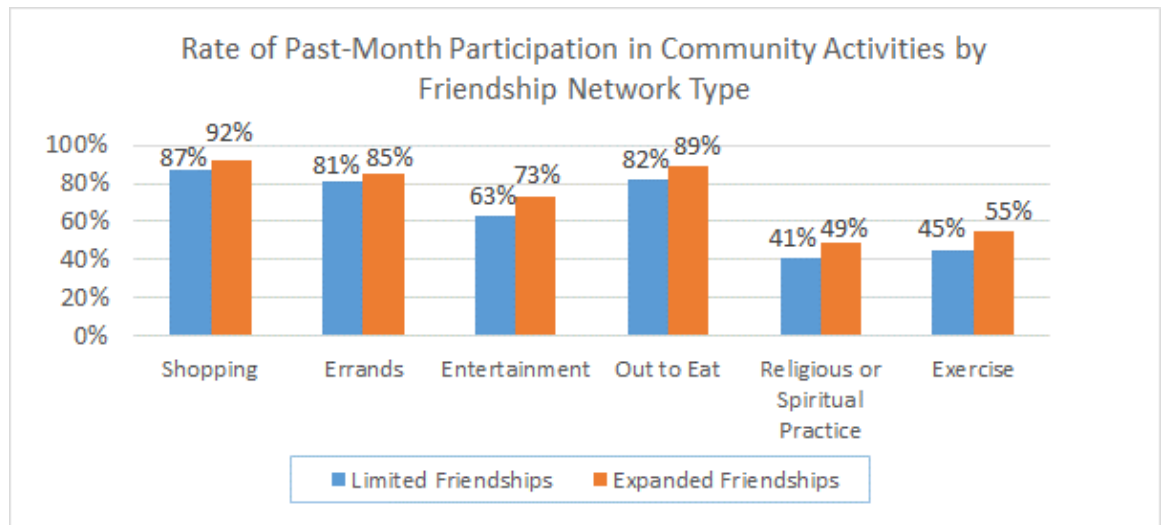
Individuals with expanded friendships saw more positive relationship outcomes compared to those with limited friendships. Those with expanded friendships were less likely to report feeling lonely and more likely to be able to date without restrictions.



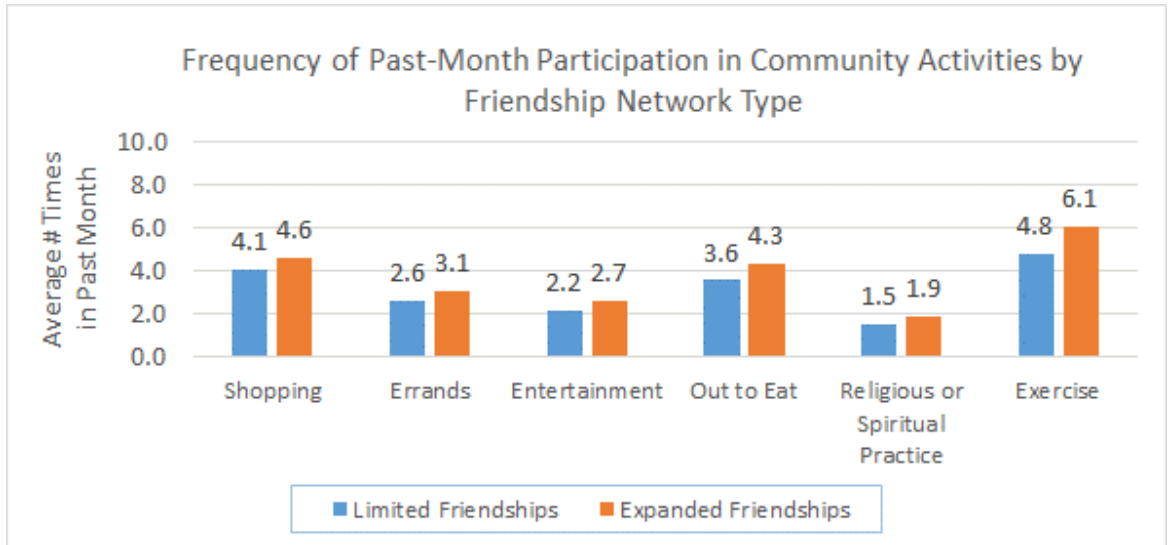
Those who reported having expanded friendships were also more apt to have someone to talk to if they feel afraid (94% vs. 86%) and to have participated in a self-advocacy group, meeting, or event (33% vs. 25%).

### Community Inclusion

Individuals with expanded friendship networks were more likely than those with limited friendship networks to have gone out into the community in the past month to take part in the following activities: shopping, on errands, for entertainment, to a restaurant or diner, for a religious or spiritual practice, or out for exercise.



Within the past month, respondents with expanded friendships also reported having participated in community activities significantly more frequently than those with limited friendships.



## Summary of Findings

### ***Demographics:***

- The vast majority of respondents to the NCI Adult Consumer Survey reported having friendships that extended beyond family and staff (*expanded friendship networks*; 74%); 26% reported only having friends who were family or staff or having no friends (*limited friendship networks*).
- A higher proportion of females than males reported having expanded friendship networks.
- A higher percentage of individuals with limited friendships were reported to be in limited or full guardian relationships.
- Individuals with expanded friendships had lower rates of diagnoses of mental health, psychiatric, and behavioral challenges.

### ***Communication and Mobility:***

- Respondents with expanded friendships were more likely to communicate verbally.
- Those who had greater mobility were more likely to report having expanded friendship networks (75% who were fully mobile and 73% who moved with aids) compared to those who were non-ambulatory (66%).

### ***Home:***

- Individuals with expanded friendship networks were more likely to live in independent homes or apartments, while those with limited friendship networks were more likely to live in group homes or in ICF settings.
- Those with expanded friendships were more likely to like their home compared to those with limited friendships (91% vs. 89%).

### ***Employment:***

- Individuals who had expanded friendships were more likely to be employed in a paid community job (23% vs. 15%).

### ***Rights and Privacy:***

- Compared to those who reported having limited friendships, those who had expanded friendships tended to report having more privacy; they also reported having their rights respected at greater rates.

### ***Relationships:***

- Respondents with expanded friendship networks reported feeling lonely at a lower rate than those with limited friendships (37% compared to 39%).
- Those with expanded friendships were more likely to say that they could date without restrictions (74% vs. 58%).
- Individuals with expanded friendships were also more likely to feel they had someone to talk to if they ever felt afraid or scared (94% vs. 86%) and more likely to report they'd attended a self-advocacy group, meeting, or event (33% vs. 25%).

### ***Community Inclusion:***

- For all community inclusion measures assessed in the ACS, respondents with expanded friendship networks were more likely than those with limited friendship networks to report having gone into the community to take part in specific activities; they also reported participating in these activities with greater frequency.



## Additional Information & Resources

NCI data shows that adults with I/DD who have expanded friendship networks experience greater well-being and desired outcomes than those with limited friendship networks. This data brief can be used to raise awareness about the importance of friendships on well-being, and specifically about friendships beyond relatives and paid staff. Knowing what we know about the connection between the presence of friends in people's lives and their well-being, it is essential to focus on expanding the friendship networks of people receiving services, particularly those who do not use speech to communicate, have mental health conditions, are identified as needing behavior supports, live in congregate settings, or who are of working age but not yet employed in a community paid job.

One factor to keep in mind in supporting friendships among people with I/DD is their socio-economic characteristics. As the World Health Organization notes in its 2003 publication, *Social Determinants of Health, The Solid Facts, 2<sup>nd</sup> Edition*, the health and welfare of people today is dependent on social and economic conditions. It is well-known that people with I/DD experience social segregation and poverty at greater rates than individuals in the general population; these conditions place people—all people—at risk. "Social exclusion also results from racism, discrimination, stigmatization, hostility and unemployment. These processes prevent people from participating in education or training, and gaining access to services and citizenship activities. They are socially and psychologically damaging, materially costly, and harmful to health. People who live in, or have left, institutions, such as prisons, children's homes and psychiatric hospitals, are particularly vulnerable."<sup>7</sup>



The Centers for Medicare and Medicaid Services (CMS) new rules for home and community-based service settings aim to reduce the isolation of people with I/DD and ensure that public funds support full integration.<sup>8</sup> The emphasis placed on reducing the isolation of people with I/DD may lead to increased attention on social inclusion and friendship. CMS has set 2019 as the target date for States to complete their transition to fully integrated services in the community. All states are engaged in systemic change initiatives to adapt the focus of existing policies and services to one which emphasizes people's experiences in their community. The data on friendships available through NCI suggests some of the areas which may assist states with their efforts.

Selected resources for supporting people with I/DD individually to develop their relationship networks are provided below.

**Free Guide and Activity Workbook:** *Friends, Connecting People with Disabilities and Community Members*, by Angela Novak Amado, PhD. This free resource is an easy to understand how-to guide for direct care professionals, managers, and others to assist people with disabilities to

form relationships with people in their communities.  
Available at: <http://rtc.umn.edu/friends/>

### **State Friendship Initiative and Toolkit for Building Friendships at Work:** The Massachusetts Department of Developmental Disabilities recognized the

important role that friendships play in quality of life and launched an initiative called “Widening the Circle” to educate all people about the benefits of relationships between people with disabilities and people without disabilities, and to provide resources to help people engage in and sustain relationships. One resource is a toolkit for supporting friendships at work. It can be used by employment specialists, job developers and job coaches. The free toolkit includes suggestions on how to maximize the chances of meaningful relationships between people with I/DD and their co-workers at key stages of the employment process. Available at: <http://thearcofmass.org/building-friendships-at-work-toolkit/>

## Questions? Comments? Contact Us

For additional information on the National Core Indicators (NCI) initiative, public reports, and past data briefs, please visit: [www.nationalcoreindicators.org](http://www.nationalcoreindicators.org).

We welcome your feedback and questions. If you want to discuss this report or have questions about the NCI project, please contact: Dorothy Hiersteiner, NCI Project Coordinator, at [dhiersteiner@hsri.org](mailto:dhiersteiner@hsri.org)

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- <sup>3</sup> Ellis, A., (2016, January 31). Loneliness grows from individual ache to public health hazard. *The Washington Post*. Available at: [https://www.washingtonpost.com/national/health-science/loneliness-grows-from-individual-ache-to-public-health-hazard/2016/01/31/cf246c56-ba20-11e5-99f3-184bc379b12d\\_story.html](https://www.washingtonpost.com/national/health-science/loneliness-grows-from-individual-ache-to-public-health-hazard/2016/01/31/cf246c56-ba20-11e5-99f3-184bc379b12d_story.html)
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- <sup>5</sup> Kroenke, C.H., Kubzansky, L.D., Schernhammer, E.S., Holmes, M.D., & Kawachi, I. (2006). Social Networks, Social Support, and Survival After Breast Cancer Diagnosis, *Journal of Clinical Oncology*, (24/7), 1105-1111. Available at: <http://jco.ascopubs.org/content/24/7/1105.full>
- <sup>6</sup> States included in the 2014-15 administration of the Adult Consumer Survey are: AR, CA, CO, CT, DC, DE, FL, GA, HI, IL, IN, KS, KY, LA, ME, MI, MN, MO, MS, NC, NH, NJ, NY, OH, OK, PA, SC, SD, TN, TX, UT, VA, VT and the Mid-East Ohio Regional Council (MEORC).
- <sup>7</sup> WHO, 2003, p. 16. Available at: [http://www.euro.who.int/\\_data/assets/pdf\\_file/0005/98438/e81384.pdf](http://www.euro.who.int/_data/assets/pdf_file/0005/98438/e81384.pdf)
- <sup>8</sup> CMS webpage on Recent HCBS Guidance, <https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Home-and-Community-Based-Services.html>