The Role of Non-Profits in Shaping Civil Rights:
Understanding of Disability in Families of Children with Autism

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Abstract: Challenges associated with disability are increasingly linked to civil rights oriented policy solutions. Nevertheless, public policy theory suggests that issue definition includes competitive promotion of preferred linkages of problem definitions to policy solutions among stakeholders. In this article, we use the case of autism to examine the role of nonprofits in shaping understandings of disability.

Key Words: Autism, nonprofits, families

Introduction

The extent to which framing of rights through social movements benefits all members of society, including the disadvantaged, creates enduring questions for political science (Lichbach, 1998). Such questions surround how and whether adoption of a rights-based problem definition for disabilities correlates with differences in income and geographic location, and in tandem with interactions with non-profit and private groups. Although the distribution of a rights-based orientation helps to determine citizen demands and subsequently whether citizens benefit from public programs, scholars have paid little attention to how rights-based framing of problems varies across individuals within the United States. This article employs the case of autism to examine how recognition of disability as connected to rights-based policy challenges is related to individual connection to nonprofit organizations. It is our core hypothesis that nonprofits play a formative role in the dissemination of the rights-based understanding of disability.

Social Movements: Making the Personal Public

During the late twentieth century, many social policy arenas were newly constructed as rights-based issues. How a social problem is defined in public discourse directly affects both the policy making process and the substance of public policy (Baumgartner & Jones, 1993; Rochefort & Cobb, 1994). Furthermore, problem definition also impacts policy implementation by influencing potential clients of public problems and the administrators who run public programs.

Because problem definitions are temporal and fluid (Stone, 1988), interest groups and social movements play a large role in influencing problem definitions. The influence of interest groups varies, however, across citizens with some citizens adopting a particular problem definition while others do not. Furthermore, social movements and interest groups play an essential role in determining whether support exists for the idea that a particular problem requires governmental response (Lieberman, 2002). As a result, programs implemented in a rights-based

policy environment might be expected to actively encourage a rights-based engagement on the part of clients and other stakeholders.

The creation of social policy arenas involves an exercise in problem definition wherein what was once a personal issue is recast as a public one (Freeman, 1975; Yongjoo & Haider-Markel, 2001). Up until the twentieth century, disability represented an extremely private and all too often shameful experience (Ward & Meyer, 1999). Individuals with disabilities were systematically excluded from participating in the defining activities of citizenship. Children with disabilities were routinely barred from public schools, regardless of their capabilities, until the 1970s. Adults with disabilities often experienced disenfranchisement as a result of either logistical difficulties, such as inaccessible transportation, or being illegally denied the right to register to vote. Furthermore, the unemployment and underemployment rate of adults with disabilities greatly exceeded that of the general population (O'Brien, 2003; Krieger, 2003).

In the western democratic context, when a society excludes a particular segment of the population due to an unfair or irrational response to the individual characteristics of that sub-population, civil or human rights-based solutions tend to be favored (Dowding & Van Hess, 2003). Whereas human rights-based strategies use the society at large as the unit of focus, civil rights-based policy solutions depend on individualized remedies. In the United States, civil rights-based solutions tend to be favored. In a civil rights-based context, citizens are protected against violations of their rights and liberties, assuming that the individual fulfills his or her side of the social contract by acting as a responsible, law abiding citizen. To protect human rights, positive policy solutions are most often employed, meaning that a society takes it upon itself to create the conditions under which all individuals can exercise the right. To protect civil rights, on the other hand, society takes it upon itself to ensure that those who violated the rights of others are punished.

Limitations on social and political participation persist despite ongoing governmental efforts directed at improving the inclusion of individuals with disabilities. Many disability activists and advocates consistently question the efficacy and integrity of governmental programs designed to support the efforts of individuals with disabilities and their families in securing full participation in society. Others, however, criticize the civil-rights basis of many disability policies, especially the Individuals with Disabilities Education Act and the Americans with Disabilities Act, as unnecessarily litigious, counter-productive, and not representative of all stakeholders' interests. These differing interpretations of policy effects highlight the need for a better understanding of the relationships between differences in stakeholder's perception of rights and personal characteristics.

Construction of Rights: Class, Communities, and Nonprofit Participation

The impact of social movements and interest groups on issue definition varies across individuals. Adoption of particular problem definitions takes place differently at the individual level depending on the ecology of the given person (Rochefort & Cobb 1994). Why does one individual view their social problem as a public one, while another does not? The scholarly literature points to three types of variables that might affect the influence of social movements on

shaping problem definitions among individual citizens including income, community setting, and involvement with non-profit organizations.

Income

One dominant theme in the literature on social movements in the United States is that they are class based (Hooks, 1981). First, research indicates income correlates with general political participation. Higher income people engage in political activity of all types at higher rates (Milbrath & Goel, 1977; Verba, Scholozman, & Brady, 1995; Wolfinger & Rosentstone, 1980). People with higher incomes develop more civic skills to participate in politics (Verba, Scholozman, & Brady 1995).[1] Political participation develops alongside a more intense, if not necessarily more accurate, understanding of the political environment, including the construction of civil rights in a given social context. Because of this, personal investment or involvement in the political process likely improves with an individual's increased understanding of negative experiences such as social exclusion, policy implementation failures, or even violence, as violations of individual rights. As a result, in the disability policy arena, we would expect that higher income would be positively correlated with a tendency to report the violation of rights as a result of disability. Presumably, an individual must adopt a rights-based construction of disability in order for them to feel that a right has been violated on the basis of disability. In so far as the disability social movement includes a class basis, we would expect that middle and upper income people are more likely to have adopted the social movement's rights-based problem definition than those with lower incomes.

Securing rights often involves not only an awareness of these rights, but also the investment of personal resources, such as lawyers' fees associated with costly court battles surrounding the specifics of individual's publicly provided services. Families with higher incomes are more likely to be able to spend resources in an effort to secure rights. However, those with middle incomes might be expected to be most likely to expend these resources because the wealthy may elect to pay for services privately rather than fight for access to publicly provided services. Facing such adversities, those with less resources, unless particularly fortunate, are likely to go without.

Community Setting

In addition to income, the influence of many social movement groups is expected to vary by community location. The experiences of individuals living in rural settings are increasingly understood as different from those in cities, and different again from those living in suburban settings. As is discussed above, issue definition generally involves the reconstruction of an understanding of a transcendent element of human experience as a problem to be addressed by a favored policy solution. This efficacy of and response to this type of social construction likely depends not only on the larger society, but also on the community into which policies using a particular definition of the issue are implemented. To the extent fundamental differences exist

between types of communities in the United States, the conception of civil rights is likely to be observably different.

Two competing possibilities exist for the nature of this difference. The first, which draws more heavily from social movement theory, is that individuals living in rural settings would be less likely to have transitioned toward a rights-based understanding of a once-personal challenge. The theoretical assumption driving this expectation anticipates a relative lack of advocacy and activist groups in rural settings. From this perspective, one might easily derive the expectation that a higher density of civic organizations will make citizens more informed and effective in their efforts to gain responsiveness from government. Unfortunately, this possibility has received little attention: most research on civil society and political participation tends to ignore citizen demands aimed at government programs (Anechiarico, 1998, but see Soss, 2000 as an exception).[2]

Nevertheless, one might expect that in order to maximize their influence on the larger society, interest groups tend to concentrate in areas with high population. This expectation leaves people in rural areas with fewer opportunities to become involved, or at least makes participation more time consuming and expensive for each individual. Even those interest groups focusing on rural issues tend to be headquartered if not in the largest of cities, at least in medium sized cities, such as state capitals. Furthermore, given the limited budgets of most nonprofit organizations, it is often in the best interest of groups to concentrate their efforts in areas with denser populations. This is especially the case for groups seeking to affect changes in policy, such as those dedicated to the advancement of the (newly-constructed) rights of individuals with disabilities. After all, both the representatives and institutions of political power tend to be located in urban settings. Given this urban concentration, it might be expected that individuals in rural communities would be less likely to understand negative experiences resulting from disabilities as being violations of their civil rights.

On the other hand, a rural community might be more likely to be a setting in which an individual might develop a rights-based conception of disability in the current era. Rural settings are archetypically understood as locations where individuals have a deeper level of interconnectedness. Especially in the case of differences that do not necessarily require (medical) treatment for survival, rural communities might be less likely to see a given human difference as one that cannot be accommodated. Furthermore, exceptions to a convention of inclusion—however real or imaginary in the historical experience of the particular community—would be less likely to be excused or tolerated by the individual and his or her family.

As a result, violations of the rights of individuals with disabilities or their families could become both more remarkable and more public than would generally be the case in an urban or suburban environment. Furthermore, with the increasing availability of the Internet, access to information about the basic elements of disability rights, including the unique right to a free and appropriate education for children with disabilities, became more universal. To the extent that the implementation of these rights depends more on an inclusionary disposition on the part of the public and public infrastructures than on material resources, rural communities could be a more likely setting for the development of a rights-based understanding of disability on the individual level.

Nonprofit Participation

As mentioned earlier, nonprofits played a role in advocating for a rights-based view of disability. We would expect interactions with nonprofits to increase the likelihood that citizens will adopt a rights-based problem definition of autism. We also expect such interactions make individuals more likely to assert those rights.

Civic organizations facilitate demands on government by providing them with information about public programs and by informing citizens of their rights (Soss, 2000). Participation in civic organizations make it more likely that citizens will assert their rights because organizations build political skills, bring individuals into contact with others in similar circumstances, and provide opportunities for recruitment into the political process (Verba, Scholman, & Brady, 1995). As a result, participants gain a better understanding of government and government programs. Particularly when disability programs are designed in the context of a rights-based understanding of disability, participation in disability oriented nonprofit organizations is likely to promote the development of a stakeholder's rights-based understanding of negative experiences associated with disability. Indeed, states with a higher density of civil society organizations produce more applications for cash assistance for disability in the Social Security Disability Insurance and Supplemental Security Income programs (Soss & Keiser, 2004).

Finally, nonprofit organizations engage actively in not only the promotion, but also the construction of disability-specific information. When individuals and families become personally connected with a particular type of disability, they likely seek information not only about disability in general, but also about the specific disability affecting themselves or their families. For example, Organizations such as Cure Autism Now, the Organization for Autism Research and Families for the Early Autism Treatment help shape knowledge about autism, as either sponsors or promoters of the development of selected types of information about autism. Because much of the discourse used to argue for the expenditure of more resources toward the development of specific knowledge is expressed in the language of disability rights, stakeholders who rely more heavily on nonprofit organizations for disability-specific information might be more likely to develop a rights-based understanding of negative experiences associated with disability.

Method

As mentioned earlier, we are interested in explaining variation across individuals in adopting a rights-based approach to disability as it relates to their interaction with nonprofit organizations. While we are particularly intrigued by the role of nonprofits, we will also examine the roles of income and geography, as more established explanations of such variations in the acceptance of the rights-based paradigm in our sample.

Case Description

Autism is a neurological disorder of unknown cause, manifesting itself along a spectrum ranging from relatively minor social impairment and behavioral differences (typically called Asperger's syndrome) to a complete withdrawal from interpersonal interaction combined with a tendency toward self-injury. When autism was first identified in the 1940s, it was believed to affect approximately 1 in 10,000 individuals (Feinberg & Vacca, 2000). During the past 15 years, the reported incidence of autism increased dramatically worldwide and, in recent years, autism became the fastest growing disability reported within public schools in North America. Though the prevalence of autism is hotly debated today, the more conservative estimates suggest that at least 1 in 500 children have an autism spectrum disorder (Newschaffer & Curran, 2003). Whereas autism was once believed to affect predominantly Caucasians, the reported cases of autism currently distribute relatively evenly across socioeconomic and ethic groups. Boys are approximately 4 times more likely to be affected than girls. Most children with autism first develop symptoms some time between their first and third birthdays (Rutter, 2000).

Since in the past individuals with autism tended to be institutionalized or otherwise removed from social participation and access to education and employment, the prognosis of the current generation of children with autism is largely unknown (Ward & Meyer, 1999; Bryson, Rogers, & Fombonne, 2003). Furthermore, many more of the children identified as having autism in the current era are so-called "higher-functioning" and presumably, therefore, less likely to need intensive social services as adults (Newschaffer & Curran, 2003). As a result of the growing pressures on school and other systems serving a ballooning population of children with autism, an ever-improving understanding of the types of programs and treatments for autism, and the changing population of children with autism, an improved understanding of the construction of civil rights with regard to neurological differences becomes important (Kohler, 1999; Bryson, Rogers, & Fombonne, 2003).

Research Design

To explore variation in the use of a rights-based understanding of disability, we use the Families' Experiences with Autism Survey (FEAS). FEAS was developed specifically for use with families with children with autism and is correlated to similar surveys used to collect stakeholders' impressions of the relationship between disability and public infrastructures, especially the Participation and Activities Limitation Survey (PALS) first implemented by Statistics Canada in 2001. FEAS includes 45 questions on aspects of families' experiences including perceptions of disability, disability history, participation in public programs, economic effects of disability, and general socioeconomic indicators.

FEAS was launched in Missouri in July, 2003. 452 responses were collected. Because children with autism constitute a "rare" population, purposive sampling techniques were more appropriate than random sampling (Hinton, 2003). A snowball sampling methodology with multiple entry points was used. Responses were collected both online and on paper.

The survey posed two questions that are especially relevant to our purposes here. First, the survey asked respondents whether their child's rights have ever been violated as a result of his or her autism or related condition. According to a rights-based problem definition, most children with autism have had their rights violated in some way either by having activities or

speech restricted when not absolutely necessary, through social exclusion by their peers, failure on the part of social and public infrastructures to accommodate differences, or through more traditional violations such as becoming targets of violence or abuse motivated by discriminatory intent. In addition, children with autism were expected to have experienced illegal limitations of their right to a free and appropriate education under the Individuals with Disabilities Education Act, as interpreted by their parents or other stakeholders (Scherer, 2003).

It is important to note, however, that this measure does not capture the severity of a rights violation or even if a rights violation as it is currently defined by law or other standards in formal public policy occurred. Rights violations such as peer victimization motivated by differences, represent a near universal experience for individuals with disabilities. Previous research documented the pervasive nature of these experiences for the subpopulation of individuals with disabilities as a whole (Li, Ford, & Moore, 2000; Walden, 1996). For example, one study found that 94% of children with Asperger's Syndrome or nonverbal learning disability experienced peer victimization in a single year (Little, 2001). In the absence of a rights-based understanding of disability, however, these experiences are not necessarily understood as a violation of civil rights. A measure of perception is most appropriate for our purposes because we are interested in explaining variation in problem definition, which by nature is due to perception. Respondents who answer affirmatively on this question have adopted a rights-based orientation.

Findings

38% of the parents and primary caregivers reported their child's rights had been violated as a result of their autism or related condition. Furthermore, approximately 50% of the respondents reported that their children were not in inclusionary educational settings, one of the basic tenets of the educational rights of almost all children with disabilities. Parents and primary caregivers who reported that their child's rights had been violated were asked to describe the most recent incident. The descriptions were almost universally related to negative rights. Some of the more extreme examples involved the misapplication or misinterpretation of physical discipline. For example, one parent wrote:

> "He was put in foster care for a week by the Department of Family Services because his self-abusive picking at his skin all the time was reported as child abuse. It took $1200 in attorney fees and 5 months for that to be cleared up. At school he has been spanked, sent to the police station, put face down on the floor with his hands behind his back, been restrained with plastic restraints, and spent the last 4 weeks of this school year in the timeout room in the high school classroom."

Similarly, another parent related that the "teacher and aide bruised and assaulted my son, family doctor confirmed abuse, DFS (Department of Family Services) found our complaint to be unfounded." Another mother explained, "Because of the lack of understanding on the juvenile officer's part and the Department of Family Service's part the family has been put through hell with dad being kicked out of the home for a month only to find out he did nothing."

In addition to civil rights violations in the form of direct physical harm, various overt violations of specifically protected civil rights were also reported. Many parents described situations in which schools or school officials did not follow the Individualized Education Program (IEP) plans established as a civil right of children with disabilities under the Individuals with Disabilities Education Act. For example, one parent stated that the "school did not learn about Asperger Syndrome nor follow the IEP. He was harassed by others and picked on by certain teachers." Several parents reported that their children, as young adults with autism, had been denied voter applications at the Department of Motor Vehicles. Another parent reported "my dependent coverage life insurance at work (work for State) denied me obtaining a life insurance policy for my child, citing reason being a preexisting medical condition of autism. I contacted Division of Insurance stating it was discrimination, that autism is not life threatening, etc. To make a long story short, he now has a policy the same as my other two children (I won)."

In addition to these instances interpreted by parents and primary caregivers as violations of their children's rights, a lack of protection of positive rights was frequently experienced by families with children with autism. 78% of the parents and primary caregivers reported that their community activities have been restricted as a result of their child's autism. These restrictions often included a failure on the part of privately run businesses and activities to include individuals with autism. For example, several parents and primary caregivers explained that their children were not allowed to participate in church activities due to their autism or related condition. Another reported that her family was "kicked out of the children's zoo because child (24 months) was stimming (making repetitive noises) during a sea lion show." Others had difficulties with extracurricular activities. For example, one primary caregiver reported, "I enrolled our grandson in swimming lesson classes last year and they flat out told me that they didn't think he should stay in the group classes because they just didn't have time to spend with him. I then tried to get him in private lessons and the person they gave me to contact never returned the phone call."

When the children with autism discussed by the respondents escaped civil rights violations, it was often described as having less to do with accommodation on the part of public infrastructures than with preventative effort on the part of parents. For example, when responding to the question asking whether her child experienced violations of his rights as a result of autism, one mother responded, "Oh hell no. Not while I am alive and breathing." Another suggested that "an agency must be established with the authority, courage, and the ability to actively and effectively sanction, monitor, and punish those people and agencies who deny and/or abuse the civil rights . . ." The descriptions provided by parents were varied and in keeping with previous research indicating situations that are interpreted under a civil rights-based understanding of disability. Violations of civil rights are as commonplace for this minority group, as for other subpopulations with a history of oppression.

However, the results of the cross-tabulations of the indicators of an adoption of a civil rights-based understanding of disability and the selected independent variables are mixed. Most of our preliminary findings match our expectations whereas others are more surprising.

Income

As is described above, one of our hypotheses was that higher income would be correlated positively with the adoption of a civil rights-based understanding of disability. Individuals with higher incomes (upper middle class and above) were expected, therefore, to report a higher incidence of civil rights violations and to be more likely to have their child included in a general education setting.

The results of a cross-tabulation of answers to the question, "Have your child's rights ever been violated as a result of his or her autism?" and reported income for 2002 showed the group most likely to report that their children's rights had been violated were those in the middle class, with incomes between $40,001 and $60,000. The second group most likely were those living in poverty with incomes below $20,000. These findings suggest that income may be less significant as a determining factor of the adoption of a rights-based understanding of disability than other characteristics. These income results may also reflect a difference in reasons for the perception of rights-based violations. Those in the highest income category may in fact, be removing their children from settings, such as public schools, where the violations are most likely to occur. The lower middle class income group may be the least engaged in public programs due to incomes above program limits as well as less likely than the slightly wealthier to become civically engaged.

Community Setting

Our second variable of interest was whether the type of community setting was correlated with the adoption of a rights-based understanding of disability. As is discussed above, previous scholarship suggests competing hypotheses about the effects of community setting on the conception and perception of civil rights.

The result of a cross-tabulation between the reported experience of civil rights violations and rural vs. urban community setting suggests that those living in urban settings are more likely to be have adopted a rights-based understanding of disability than those living in rural environments. This finding is in keeping with the argument that barriers, including distance and a less intensive presence of advocacy effort, have impaired the development of a rights-based understanding of disability in rural areas.

Closer examination of the urban responses also proved interesting, in that there was some difference in the reported rate of civil rights violations. Table 1 below shows these results.

Rights Orientation by Geography
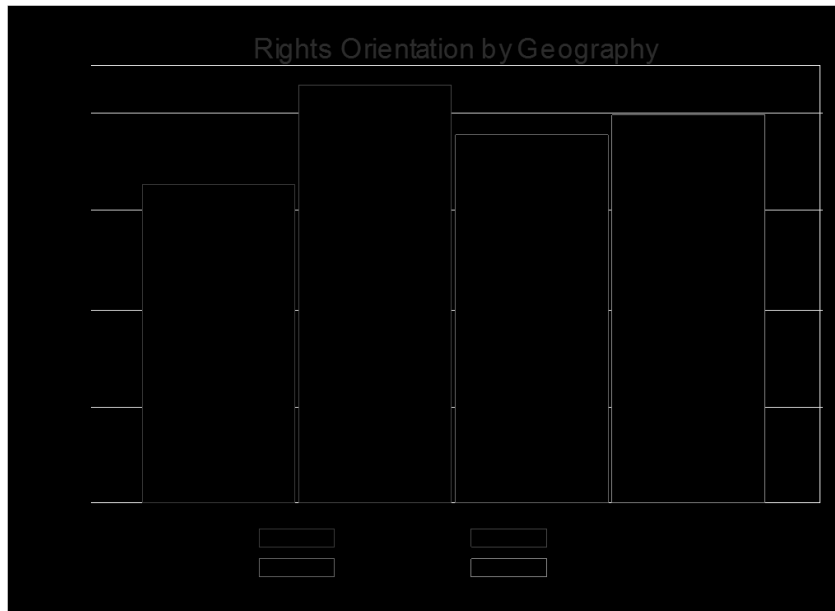
Respondents were asked to identify whether they lived in a big city, small city, or suburban environment. In each of these categories, a higher percentage of respondents indicated that their child had experienced rights violations due to his or her autism than the rural respondents (34%). However, the percentages were slightly different across urban categories with 42% of those living in big cities, 40% of those living in suburban settings and 37% of those living in small cities reporting that their child's rights had been violated as a result of his or her autism.

Analyzing the variable further showed more dramatic differences. The percentage of parents and primary caregivers reporting that their child's rights had been violated varied more by income in rural than in non-rural communities. Whereas the $40,001-$60,000 income group was the most likely to have reported violations due to autism in non-rural areas, in rural areas, the highest percentage of reported rights was in the lowest income group. Acceptance of the rights based paradigm of disability depends on differences in circumstances above and beyond a family's income. These results are shown in Table 2 below.

Rights Orientation by Income and Location

Nonprofit Participation

Nonprofit participation was also expected to

play a role in the development of a rights-based understanding of disability. Nonprofit organizations, especially those surrounding emerging disabilities such as autism, tend to encourage their clients to adopt a rights-based understanding of disability. It was our hypothesis that nonprofit participation would be correlated positively with the adoption of a civil rights-based understanding of disability. The cross-tabulation of answers to the question related to who usually provides families with needed assistance, and the reported experience of civil rights violations was in support of this hypothesis. Whereas only 1/3 of parents not reporting help from nonprofits reported rights violations, close to 1/2 of those with nonprofit help reported rights violations.

The relationship between types of organizations that families reported they usually depended on for assistance and the reported violation of their child's rights was different for different types of communities. The gap in percentage for non-rural respondents was almost four times larger than the one reported by rural respondents. Engagement with a nonprofit organization appears more likely to motivate acceptance of a rights-based paradigm of disability in those living in non-rural environments. This finding may be related to the level or nature of involvement with the nonprofit, as well as to the types of nonprofits extant in different types of communities. Residents of non-rural communities presumably tend to be proximate to a greater and more diverse set of organizations with which they can participate in person. While residents of rural communities can participate in a great variety of organizations electronically, it is less likely that a large number of nonprofits will be directly engaged in the provision of programs and services close to their homes. Nevertheless, increased electronic participation in nonprofit organizations is correlated positively with a tendency to perceive disability issues as being rights-based. Those who reported that they most often used nonprofit organization sources were 10% more likely to report that their children's rights had been violated than those that did not.

Conclusion

The tendency to understand disability as a rights-based issue varies between individuals, with some citizens adopting the problem definition and others not. Since the problem definition influences whether or not, and how, citizens make demands on government, whether or not individuals adopt a social movements problem definition has consequences for whom benefits from government policy. The observed differences in the adoption of a rights-based paradigm of disability among parents and primary caregivers of children with autism suggests that variance in issue definition among stakeholders is affecting the implementation of public policy for children with disabilities.

In the case of parents and primary caregivers of children with autism, engagement with a nonprofit organization tended to be associated with a greater likelihood that the parent or primary caregiver would perceive their child to have experienced discrimination as a result of his or her disability. Nonprofit organizations have a key role to play in shaping stakeholders' understanding of basic philosophies underpinning issue related public policy. While the influence of this role is not constant across socioeconomic circumstances, the results suggest that involvement with nonprofit organizations is deeply connected to an understanding of disability rights.

In continuing our analysis of this question, we will be looking at other individual characteristics (such as type of autism) and their experiences (such as the specific description of rights violations) in order to expand our understanding of the construction of rights vis-à-vis the specific experiences of individuals. After all, one of the most optimistic interpretations of the data would be that the civil rights-based paradigm of disability has been phenomenally successful in that certain characteristics, such as income, participation with advocacy groups, or inclusionary communities, insulate some children with autism from the discriminatory circumstances that have been discussed as pervasive to this point. Continued investigation of the specifics of the respondents' understanding of their children's rights alongside additional family characteristics will shed further light on the mechanisms and impressions of the construction of rights in disability policy problem definition.

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Endnotes

[1] Interestingly, lower income individuals have similar amounts of free time as higher income individuals (Verba, Scholozman & Brady 1995).

[2] Putnam's study of Italy offers a partial exception to this pattern. His index of institutional performance incorporates one indicator of bureaucratic responsiveness – the ways in which health, vocational, and agricultural agencies responded to inquiries requesting information (Putnam with Leonardi and Nanetti 1993, p. 73).