

Social Capital, Social Isolation, and Family Engagement – A Deeper Dive

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Introduction

The concept of social capital first appeared in the literature in 1914. It was identified as the value brought to people's lives through their social networks. Since then Sociologists studied social capital over the years but it wasn't until the late 80's when the notion was popularized by Robert Putnam in articles, and then through the publication of his book, Bowling Alone in 2000.

The impact of social capital was not fully popularized in the disability community until the publication of Interdependence: The Route to Community in 1991. Since then, a number of researchers and rehabilitation advocates have articulated the importance of social capital in dealing with disability related issues.

Today there is much attention focused on the negative effects of social isolation, which is the opposite of social capital. That is, when people lose, or have difficulty establishing social capital they are at risk of loneliness and social isolation. The interest in this issue (social isolation and loneliness) has been considered a health risk worse than obesity, and many foundations and health insurance carriers are looking more closely at the impact of social isolation and more, ways to help people build social capital.

This paper examines two major aspects related to social capital – the notion of social isolation and loneliness and some newer research on family engagement patterns that might shed light on ways and means to building more social capital.

Loneliness and Social Isolation

First it is important to know that these two elements, loneliness and social isolation, are not synonymous. That is, you can be socially connected, yet still lonely. Further, some people who are socially isolated might not report feeling lonely. It is best to think of these notions as social isolation, being alone, and loneliness as a sense of feeling alone. Further, these elements can affect any person, although there are some groups of people more susceptible.

In terms of the negative effects of social isolation and loneliness, research has shown that people who report feeling lonely and disconnected are at greater risk of mortality and a host of negative psychological, physiological and health issues. One study suggested that loneliness is akin to the negative effects of smoking 2 packs of cigarettes per day.

Social Capital and Social Connectedness is the opposite of loneliness and social isolation. The more connected one feels the greater the contentment and satisfaction felt in life. Research has shown that these connections are related to better health, more happiness, greater recovery from illness, more resistance to viruses and even life expectancy.

Yet, loneliness seems to be on the rise. In 2018, Cigna Health Insurance released the US Loneliness Index, a survey of 20,000 Americans that examined the behaviors driving loneliness. Aspects reported in this report are:

The Cigna study used the UCLA Loneliness Scale developed in 1978 and found to valid and reliable over time. The scale is short (20 items) and uses a 4 point Likert measurement answers of “never,” “rarely,” “sometimes,” “often.” Each answer is weighted and an overall score can be rendered between 80 (always lonely) to 20 (never lonely). Here are the 20 questions from the revised scale:

1. I feel in tune with the people around me?
2. I lack companionship?
3. There is no one I can turn to?
4. I do not feel alone?
5. I feel part of a group of friends?
6. I have a lot in common with the people around me?
7. I am no longer close to anyone?
8. My interests and ideas are not shared by those around me?
9. I am an outgoing person?
10. There are people I feel close to?
11. I feel left out?
12. My social relationships are superficial?
13. No one really knows me well?
14. I feel isolated from others?
15. I can find companionship when I want it?
16. There are people who really understand me?
17. I am unhappy being so withdrawn?
18. People are around me but not with me?
19. There are people I can talk to?
20. There are people I can turn to?

Using this scale, Cigna polled 20,000 Americans, 18 and older and from all demographic groups and states. The index stipulates that the higher the score, the lonelier people are and possible loneliness scores range from 20 to 80. With this scale, they found that the total national loneliness score in America is 44. In this regard most people in the US are considered lonely! Some general, then more specific findings are:

- Generation Z (ages 18-22) and Millennials (ages 23-37) are lonelier and claim to be in worse health than older generations.
- Social media use alone is not a predictor of loneliness.
- Students have higher loneliness scores than retirees.
- There was no major difference between men and women and no major differences between races when it came to average loneliness scores.

- Individuals who are less lonely are more likely to have regular in-person interactions, are in good overall physical and mental health, have found a balance in their daily activities, and are employed.
- When asked how often they feel like no one knows them well, more than half of the respondents (54%) surveyed said they feel that way always or sometimes.
- Just under half of all those surveyed report sometimes or always feeling alone (46%) and or feeling left out (47%).
- At least two in five surveyed sometimes or always feel as though they lack companionship (43%), that their relationships are not meaningful (43%), that they are isolated from others (43%) and/or that they are no longer close to anyone (39%).
- Approximately six in ten (59%) surveyed always/sometimes feel that their interests and ideas are not shared by those around them.
- A similar proportion surveyed reports sometimes or always feeling like the people around them are not necessarily with them (56%).
- Though fewer feel as though there is not one they can turn to, more than a third of the respondents nevertheless report feeling this way at least sometimes (36%).
- Face to face interactions lessen loneliness, and those who have daily interactions have the lowest loneliness scores.
- Fair or poor physical health can be an indicator of increased loneliness.
- Balanced sleeping patterns reduce loneliness.
- Those not spending enough time with family are most likely to be lonely.
- The right amount of exercise is key to reducing loneliness.
- Adults running single parent homes are most lonely.
- Retirees and employed adults are among the least lonely.

This deeper look at loneliness offers some ideas and strategies that can be considered in dealing with the negative effects of disconnection. What we hope will happen next is a deeper dive into the loneliness perspectives of individuals with disabilities and their families.

Family Engagement Patterns

In looking at social capital as an antidote to loneliness and isolation, it is important to understand that the social protocols that are critical to relationship building are learned through observation. That is, in most formal educational curriculums there is nary an example of the teaching of these nuances. Rather, most people learn to socially engage by observing their families, parents, and older siblings engage. To this extent, the social and engagement patterns for families are critical.

Yet, many families who have children with disabilities seem to engage less. This is concerning for two major reasons. One is that families who become isolated are at risk of all the negative repercussions we see happening to individuals who are isolated. Second, and maybe more important, when families engage less, their children have less exposure to the important social protocols in building social capital.

As we looked deeper at this issue we discovered no helpful research. That is, the issue of family engagement has not been seen as an important research variable so there is no literature that explores this critical issue. This motivated us to begin to fill this void.

In 2016, using the Harvard Social Capital Benchmarking Survey, a research team from Chatham University in Pittsburgh, and CLASS, a nonprofit organization in the Pittsburgh region serving individuals and families with disabilities launched an international study to examine family engagement patterns. Partnering with a sister organization, Mamre, in Brisbane, Queensland, in Australia, we identified 50 families in both countries (US and Australia). Controls were taken to identify 25 families who had children with official disability labels, and then find 25 comparable families who had similar children, but without disability labels in each country.

Our research team then surveyed these 100 families (50 in US, and 50 in Australia) and compiled the findings. The Social Capital Benchmarking Survey was developed at Harvard University by Robert Putnam and his associates in 2000. We adapted the survey into 6 component sections. These are:

- Demographic Information – exploring size of family, type of disability, and income.
- Neighborhood – exploring type, years in setting, neighbor relations
- Activities – exploring social patterns and frequency
- School Activities – exploring educational programs and social relationships
- Chore Support – exploring assistance available
- Personal and Emotional Support – exploring personal assistance available

The results of this study allowed us to compare and contrast 4 key cohorts. These are US Families/disabilities – US Families w/o disabilities – Australian Families/disabilities – Australian Families w/o disabilities. Some of the general findings were:

- Children w/disabilities are less likely to stay connected with other via the internet than are children w/o disabilities, and this appears more prominent in Australia.
- Families who have a child with a disability are more likely than families w/o disability to report not receiving enough supports, and this appears more prominent in Australia.
- Families in Australia are less like to engage family members to help with chores and this is more prominent for families w/o disability
- Families in the US tend to be more likely to indicate that they have family members who can help with chores
- Both in US and Australia, children with disabilities tend not to see their school friends outside of school as often as children w/o disabilities.
- In both US and Australia, children w/o disabilities are much more likely to have friends who do not have disabilities, but there is no significant difference in whether the two groups have friends with disabilities.
- Families in Australia who have children with disabilities are much less likely to go to a friend's home or a community event compared to all other groups.
- US families were more likely than Australian families to go to public activity venues.

- US families (both cohorts) were more likely to go out to dinner; and Australian families with disabilities were least likely.
- Neither language nor transportation appear to be a barrier for any of the groups.
- Australian families with disability appear to feel most lonely in their neighborhood compared to all other groups.

In review of these findings there seems to be 3 key factors that prevent families with disabilities to engage more frequently than families w/o disabilities in both countries. These are:

- Economic aspects – families with disabilities tend to have lower financial resources and most engagement venues requires some disposable income. It might be that this financial disparity is related to the costs associated with disability that are not bore by other families.
- Logistical aspects – families with disabilities reported to us that they must do preliminary research as to access, parking, bathrooms, and environmental stimulations before going out. In some cases this can be so demanding that it is easier for these families to just stay at home.
- Stigma aspects – families with disabilities reported to us that they sometimes experience social cues that suggest they are not welcomed in the public venue. This seems most prominent when children with disabilities have social or behavioral issues

Conclusion

Given this deeper dive into these social and community issues there seems to be some important variables to be considered in both the loneliness and engagement areas. We know through study that folks with disabilities have lesser social capital. We also know that with lesser social capital people are at risk of loneliness, and with loneliness comes a host of negative life issues that affect health, happiness, self-image/confidence, and even life expectancy. Finally, we know that people learn the social skills to develop relationships by observing others, and, if they have less opportunities to engage, they struggle more with social protocols.

As we connect these dots it is imperative that we have ways, means, and supports designed to help people build social capital. This agenda will not only promote more relationships, but will also promote a macro perspective that will begin to influence attitudes in the greater community.