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THE IMPACT OF SOCIAL CAPITAL ON PEOPLE WITH DISABILITIES

Abstract: This paper seeks to ascertain the usefulness of the theory of social capital as a framework for developing and sustaining the inclusion of people with disabilities and families in community life.
. It is argued that to date, people with disabilities and their families have largely been excluded from the broader social capital debate and that social capital thinking has had minimal influence on efforts to achieve the inclusion of people with disabilities into community life. It is further argued that new paradigms of support are needed that build capacity and social capital
through working alongside individuals and families to influence not only outcomes for them It is concluded that social capital theory can
make a contribution to inclusion theory and practice but we should use it with
circumspection.

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Introduction

I was married in 2003 and in 2004 my daughter (Sara) was born. In 2007, my son (Yousef) was born. I was very happy to visit him. After his first year, I began to notice that he was not acting like the captain of his generation, and from here I began my journey with Yousef and the doctors and specialists until I was told that Yousef suffers from autism disorder.

I did not accept it at the beginning like a father and I did not know anything about autism and began a journey to seek treatment.

Yousef was not accepted by the community at first because his actions were disturbing to him and others.

But after the age of five Yousef was placed in a suitable framework for him and his teacher specialized for Autism and today I consider Joseph as beautiful gift to me from God.

Recently, researchers across the social science disciplinary spectrum have embraced the concept of social capital (Moody & Paxton, 2009; Portes, 1998). As a generic concept, social capital refers to a set of relationships and social ties, with organizations and to individuals, that can expand one's choice-making opportunities, increase one's options, and lead to a more enriched quality of life. There is no undisputed definition of social capital that is broadly accepted.

Definitions of social capital vary considerably since researchers often include within them expressions of their disciplinary goals, their views about where social capital originates or resides, or how its service capacity can be changed (Robison et al., 2002). However, there is an emerging consensus that social capital, at its core, comprises a set of relationships and social structures.

These relationships and social structures are based in trust and norms of reciprocity, which in turn are governed by values and/or rules of law. Articles published in the past 25 years on the construct of social capital largely divide into two groups: a) those that view social capital as an

attribute of the individual and b) those that view it as an attribute of groups and/or the larger community (Portes, 2000).

For my purposes here , social capital is defined as follows: the personal and collective power of people with disabilities and organizations to further their full inclusion within the community, to access social support networks, and to increase their quality of life (Walker ,et al., in press).

A fundamental, core value at the heart of social capital is trust; that is, the trusting of others within one's social network and trusting of those whom your friends trust. Other important values associated with social capital include having friends and allies who are on your side, developing connections to others who can help you, and being of assistance to others (Gardner, Ward, & Weintraub, 2010). Individuals with high levels of social capital are expected to work toward the common good of everyone in their community or network. Social capital is strongly connected to self-determination in that it gives the individual the power to make decisions, have choices and adds control and direction to one's life.

Based on the social capital literature there are three key elements in the development of social capital :

1. Family / parent participation and advocacy in the lives of people who are just developing their own social capital repertoires are vitally important. Research shows that like other forms of capital, social capital is often transmitted from parent to child (Bordieu, 1986)
2. Social capital involves developing and sustaining as many peripheral social ties as possible. Peripheral ties of this nature are often the most important when accessing opportunities outside one's bonded or primary social network.
3. Connecting to and/or joining important social structures (i.e., volunteer organizations ,churches, advocacy associations, work related groups, etc.) is of critical importance in accessing friendships and different social support networks. Individuals not only gain personal social capital in this process but alsoaccrue the benefits of these groups' larger pools of social capital.

A preeminent need for people with developmental disabilities in particular is to achieve a higher quality of life; a life that includes family, friends, associates and community engagement . a crucial mediating variable for achieving a higher quality of life involves the development of social capital. While the three steps highlighted above apply to all people, a special emphasis should be placed upon using them to develop social capital for people with disabilities. As Portes (1998) has observed, social networks are not a natural given; they require effort and must be constructed through multiple investment strategies.

Now I will state the key elements of social capital with examples of how these elements should operate for people with disabilities and their families.

Participation

One of the key concepts in social capital is the participation in various networks through family and friends, neighborhoods and work.

Social capital is generated through these networks and associations. This participatory approach would suggest that people with disabilities and their families become involved in naturally occurring networks within their own communities the researchers found that isolation from such networks is more often than not the powerful experience of vulnerable people

Reciprocity

Bullen and Onyx (1999) suggest that social capital is about the exchange of resources or supports or services between people. It is not based on the 'Immediate return' requirement that is inherent in the business contract but rather on the notion that people provide a support to others based on a general expectation that someone will return the favor at some time in the future. Again, the researchers found that reciprocity is less likely when the person has a disability, or the family is caring for a person with a disability.

Trust

All discussions of social capital refer to trust-that people will act inmutually supportive ways and do no harm to each other. The principle of reciprocity rests on this basic requirement of trust. researchers found that many of the people their difference tends to alienate people.Their 'naturally occurring networks' based on trust are largely limited to their immediate family members or to paid professionals.

Social norms

Social capital is said to be related to the upholding of social norms. This is one of the most powerful determinants of difference. Social norms within society established what it is to be 'normal' and to be a member of the 'inner core' of that society. To have a disability, to be mentally ill or infirm, means that one of the most powerful norms is challenged. It becomes extraordinarily difficult for an individual to overcome such norms and establish their capacity within a community.

Common resources

Bullen and Onyx (1999) suggest that all the factors above create communities with a strong sense of and commitment to shared ownership of resources. These are pooled resources owned by the community separate individuals. Such resources are 'tapped into' by competent individuals and community leadership enables an equitable redistribution of such resources. However, such resources are reliant on some form of 'giving back'. It becomes difficult continually to draw on them, without being able to replenish them.

Proactivity Social

capital constructs the citizen as a creator, rather than a consumer of resources. This makes establishes its fundamental difference to, for example, the human services where people are in receipt of services. Social capital is predicated on having community members who are proactive, engaged and active participants solving not only current but potential problems. Such proactivity is largely denied to people with disabilities and their families.

Tolerance of diversity

This important and fundamental aspect is somewhat contested. Critics argue that social capital promotes inclusion of only those who 'fit in 'Putnam (2000) argues that there is a connection between high social capital and tolerance of diversity and that America is a more tolerant society now than it was in the 1950s. Such a broad statement, which tends to elide the growth of homelessness, of poverty and of class and race differential in all Western industrialized nations, demonstrates the need to more carefully research the impact of capitalism, and to deconstruct some of the discourses surrounding social capital.

Implications for people with disabilities and their families

Several issues arise when considering the ways in which social capital theory and ideas might be applied to the experiences of people with disabilities and families, there are five themes that relevant to social capital.

1. Few resources to invest in social capital building

First, social capital would appear to be predicated on people having sufficient economic and emotional resources to allow a person participate in networks. People who do not have secure economic and family situations or who are facing a crisis of some sort are often internally focused on the task of survival with no 'surplus' resources to contribute to the building of social capital. Paradoxically, these individuals are clearly those who would benefit from being a member of a community with high social capital. The individuals and families were often fully occupied with tasks associated with living with a disability. For example, people were fighting for in-home support funding, or negotiating for their child to attend the local school or having to attend numerous health appointments-sometimes travelling long distances to do so. Some parents were also occupied in hands-on career roles bathing, feeding and attending to the daily needs of their child or family member.

For some people, involvement with internally focussed tasks of living and survival were episodic, for example in cases where the person has a mental illness or multiple sclerosis. For others, resources were fully utilized at various critical periods or transitional life stages as in the case of one family who found they were fully occupied with finding a school that would accept their child. Another example was that of a family whose child with spina bifida had to undergo renal surgery which required one parent to stay at the hospital many hundreds of kilometres away. However, for many families with a member who has a disability, their emotional and financial resources were stretched most of the time. As one mother of three children, one of whom had severe physical and intellectual disabilities.

2. Social isolation

There is significant evidence to show that many individuals with disability and their families are socially isolated (Gething 1997, Kitchin 1998, Kerr and Mclntosh 1999). studies found that people were socially isolated from both family and other social contacts. Given the nature of this sample with many peopleliving in regional and rural areas, some of this isolation may be explained through geographical factors. However, many people expressed the view that they did not feel part of or even welcomed in the local community .

Researchers found that this was true for those families who had lived in the area for a long time, as it was for those who had come to the community more recently. Poignantly, one family, where the adult son was living with an acquired brain injury, and whose mother and father had been born in the town, were experiencing powerful rejection from a community that previously, they had thought of as inclusive and accepting. Many people with disabilities and their families have a greatly reduced capacity to form networks. If reciprocity is a central tenet of social capital then the capacity of some families to contribute will diminish as they focus on internal tasks of everyday living, supporting their family member with physical and daily living needs. This means that they are therefore not able to build those networks that may be able to provide some support when needed. This sets up a cycle of rejection where the demands of disability reduce the capacity to invest in social networks and therefore leads to social isolation. Being socially isolated means there is very limited access to external supports consequently, individuals increasingly rely on internal resources (from within their own family) to meet those needs.

3. Reality of rejection

While communities may be high in social capital, they may also exclude people with disabilities as different from other community members. Sometimes this exclusion takes a violent form. some researches highlighted the reality of rejection of many people who spoke of their experiences of bullying, exclusion and violence. One family moved their child with a disability from the local school because he was repeatedly bullied by other children. The school's response was to send him home to avoid further bullying thereby excluding him from school. Another woman with physical disabilities who had her own small office services business found she could not 'break into' the business community because she was not known to the business leaders and her efforts to make contact with them had failed. Another man with a psychiatric illness and an intellectual disability and living in a small country town was beaten up and robbed of cigarettes twice in his local park. He was admitted to hospital for surgery to his shoulder, which is now seriously impaired. Perhaps the most concerning aspect of this rejection is the potential for violence against the person with a disability that is so often present.

4. Invisible voluntary contributions

One of the key elements of social capital is the voluntary contribution to community and civil society. researches over many years has underlinedthe important fact that many people with disabilities and parents of people with disabilities do make significant voluntary contributions to our society on a continuing and regular basis. This occurs on two levels. First, people contribute more formally as members of groups or committees such as boards of disability service organizations,

advocacy groups, advisory committees to government or lobby groups for better services. Many people reported that they had been a broad member of a local service for several years, or had participated in other committees for government. Second parents and family members also contribute less formally, though substantially in terms of efforts, through the unpaid caring work they perform daily and for many years. For example, a mother of a man of 35 years of age with Down's syndrome, explained how she had never had any support from any service or agency after she was asked to keep her son at home from school after 3 weeks in the first grade nearly 30 years ago. Over those years she has cared for him, given him an education (albeit rudimentary) and prepared him for adult life in the small town where they live without ever having any respite or formal service assistance.

We argue that much of this voluntary contribution is invisible to the wider community yet clearly represents significant contributions made by people with disabilities and families to their communities. Who sees this caring contribution or notices the impact that it has for the wider community? Much of it is undertaken 'behind closed doors', and the energy it requires leaves little capacity for other, more public, activity. There is another question underpinning this phenomenon. Are some voluntary contributions are more valued than others and therefore seen to more actively contribute to social capital building? Hampshire and Healy (2000) in a study of social capital involving a non-profit organization, argue that social capital contributions of non-profits are undervalued. We argue that this is even more pronounced where the contribution is at an individual level. reciprocity requires that the contribution needs to have immediate and recognizable benefits to the contributor and in the case of vulnerable people such immediate reciprocity becomes difficult to maintain.

5. **Bonding social capital of disability groups** findings suggest that some people with disabilities and families do have links with other individuals and families and that the resultant networks are supportive. This was also reported by Clear (1999) in his study of experiences of families with a child with a disability. He found that families were more supportive of and connected to other families with children with disabilities than to others in the general community. Our research involved a number of parents who were members of State-wide parent advocacy organizations or who were connected to other parents through local lobbying or self-help efforts. We also interviewed some people with disabilities who similarly chose to form informal groups or friendships, or who were members of self-help groups. People reported that these social contacts were 'easier' because there was less risk of rejection and that the other person 'knew what it was like'. The energy associated with dealing with potential rejection by 'normal' groups could then be used more effectively. Such networks appear to be high on bonding social capital but weak on bridging social capital. For inclusion to happen it is apparent that all types of social capital are necessary. Bonding social capital was valued by the people we met who reported that they had some social contacts in an accepting environment. However they did not feel they could call on such people for assistance or support because they were acutely aware of the caring efforts that they were engaged in. In needs to be pointed out that true inclusion is about the participation in ordinary and general social networks not segregated ones. We are certainly not advocating a separation model here-quite the contrary. Elsewhere, we have written of the important role of the human service practitioner in building the bonding social capital capacity of individuals and their families (Chenoweth and Stehlik 2001). Note that here there is some early evidence that governments, more recently, have become aware of the importance to support social capital building while taking note of the need for inclusion. The Local Area Coordination model was established, in part, to deal with this paradox-time will tell whether it will achieve this goal.

“The more actively the citizens communicate with one another and the bigger the number of their societies, associations and unions within which their contacts develop, the more considerable is the increase of “social capital” of a society. While the physical capital includes material objects and the human capital – the qualities, competence and the creativity of the individuals, the social capital is “characterised by the relations among people – the social nets and norms of mutuality and trust that

emerge on their basis. In this sense, the social capital is closely related to what some people name "civil virtue". The difference between them is in the fact that the civil virtue becomes strongest in time when implants itself in the nets of mutual social relations." (Tonev & Stoyanova-Toneva, 2020, p. 20) "Society, consisting of complexity of virtues, but isolated individuals, does not necessarily have to possess a big social capital." (Putnam, 2000, p. 19) This thesis of Robert Putnam is completely valid for the relationships that are the subject of analysis in this article.

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