Community
Building
Reports

White Paper Series

◆ **Community Engagement and Disability: The Australian Experience.**

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interdependence
NETWORK

Introduction

The concept of "community" is a really powerful element in our lives. Quite literally the term community means "with togetherness" and it does more for us than we tend to give credit. Some anthropologists suggest that community is the primary reason why human beings have not only survived, but thrived as a species. Certainly as an animal, humans lack many of the acute skills and abilities of physicality to succeed on our own and so by sharing, collaborating and cooperating everyone does better. This is the history of human success.

Think about it. In spite of our individual skills or abilities, anyone of us who have experienced success, have not realized this totally on our own. Our success is a compilation of people, and engagement with other people that have informed, inspired, challenged, or cajoled us into performance or activity that lead to the success we have enjoyed. From our parents, to teachers, coaches, to friends, life is riddled with relationships that have made us better people.

It is this reality that has driven social scientists to come to the conclusion that life success is promoted, not just by our individual skills, but more by the social capital and community engagement we have developed around us. Today researchers are convinced that all good things of life; health, happiness, advancement, achievement, and even life expectancy, are directly related to social capital. Indeed, the term "social capital" is a deliberate effort to remind us that our relationships are tangibly valuable to us.

More, we also know through research and study that the more diverse our social capital is, the more we grow or broaden in our perspective of self and life. Quite simply, when we build a relationship with someone who has some differences from us, we become more tolerant, and willing to accept or even respect their difference. This is an important, maybe even critical phenomenon because we also know that when people have or experience key elements of difference, they are at risk of societal segregation and devaluation. The antidote for devaluation is to be included in the bigger mix, and so with an inclusive agenda for community engagement, we have an interesting and powerful paradox.

Quite simply, people who are different or outside of the community "norm" are at risk of devaluation and segregation. This happens in a variety of situations, some direct, others more subtle, where people who have some difference from the norm are formally offset. Yet, when diverse people are welcomed into the greater mix of community, everyone is better off, and society advances.

To this end, diversity in community becomes an important variable in promoting a better, more successful collection of people. That is, when people who have some significant difference from each other (age, race, lifestyle, disability, poverty, etc) come together around things they have in common, good things happen for everyone. In this regard, inclusive community should become a goal for all of us. Essentially diversity and connectedness makes us a better community.

At the core of this issue is the action of engagement. That is, just being together is not enough. Relationships form when people endeavor to do something together – to engage. To this end, if

we want to explore relationships, we must intersect with engagement. What brings people together; what are the commonalities that create a connection?

How Engaged Are We

Getting a handle on diversity and community engagement is not an easy task. Still, in the past 20 years or so, social scientists have begun to explore this notion, building on the construct of social capital and have developed a template for study. Most notable among these studies has been the work of Robert Putnam at Harvard University in the United States.

Putnam has worked to define the elements of social capital and community engagement and in 2001, developed a survey to examine benchmarks and start points for measure. This survey, the Social Capital Benchmark Survey (SCBS) has been used now for over a decade to measure social capital in communities all over the United States; however, Putnam was deliberate to not include people with disabilities as he was looking to develop purely typical normative benchmarks.

The SCBS instrument examines a person's social capital by assessing seven factors of connection and engagement. These include:

1. Relationships and Friendships - these connections supply us with the social capital needed to be healthier, happier, and more successful. This dimension asks questions about various types of relationships
2. Associational Involvement - this dimension is measured across 18 broad categories of formal community groups, such as neighborhood watches, sports clubs, hobby groups and the like.
3. Informal Socializing - here Putnam looked to measure the degree to which individuals participated in activities in the community, such as having friends over, and going out to public places.
4. Social Trust - at the core of social capital is the notion of trust and the survey probes in this area.
5. Social Support - this index assesses social support, including emotional, instrumental, and informational dimensions. These elements are the essence of of social capital.
6. Political Participation - another key measure for how we engage in community is tied to our political and civic activities.
7. Civic Leadership - this final element captures how frequently respondents took leadership roles in their clubs, groups, and associations.

Putnam then used this survey to examine over 30,000 American's patterns and activities in the community and established some basic benchmarks in these dimensions.

Subsequently, a North American advocacy group, the **Interdependence Network**, adjusted the Putnam Survey, and began to use it in measuring the engagement patterns for people with all types of disabilities to examine how they might compare. This was not a formal research study, but more of a moment in time in comparison, and they have reported and disseminated their findings on their website, www.buildingsocialcapital.org, and in articles and presentations.

The IN captured their findings by conducting interviews with adults with a variety of differing disabilities, who receive direct services from partner agencies in Toronto, ON; Vancouver, BC, in Canada, and Portland, ME; Pittsburgh, PA; Kansas City, KS; and San Jose, CA in the United States.

Engagement Patterns in Queensland

Intrigued by the comparisons in Australia, officials from Mamre Association in Brisbane, QL, set out to explore how people with disabilities compare "Down Under." Mamre is a nonprofit organization that has been providing services and supports for individuals with disabilities and the families that support them in Queensland since 1955. In that time Mamre has become one of the leaders in the disability rights movement and empowers families and individuals with disabilities in receiving the important services necessary for people to lead successful and engaged lives in the community.

Aligning with Dr. Al Condeluci, one of the initiators of the Interdependence Network in North America, Mamre conducted a moment in time exploration utilizing the same adapted Social Capital Benchmark Survey (SCBS) on 102 adults in the greater Brisbane area. Of these respondents, 69 subjects did not have disabilities, and 33 subjects had primarily Intellectual Disabilities.

The surveyors were trained by Dr. Condeluci in how to conduct the survey so that consistency and protocols were followed in each of the interviews conducted. Initially, the surveyors took the survey themselves, and then identified other individuals in the greater Brisbane community to establish a generic benchmark. Efforts were made to survey individuals from a mix of experiences and walks of life to get a broad of a spectrum as possible.

Next, the survey was conducted on random adults with disabilities known in the community. The common factor with the Australians with Disabilities (identified as A/w/D in the results and impressions section) is that all of the 33 respondents experience an intellectual disability and receive some direct service from agencies like Mamre.

Finally, the survey was taken with families who have children with disabilities (0 to 18) that live with them, as well as families who have adults with disabilities (19 and older) in their residency. This addition of families was unique to how this survey has been used in North America, but merits consideration given the anecdotal evidence that families who provide disability supports may also be limited in community engagement. The analysis of this data will be saved for a separate paper that will focus exclusively on family patterns.

What follows in this paper, is an initial overview of the findings of individuals, mostly displayed in comparisons and impressions. That is, we have taken some key engagement and social capital issues for A/w/D and offered a comparison with generic adults in the greater Brisbane area. We are convinced that the more we examine community patterns, the more we can look to adjust and focus human service and government supports in more relevant ways.

The Results and Impressions

Realizing that this information is merely a moment in time and may, or may not be generalizable, the results are offered in a simple display (by percentage) that compares and contrasts some key areas, and the responses between a cohort of respondents without disabilities, and then a cohort of respondents with disabilities (mostly intellectual disabilities), both groups being polled in the greater Brisbane area of Australia. The final column displayed is from a cohort surveyed in 6 North American sites using the same survey in 2011, and their responses to the questions.

Subject/Information	Generic Group Without Disabilities	Australian With Disabilities	American/Canadian
N - 102.	N - 69.	N - 33.	N – 218

Demographics

Gender

Male.	21.3.	39.4.	62
Female.	78.3.	57.6.	38

Age Range

19-24.	14.5.	12.1.	16
25-29.	5.8.	12.1.	9
30-39.	27.5.	21.2.	20
40-49.	23.2.	27.3.	30
50-59.	17.4.	18.2.	20
60+.	11.5.	9.1.	5

In looking at the gender and age range of the Australian sample, our subjects had a variation to the typical patterns found in Australia. Generally, of the overall population 23,359,900 (2014 data), 50.5% are female and 49.5% are males and the current age percentages are as follows:

0-14 - 18.2%
15-24 -13.5%

25-54 - 42.2%
55-64 - 11.8%
65+ - 14.4%

Regardless, our exploration was more a look at community, connectedness, and relationships, and not meant to be a demographic comparison.

Home and Neighbor Situation

Home Status

Own.	68.1.	18.2.	27
Rent.	20.4.	12.1.	46
Public Subsidy.	1.4.	69.7.	27

Rating Neighborhood

Excellent.	21.2.	15.2.	30.3
Very Good.	59.1.	18.2.	29.8
Good.	18.2.	30.3.	28.4
Fair.	1.5.	18.2.	6.9
Poor.	0.	18.2.	4.6

Time in Current Neighborhood.

1-6 mos.	6.1.	0.	2.3
6 mos - 1 yr.	12.1.	9.1.	5
2-5 yrs.	33.3.	18.2.	29.8
6-10 yrs.	22.7.	33.3.	13.8
10+.	25.8.	39.4.	40.8

Neighbors Names Known

0.	6.1.	66.1.	38.2

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1-2.	19.7.	9.1.	23.1
3-4.	19.7.	15.2.	22.1
5-6.	21.2.	6.1.	16.1
7+.	33.2.	3.0.	0

Neighbors Spoken to

0.	0.	60.6.	47
1-2.	31.8.	24.2	30
3-4.	30.3.	3.0	8.2

Neighbors Homes Entered

0.	34.8.	81.8.	53
1-2.	48.5.	15.2	43

This initial neighborhood and engagement data speaks for itself. There is a clear, yet stark discrepancy between the generic and disability audiences in home ownership. Certainly in looking at employment patterns, the survey found that only 19% of the respondents with disabilities were employed (compared to the 84.9% of Adults without disabilities) This employment discrepancy, and the economic differential between Australians with and without disabilities it suggests, is probably the reason for the gap in home ownership. Further, the percentage of A/w/D in public housing (69.7% in this sample) compared to North American's (27%) is stunning.

Another striking finding in this section is the extent of engagement (speaking to, or visiting neighbors) with people who live nearby. The survey found that 40% of the A/w/D had lived in their neighborhood for 10 years or more. Sociologically, this is an extensive period for engagement penetration, yet 66.1% did not know their neighbors names, 60.7% had never spoken to a neighbor, and 81.8% had never entered a neighbor's home. Interestingly enough, when we asked A/w/D if they "wish they knew more neighbors," 87.9% said they did and 72.7% reported that they "feel lonely in their neighborhood."

Important Relationships

Are You in a Long Term Relationship

Y	80	13.8	10
N	20	86.2	90

Do you live with your Long Term Relationship

Y	78	10.3	5
N	22	89.7	95

Do you use the Internet to stay connected

Y	90	37.9	35
N	10	62.1	65

Do you use the Internet to meet new people

Y	16	6.9	5
N	84	93.1	95

Beyond neighbors, the survey looked at significant relationships and people who are relied on to offer emotional and instrumental (chores or tasks) that people might need some help with. In looking at significant relationships, 80% of the respondents without disabilities reported having significant relationships as compared to only 13.8% of A/w/D. Sadly, 86.2% reported having no significant relationships. This is an astounding statistic that suggests deep loneliness and isolation.

The literature is clear in Social Capital, that significant relationships are the cornerstone for basic self-esteem and stability. The mere fact that the great majority of respondents with disabilities, both in Australia and the US, are this deeply isolated should call for dramatic shift of perspectives in formal human service programs.

More, the survey found 79.3% of A/w/D did say they had someone they could rely on for emotional support, but that person is primarily (75% of the time) a professional. This comparison to respondents without disabilities showed that 93% of them had emotional support (with 70% of the time offered by the significant other) and only 8.2% of the time goes to a professional.

This professionalization for emotional and instrumental support is troubling and revealing. In this conservative era, when public expenditures are scrutinized, there seems to be some opportunity to consider other directions here. That is, if A/w/D are supported to build social capital and to participate more in community engagement, and the corresponding relationship

numbers increase, there should be then a decline in the amount of professional emotional support, as this need shifts to friends and relationships. If such a shift occurred, then released dollars can be used to serve more individuals, or to continue to promote more opportunities for engagement. It is an upriver investment, to produce a downriver savings.

Recommendations

Thoughtful societies and people should be open to new ideas or approaches. As the times change, and thinking advances, new paradigms and efforts must follow. In disability supports, the prevailing paradigm has emanated from a medical/micro approach. That is, people in our society have come to see people with disabilities as having problems that should be addressed or fixed. This micro paradigm indicate that if the deficit, or shortcoming that the person has is addressed, mitigated, or fixed, the person can then move on to a position of success.

Unfortunately, this perspective has been shortsighted, and flawed in its impact. Indeed, in spite of all types of micro programs and services, more today than ever, people with disabilities are still isolated, disconnected, and devalued in our society. Our survey captured how disparate our A/w/D sample is when compared to what is more typical for people without disabilities. To this end then, our study demonstrates that the micro/treatment paradigm is not viable in helping people become engaged. Simply it is the wrong approach for what is needed.

If we are to believe that social capital and community engagement are better for all people, then we need to advance an alternative paradigm. Our recommendation, then, is to initiate a macro change model, and advance an interdependent paradigm that is more about changing the attitudes, assumptions, and actions of the greater community, than to fix or change disability.

This perspective suggests that it is not our differences that divide us, but our judgments about these differences. That is, once our judgments expand, then the challenge of inclusion lessens. Think about it. You have had a particular judgment about something, bore out of ignorance, misunderstanding, or naivety. But once you became more closely introduced to a situation, your judgment might have changed.

A macro agenda redefines the problem; it begins to re-interpret what normal might be and has its roots in culture change. It is an anthropological perspective, not a clinical or therapeutic one. Now this notion of culture or macro change is not a "silver bullet" or panacea. It is not some easy quick fix. One just need look at macro, community history of any social movement to understand how challenging and tedious it can be.

Still, in the scheme of things, this macro agenda offers so much more of a possibility to a society, than the micro, change the person approach.

Conclusion

It is important to remember that this survey was just a moment in time in talking with a small sample of people. Still, in looking at key dimensions, some reported in this paper, and others that will be released later, we are getting a portrait that suggests significant disparities in social capital and community engagement patterns for Australian's with disabilities. Most human

service officials would probably predict these findings, but when you see them in print, and fathom the stark differential between people with and without disabilities, it screams out at us.

Certainly in our society we speak of fairness, basic equity, and opportunity. These are the hallmarks of a successful culture. Yet, on the most basic, and human level, the disparities found in this survey should be cause for serious study and debate. This is even more pronounced if you subscribe to the notion that disability is within the typical course of life. That it can happen to anyone, in the most unpredictable of times, and that nary a one of us will not be personally touched by its reality.

Mamre Association has opened its eyes to this reality. We subscribe to the notion that if one of us is at risk of losing social capital, or limited community engagement that disability seems to impose, then any of us are at this same risk. Further, we believe that these patterns of isolation and limitation can be addressed in a macro change perspective.

We are ready to lead this challenge and hope you will join us in this cause.