

Perspectives on networking, cultural values, and skills among African American men with Spinal Cord Injury: A reconsideration of social capital theory

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Abstract. Unemployment among African Americans with SCI poses a serious challenge to successful recovery and community reintegration. Recent research and public discourse about documented racial disparities in employment following injury is often laden with assumptions about the absence of “social capital,” including networks of support, appropriate skills, work ethic or viable work history profile. Such assumptions inform social policy aimed at assisting the unemployed, including African Americans with SCI and are embedded in explanations for reducing the role of government or the “state” in addressing poverty and related social issues, one consequence of which has been a reduction in programs and funding for persons with disabilities. Social capital theory has also been used to justify an increased reliance on non-governmental networks and institutions (particularly faith-based) to address concerns of individuals and families struggling with employment, health care or other issues traditionally addressed by the state. The emphasis on individual initiative and cultivation of networks of support assumes the absence of both among those who are unemployed. The purpose of this paper is to describe and discuss the attitudes of African American men with SCI toward work and their perceptions of obstacles and supports in their attempts to seek and secure employment in comparison and contrast to explanations presented in “social capital” theories. Using the qualitative component of a larger project, which used mixed method design, we identify and present the perspectives of African American men with SCI. The results of this study raise questions about assumptions and policies based in social capital theories and suggest a need to reconsider and reframe explanations for unemployment and those social reintegration strategies embodied in related policies.

Keywords: Social capital, work, spinal cord injury, employment, health disparities, African Americans

1. Introduction and background

Research has consistently shown high unemployment among persons with spinal cord injury (SCI). The unemployment rates for African Americans are even

higher, mirroring similar disparities in the general population. Severity or nature of SCI does account for some of the difference; however, even when controlling for these and other factors, statistically significant differences remain [15,20]. Researchers have attributed the remaining disparities to attitudes toward work, deficient work histories, or a lack of “social capital” [1,28, 30] Current social policy is informed by assumptions regarding resources and skills possessed by or available to African Americans with SCI. When generally ac-

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cepted variables used to explain differences in recovery do not explain racial disparities, there is a presumption of the absence of appropriate values, work ethic, educational background or training. Programs are then designed to compensate for such 'deficiencies' [1,27,28,30]. The purpose of this paper is to explore the perspectives of African American men with SCI toward work. Listening to African American men with SCI can help us understand the limitations of approaches that presume the absence of networks, beliefs and attitudes toward work that are considered necessary and culturally valued. This approach will also help identify concerns, challenges and sources of strength and resilience.

While some theories on employment and SCI are derived from large-scale quantitative research, more recent medical research [2–5,14,19,25] employs qualitative methods such as interviews and focus groups to "provide rich and descriptive narrative, bringing the phenomenon under study to life." According to Devers, qualitative methods "... are particularly well-suited to explore phenomena that have not yet been fully described, that are social and interactional in nature, and are both complex and multifactorial" [9, p. 241]. This method allows a theory to emerge from a careful reading of the data. Alternatively, it also allows interrogation of extant theories and interpretations. Consequently, our decision to use qualitative methods was based in our need to elicit information from groups underrepresented in spinal cord research, and to observe relationship dynamics in group settings. Given the paucity of data on African Americans, Hispanics (Latino/as), Asians, women, and children with SCI, focus groups and interviews provided an opportunity to listen and record perspectives of persons from these groups. For the purpose of this paper, we focus on African American men whose perspectives are absent from much of the research on SCI but whose "social capital" (or absence thereof) is often the focus of public discourse and policy.

1.1. Social capital theories

The term "capital" is, fundamentally, an economic term referring to production transactions involving goods and money. However, by 1960, economist Theodore W. Schultz laid the groundwork in his presidential address to the American Economic Association for subsequent theoretical work that purported to identify and measure "human," "cultural," and ultimately, "social" capital as exchangeable and negotiable

resources. Sociologist James Coleman was responsible for bringing social capital into wide use in the latter part of the 20th century, although the term dates back to the early 20th century. Coleman conducted a study of drop-out rates in high schools in the US and concluded that the lower drop-out rates in Catholic schools were related to the stock of social capital held by families of children in parochial schools [8]. In 1995 Political Scientist Robert Putnam, sparked interest in the concept with his book *Bowling Alone: America's Declining Social Capital*. In this book, Putnam explores the erosion of participation in civic associations and political activities that he attributes to a decline in "relationships of trust embedded in social networks," i.e., social capital. This spawned "a veritable avalanche of interest in social capital theory" [12, p. 143]. Revised theories, steeped in problematic ideological assumptions viewed social networks as exercises in self-interested pursuit of "the bottom line," crossed disciplines and began to inform social policy. According to Hutchinson, the concept has fostered "... a new appreciation of the efficacy of culturally sensitive networks in sharing information about health maintenance" and "is strengthening prevention strategies that seem likely to yield important improvements in the health of disadvantaged and socially isolated groups" [12, p. 143]. Putnam acknowledges that the theory has attracted a "wide range of theorists and practitioners" and has made it vulnerable to criticisms of "conceptual overstretch, as commentators from very different disciplinary and ideological backgrounds seek to express their varied insights in terms of the new vocabulary" [12, pp. 142–143].

Social or human capital has come to be associated with possession of networks of social resources, particular cultural values, and of an insinuated but unstipulated level of education, experience and training. Theoretically, these networks translate into organized power holding the potential to impact institutions, agencies, and structures that control resources. Failure to possess these forms of "social capital" is presumed to explain many social ills, including unemployment, as social capital is viewed as a kind of fungible currency that can be exchanged for goods and work in the marketplace [27]. The notion of social capital has wide currency. It is used to describe a broad range of social activities. Research based upon social capital theory has shifted its focus from the need to simply develop appropriate skills, attitudes, and networks to include some consideration of social context, but public policy continues to be informed by the basic premises of social capital theory. Smith and Kulynych urge caution

in use of the term, preferring the terms social resources or social capacity in order to avoid the ideological implications of the term ‘social capital’ [27]. Activities generally studied under the rubric “social capital” merit inquiry but conclusions generally drawn about the relationship between networks of support and the ability to secure employment or other resources, particularly as these apply to African Americans with SCI are debatable. Since ideas about social capital have migrated from economics, the discipline that parented the concept, into political science, sociology, urban planning, and health care fields (including rehabilitation counseling), it is important for research to explore the relevance of this influential theory in contexts where it is used to design job-training and employment programs. In the case of this research, what are the perspectives and attitudes of African American men with SCI about job skills, social networks, and a cultural ethic of work? How might these perspectives help us understand what efforts could best assist African American men with SCI to find jobs?

2. Qualitative method

Data from for this study was extracted from information collected as part of a larger project – the Needs Assessment of Virginians with SCI. The larger project used a mixed method design with both qualitative and quantitative components to collect information of individuals with SCI, particularly from the traditionally underserved populations of women and individuals from racial and ethnic minority groups. This study is based on the qualitative aspect of the project, which is described below.

Twelve focus groups and sixteen individual interviews of persons with SCI were conducted to learn about the challenges and strengths of persons with SCI in Virginia.

2.1. Interview instrument development

The research team created the Virginia Spinal Cord Injury Focus Group Interview Instrument in 2004. During the instrument development period, decisions about content were informed by prior research and personal and professional experiences related to living with SCI. Prior research refers to both published and unpublished studies, including previous qualitative research conducted by the researchers. Personal and professional experiences refer to the experience of the researchers in

working with individuals and families living with SCI as well as the experiences of members of the project’s advisory board as either individuals living with SCI and/or professionals working with individuals and families living with SCI. The process of interview instrument development was iterative, with repeated review and comment by the research team, the advisory board, and content experts working in the field of SCI. After a period of review and revisions, the instrument was piloted with a group of purposively selected individuals living with SCI.

2.2. Recruiting focus group and interview participants

The qualitative component of the project involved collection and assessment of data generated from focus group and individual interviews to identify and present the perspectives of the participants. Individuals with SCI were recruited through the use of advertising methods approved in our research protocol, including direct mailings, cards and brochures left at hospitals, service agencies, and community organizations, and notices in newspapers and magazines targeting the disability community. In particular, advertisement cards were sent to individuals listed on the Virginia Spinal Cord Injury Registry. This aspect of the *Needs Assessment* was designed to gather information on underserved populations of individuals with SCI (e.g., women, children and individuals from racial/ethnic minority background.) All participants (both individuals with SCI and family caregivers) were paid \$50.

The qualitative data used in this study comes from persons with SCI who were interviewed either individually or as part of a focus group to determine their needs, strengths, challenges and recommendations. At the start of the interview, informed consent and HIPAA documents were distributed, explained, and signed.

All interviews were audio-taped, transcribed and ‘cleaned’ of identifying data. The cleaned transcripts were reviewed by the actual interviewers and by all members of the research team in weekly meetings. Discussions of the data provided opportunities to check interpretations and information, and to code the data. Data and information from the qualitative interviews were examined to determine themes related to employment in order to provide increased understanding of the topic.

2.3. Conducting focus groups and interviews

This was a collaborative research project involving a rehabilitation psychologist, a political scientist, a quantitative researcher, and a social worker. Four graduate student assistants, three of whom had previous interviewing experience, were trained to conduct and assist with focus group and individual interviews. Two of the students were in psychology, one was in social work, and one was studying physical therapy. As is often the case with qualitative research, the scope, breadth and richness of the data generated unanticipated responses. These were used, subsequently, to help design a quantitative instrument, the *Virginia Spinal Cord Injury (SCI) Needs Assessment Survey*, used to assess needs and challenges among a much larger sample.

Five of the twelve focus groups were all male, and five were all female. There was one mixed gender group. Additionally, we conducted one focus group with caregivers and four individual interviews with caregivers. A total of 77 individuals were interviewed over the course of the grant. Of those 77 individuals, thirty-seven were African American. Two Asians and two Hispanics/Latino/as participated. Two participants identified themselves as biracial. Of the fifty-two persons who participated in focus groups, twenty-seven were females and twenty-five were males. Eight of the individual interviews were conducted with males and eight with females. However 'balanced' this demographic distribution may look, it was not "planned" in that we were dependent upon voluntary participation in the study. We can attribute the success of our recruitment to the enthusiasm of our participants and the support of agencies and advocacy groups that helped advertise the study.

2.4. Thematic focus: Work

Work—the ability to find and maintain paid employment—emerged as a consistent theme in focus groups and individual interviews. The focus group and individual interview responses of the 31 African American men who participated are the basis of the following discussion.

This paper is based upon a careful and systematic review of this particular theme. Given the volume of narrative, what follows is a distillation of perspectives expressed by African American males in relation to discernible themes. What follows are the identified themes and perspectives of study participants. We con-

clude with the implications for policies and practices in SCI rehabilitation related to work.

Although we did not include an explicit question about social or human capital in our interview instrument, respondents discussed extensively those qualities, values, relationships, and skills they considered important to securing employment as well as the obstacles they faced in their efforts to find paid work. We present the words and attitudes of African American men with SCI in three broad categories: 1) networks of support and trust; 2) cultural values, and 3) education and training. Under networks of support we include attitudes about the role of family, friends and others with SCI. Cultural values includes work ethic. The role of state and social service agencies, faith-based institutions, advocacy organizations, and employers is included under education and training. In all of the focus groups there was a forthright sharing of information about the nature and extent of injury and the impact it has had on the ability to find and maintain paid work:

3. Results: Themes, perspectives and narratives

3.1. African American perspectives: Networks of support and trust

Key to securing work for those with SCI is a support network that can help one through the initial trauma of injury. The African Americans interviewed in our study turn to family, friends, others with SCI, faith-based communities, and social service agencies for support and for information and job prospects. On rare occasions, places that employed a respondent at the time of injury have provided assistance and employment, usually in a different capacity.

3.1.1. Family and friends

Robert speaks with authority derived from the many years he has "spent in the chair." Still, he remembers vividly the night he was injured. He left the "friend" he probably would have married at the juke joint, as he finally relented to take some people home, telling her he'd be back soon. He speaks of rushing and how he never made it back; how, eventually, he told his girlfriend to move on.

I had left my friend at the place in the country; they used to call it a juke joint. I left her at the juke joint. I was running to take some guys home. I didn't want to do it, but they kept on insisting. So, I got hurt in taking them home and never got back to her.

He didn't know that eventually, he would recover and be able to work and have an intimate relationship. Currently, he provides leadership and inspiration for others in the way family and friends did for him, weaving a network of support that carried him through difficulties and challenges. Other focus group members nod in agreement as Robert talks about the things his mother taught him that proved so helpful in his recovery. These 'skills' also reflect a strong work ethic and belief in self-sufficiency and independence echoed by most of the study participants:

I cook, clean, wash. As we was growing up, my mother said, "Now, I'm going to show you how to fry an egg and I'm going to show you how to get a little dirt out your clothes and I'll show you how to get a few wrinkles out your clothes." And I learned how to run the iron over to get a few wrinkles out. And I learned how to put them in the washing machine to get a little dirt out. So, I've been taking care of myself every since then.

Others agree that family is a source of strength and support without which life would be much more difficult:

I mean, I think if it wasn't for family and friends or some type of support field, a lot of us would probably still be depressed. This is not something you can just do by yourself. You need support, whether it's family, friends, or whether it's programs. You need some type of support from somewhere.

When Maurice was first injured he had been married 11 years. He says:

I told my wife while I was still in the hospital that I wasn't going to hold her to a contract that was changed. And she said she married me for better or worse and she was staying. That's been the foundation for me for these last 26 years.

The shift in roles for males from 'provider' is a challenge as many indicate that wives and girlfriends are the major source of income. This is a fact the men accept and appreciate but with which they are uncomfortable as it challenges traditional values about male roles and responsibilities.

Curtis was raised in the church and doesn't "let anything get me down." He spent over eight years in the military and was mugged about nine years before he came to the focus group. He tells us what many of the other men have said: "My girlfriend been with me the whole time when most people leaving." As well, when independent living is not possible due to lack of accessible and affordable housing or limited mobility,

returning home to live with family presents another set of challenges. Although Curtis' spirit and determination helped him to walk out of the hospital on crutches, he shares with the group that,

I take Zoloft. And that's an anti-depressant. That's not good. And I used to sit down and cry, cry, cry all the time, you know. I've got a loving wife, good wife. But she jump on me at times and raise sand about things I done did before I got hurt.

Curtis tells the group that his immediate family and his wife have been supportive but he hasn't seen his cousins in nine months:

They don't want to do nothing. They don't show up. They won't come. One of my cousins, I ain't seen her since last October. They calling on the phone all the time, "We're worried about you." You worried about me, come on here and see me. You know what I mean?"

Despite the strains of his relationship with his wife, he maintains that the injury has made the relationship stronger,

I know I got a good one. You know. And she don't worry about me 'cause I'm not running out there 'cause I know there ain't nothing out there. It takes, sometimes, a situation to find out who really love you.

Many of his challenges, like those of the thirty other African American men interviewed, are related to not being able to find work, despite his determination and best efforts.

While family is a powerful source of emotional support that helped sustain study participants through very trying times, not all experiences with family are supportive. Jason did catering work for a restaurant at the time of his injury but has done "all types of work, like a jack of all trades, almost." Since his injury, he has lived by himself in an accessible apartment complex where there are others in "chairs". He conveys a sentiment that we hear from others:

Basically, I was by myself at first. My family, I don't know. It looks like they was afraid. Just seemed like they felt I was, that I'd probably be a burden or something. . . since my injury first happened, they didn't know how to accept it, I guess.

The importance of family and friends is also bound to the capacity to find and maintain employment. Those participants that have families express concern about being able to sustain and support them. Marvin has been married 39 years. He had been married only

13 years when he was injured. At the time they had three young children. All three of his children have made it through college and he credits this to the initial and continuous support of his wife. But there are times when he is troubled because he doesn't have money for his wife's needs. He tells the group: *"I can't afford insurance for my wife... my medical care is taken care of, but the insurance is too expensive for us to handle for my wife... my wife has nothing."* His wife is in her mid-fifties and stayed home to care for him and their children. Now, it is difficult for her to get a job.

The inability to work and support their families was responsible, in some instances, for wives and partners leaving. In other instances, relationships were already strained. Allen was injured from a gunshot but he had been "in a lot of trouble with the law and stuff like that." At the time of his injury he was *"staying with my girlfriend and my daughter... when this happened, it was like over the top for her. And she stayed for a little while. We're friends to this day. But, it kind of fizzled out our relationship."*

Larry was initially in a nursing home after his injury and received social security:

When I went to the nursing home, I could not believe what happened to me financially. When I first got in there, they took my whole check every month and they wanted to ration me \$30 a month, which you pay for haircuts and all. You talking \$15 maybe. And that's one of the most hurtingest parts. 'Cause you never take a man, all his money. I mean... I just didn't understand that. How could you take a man's whole check and talk about we're going to give you \$30, which is in actuality \$15 after you pay for your haircut. You can't live off of that no month... When you're in your chair, that is some form of independence. You can go places or if I go visit my family, I want to take some money with me, not being nursed with \$10, \$15 a month.

The emotional support of family and friends, though critical to recovery, also did not often translate into employment opportunities.

3.1.2. Others with SCI

Mobility and access are obstacles to persons with SCI, well documented in research. However, hospitalization and rehabilitation provide opportunities to meet others with an injury. One of the most consistent themes addressed by study participants is the value of the experiences and perspectives of others with SCI. The best way to learn how to adjust to and manage aspects of injury, our respondents insisted, was from

others with SCI. Persons with long experience in "the chair" or with "wheels" proved to be more helpful than the rehabilitation experience alone. Learning what was possible, despite what medical personnel might suggest, was often a source of inspiration and incentive. Participants spoke of the value of peer counseling services. It became a service used and, for some, a service they ultimately provided to others:

One thing that we instituted at the VA hospital, I guess it must have been about 20 years ago now, is a peer counseling service... I've been a counselor since about '84. It's just going to talk to mainly newly injured... and giving them information that they can't get from people that walk. And this kind of information could be passed like getting on the Internet and finding stuff that you need and so forth. That's the kind of information that can be passed. Walking people don't know what questions to ask. And a newly injured patient has no idea what they need to know.

Participants spoke of the importance of organizing with others with SCI to, for instance, improve access. Jason talks of his initial difficulty getting in and out of community stores and when asked if he spoke with the stores about building a ramp, Jason says:

I asked one, but it's something that a bunch of guys in the community in wheelchairs probably have to get together and try to get that. One person I don't think will get it done.

Kevin is participating in a second focus group because the tape of the first meeting did not record properly. His enthusiasm is a comment on the value of networks, of meeting and talking with others who have been injured. He says,

I was motivated to come back... because I enjoy the company of people in similar situations with me... And it was helpful for me to find out what people in my situation is going through and the types of things that they deal with on a daily basis. It just kinda helps me know that, you know, I'm not alone in this and there's other people that's going through similar things.

Others join in with similar comments, *"I just didn't learn too much from just the doctors. I can learn more from my peers..."*

Networking is important to William who is also participating in a second focus group:

I came back for more insight, more conversing with other individuals in the same condition that I'm in. Communication is where we have our biggest

problem. This seminar right here... is the only way we have really, ... been able to get to know each other to a certain extent and to communicate."

As qualitative researchers, such comments are tremendously affirming as we are reminded that our research truly provides a rewarding experience for all who participate, a sentiment that was expressed by all study participants. While we are not injured, providing a space in which the voices of African Americans with SCI can be heard, proves rewarding for all of us. This research plays some role in expanding the networks of support. The question remains, will this lead to employment?

4. Cultural values: Independence and the desire to work

Study participants reported a strong desire to work. Citing examples of job seeking strategies and re-training, they see work as a means of earning much needed additional income. However, they also spoke of the importance of giving back to the community, of assisting others with SCI, and of wanting to be "connected." They even viewed participation in research studies as a way of staying connected and networking with others with SCI.

William has been injured for four years. He is unemployed but:

I think sometimes that I would like to do some type of work, maybe some counseling or something of that nature. Just to be into an organization where I could put some insight into anything that could help anybody, not just spinal cord injury individuals, any individual...

Charles was a counselor and worked in education. After his injury he worked as a volunteer at a youth program. He has had numerous job offers but between his social security and retirement additional income would cause him to lose "other financial resources." He is well educated and has an impressive work history but he has "*crunched the numbers every way that I could to find out what's more beneficial to me and my family at the present time*" and it isn't worth it, financially, for him to work. Not all environments are as accessible as the places he had worked and he and others talk about the need for accessible workplaces.

Study participants spoke often of being troubled by the inability to do the work they once did. Morris, a mechanic for over twenty years before he was injured, still helps people:

They'll call and ask me things. I can't do it physically, but I know just about everything you do on a car, on any type of vehicle... I still keep up with the mechanical stuff.

Jason, the former caterer, would like to do it again but makes the point:

I don't know too many people in a wheelchair working in a kitchen. I don't think I could deal with that, not in a wheelchair. In catering work, mostly it's a fast-paced thing. You have to be moving. It's something you have to be up on your feet most of the time. I don't think I could deal with that in this chair.

Larry is happier now than when he was first injured when a tractor-trailer struck his car from behind. He agrees that his family has been very supportive but he chose not to go home with his mom and sister and brothers. He is in an apartment and talks warmly about his relationship with his girlfriend. He was a truck driver before his injury and has worked in "plenty of trades." Since his injury, he hasn't worked, but, he says:

I would like to get back into, you know, running my moving business. I was into that when I was doing the tractor-trailer driving. I would like to get to that, but is that in the future, near future: It's going to be a while before I can really get that going. I would first of all have to purchase a truck. And that's one of my goals. But other than that, I've just been kinda out, getting back used to the society and malls and just going places now.

Some respondents report still being in contact with their previous employers, some of who have indicated they would be willing to "take me back." But work is now more challenging. Charles, who also does some work on cars, says:

Now I work about an hour and gotta stop and break and sit down and rest or whatever. If I lay down under one, it take awhile to get back up. If somebody see you doing that, they going to want to tell on you and stop you from getting our help and everything.

Study participants appreciated the support of family and friends but value their independence and ability to provide for themselves and contribute to the household. Many speak of the humiliation of the level of income provided by social security as barely allowing them to get by.

5. Employment and training: State agencies and social services, faith based institutions and advocacy organizations, employers

5.1. Bureaucratic strengths and challenges

State agencies are mandated, by law, to provide job counseling, information and resources. Their capacity to do so effectively is a concern mentioned by many study participants. Finding information was a particular challenge. In every focus group session, participants inevitably learned about resources and networked with others in the sessions to address particular concerns and needs. They spoke often of simply not having information or knowing where to get it. They were often unaware of existing advocacy organizations and recommended that “one good thing that can come out of this is a directory of some sort so we know how to find information.” In the words of Tyrone:

I want to highlight especially for newly injured spinal cord injury people. I think there needs to be something in place that there's a place you can go or a service that's available, if it's nothing more than to give you the brochures with names and addresses of who you can contact for different services in the area, especially.. with getting your home accessible, getting set up, with what the qualifications are for Medicare and Medicaid, ..Also, what services are available for those people and also as far as transportation... where to go for different services.

Some participants praised agencies and their personnel, others often gave up using the agencies in their search for educational or job opportunities. Tim was satisfied, but he knows the experience of someone who wasn't:

... DRS was real helpful to the point where they provided funds as far as the school to get a car for somebody to drive me to school since the buses weren't accessible. They paid for college and that kind of stuff. But, I think a big part of that was my parents. Like you said, they were advocates. If you have someone who's up front pushing for you, that's one thing. But I have a friend now who was recently injured. He was trying to go through DRS and... he's been put off. He was working when he had his accident. But after his accident, of course he couldn't work. And they said he hadn't worked enough quarters as far as getting Medicare and different things that he needed.

Mike, reports an experience we have heard before and since:

... my DRS worker got four or five interviews and I never got any response from the people I interviewed with. So, I talked to her and told her not to send me someplace that wasn't going to respond. In fact, the places that I didn't get any response from were state offices. The people that had trained me wouldn't hire me. So, they sent me to — and one other hospital. And all they did was tell me that they didn't have any position that I could fulfill at the time.

When Mike was first injured he went to school, used the assistance provided by DRS, and did not let the many obstacles placed in his way stop him. Mike is trained as a computer programmer. According to Mike, “I don't try to be loud. Just be nice but persistent.” This theme, of the need to be persistent, even to the point of feeling like managing the many dimensions of injury is a full-time job, was recurrent. Indeed, having to work up the energy to combat stereotypes, beliefs and perceptions of persons unfamiliar with SCI (and even practitioners whose stereotypes about race shaped their interactions, according to our study participants), played a significant role in everyday interactions, including the ability to find work. Attitude thus becomes an asset and a liability.

Cleve is one of the most vocal members of the group. He had been married less than a year when he was injured and had adopted his nephew two months before his surgery. (Occasionally, we wonder if our sample is biased with highly motivated, resourceful optimists.) Cleve comments about the need to be aggressive and persistent to get resources mandated by law:

... you gotta go out and look for it... Very rarely is it going to come out in the air and just come to you. It's just like looking for a job. You need to let as many people know that you're looking as possible, so they can funnel the information back at you.

Participants speak often of their frustration with state agencies and social services. Fred echoes the sentiment heard often: “... most of us do look into a lot of stuff but the resources don't do all that they're supposed to or what they say. So, it just pulls us away from using them...” But the group dynamic provides an opportunity for participants to encourage one another. Kevin says he is going to “do it without them (the agencies)” because “I asked twice. Twice is enough for me.” Charles nudges, “If resources are out there

and they tell you that you're eligible for them, twice is not enough to ask. The number of times to ask is until you get it." Charles worked in government for ten years and reminds that "... the squeaky wheel gets the oil. Squeak, squeak, squeak." The men laugh in agreement and talk in turn about how much they have done on their own—to secure resources, find jobs, grants, and programs.

5.2. Faith-based institutions and advocacy organizations

Belief in a spiritual or faith tradition was consistently reported as a critical factor in recovery. However, participants did not report making use of any faith-based services in job seeking. Many participants reported being unaware of the existence of advocacy organizations or groups that addressed the needs of those with SCI. Participating in the research project became an opportunity to network and share information. This fact highlights the need for greater outreach among advocacy groups to African Americans. It also suggests faith-based institutions might serve as supplementary resources for agencies mandated to assist African Americans with SCI in finding work.

5.3. Employers: ADA and workplace accessibility issues

Some employers maintained contact with participants after their injury, even to the point of providing health coverage, vans, and the opportunity to come back to work. This is most often the case when those injured have managerial or office-based employment that does not require heavy lifting or manual labor. In most instances, though, our participants were not able to return to their former jobs and in some instances, when injured on the job, had to sue to get benefits to which they were entitled. Study participants spoke often of the need for public and private sector employers to recognize that those with SCI have skills, and want to work.

Sam has been injured since 2001 and others in the group recognize that he seems to be doing quite well. This is related to his job situation. The group listens, stunned by the support of Sam's employer:

It's hard for me to see some of the experiences that some of these guys have because, one, when I had my injury, I was already working as full time with the company. I'd already had the education so I didn't need a lot of the same resources that they

needed. I was only out of work about six months and then I was back working, but I was working from home. The company that I worked for, they were real receptive to me. They actually remodeled the office for me to be able to continue working, and modified my job description just so it wouldn't cause any problems.

6. Challenges

6.1. Managing self-care

Extent of injury is a constraint as is management of medical complications. Fear that employers will not be understanding of the challenges (based upon experience and some level of anxiety) is also a challenge reported by study participants. The men are acutely aware that their injury imposes limitations on the kind of work they can perform. The men talk about the stress of being faced with a trade-off between the need for more income, state limits on their earnings relative to Medicaid or Medicare eligibility, and actual physical capacity to work.

Tyrone, who has been injured since he was a teenager, has to learn "to write all over again." He tells of the difficulty of simply getting prepared to go to work and of the clinical dimensions of care that are challenges for him and employers:

... I got to the point if it was a supervisor or someone, I would go to them and let them know that this is a condition that might occur and might not. But if it ever happens, I'm out of here and I'm not coming to you to tell you. So, if you happen to look up and see me gone, I'm gone. And that goes to, you know, getting to the work... you've gotta be at work at 8:00, or 7:15 for me. So, to do that, I get up at 3:30, 4:00. You have to do your bowel and bladder care and shower... it's going to take me three or four hours just to get ready to go out.

John has a similar concern, "How many jobs can you go out here and find where you're going to sit down for eight hours. I can't sit down in a chair for six hours without getting up because I get stiff."

6.2. Disincentives to work and other financial challenges

The desire and commitment to work, evident in the comments of participants, is related to an ethic of work that views work as necessary, fulfilling, and a mea-

sure of adulthood, a means of achieving independence and exercising responsibility, as Armond reveals in his comments:

A lot of people don't realize, too, that people in situations like, they can get out here and work and don't have to worry about that stuff. That's good therapy, mentally as well as physically. You know, psychologically, that's very good for a person in a wheelchair or have a physical disability, to be able to function. And that strengthens them mentally.

The low level of financial support provided by the state is also an incentive to work; however, this too is a challenge. The most frequently mentioned disincentive to working was the possibility of loss of medical benefits. Larry was injured recently and counts his faith in "the Lord" as the reason for his recovery and inner strength. His comments were repeated by all of the men who participated in this research project:

When we get a job. . . you would like to have extra income. But in my situation, if I get another job, everything will go up. It might cause me to lose more by getting that job. I haven't had a job since I've been hurt 'cause it won't help me. It'll go against me. So, if they could do something to better our situation, I'd love to go to work. When I first got hurt, I tried to go back to work, but my job wouldn't have me back. We can work. We'd love to work. Occupy our minds instead of sitting around home. [But] it can do you more harm, like your benefits, than it will help you.

Tyrone talks about a similar situation:

My thing was, okay, if I do nothing, sit at home on my behind, you all are going to send me "X" amount of dollars a month plus I get food stamps, so forth and so on. But if I go out and work, I'm in a Catch-22. That's why I mentioned earlier the financial challenges. I don't expect to be necessarily free, but I'm saying if you're going to tax me, tax me at a different bracket. Give me some type of break in that area to supplement those other things that other people don't have to pay for. Like you're saying, if he or someone who works or doesn't work is going to receive benefit and they go out and work, it's a Catch-22. . . cause then they lose the benefit.

The cost of injury is also a challenge.

We have expenses that other people don't have, especially when it comes to wheelchairs or medical supplies or that kind of thing. It's very expensive.

And dealing with the injury is time consuming. Simply making repairs or finding parts for a chair can take from a week to years and depends upon authorizations that seem, to many of the participants, capricious. Tyrone talks about how sometimes insurance works and sometimes it doesn't:

I know personally I have to go through a lot to get it. Sometimes it's not even worth it. Sometimes I just pay for it out-of-pocket because I don't want to deal with what I have to go through to get it. For example, I had the screw to break that holds this armrest in place. And I was in a hurry. It was on a Friday evening. I'm a quadriplegic so I don't have the stomach muscles to balance myself without having these here. So, I didn't want to go without it. So, I went to get it repaired. Just for the screw, it took not even five minutes to repair, it was \$42.00. And that's just one example. There are many others that take place. And even when you have insurance. . . Let's say you made \$30,000 a year. Out of that, you've got your other expenses, whatever, house, vehicle, whatever. Groceries, whatever. But when it comes to medical supplies, if you've got a \$400 or \$500 bill that you have to pay, they're going to pay a certain percentage of it, but you still have to pay it. . . on top of everything else, you have those medical supplies.

While having a van is important, Tyrone was one of many participants who talked about the need to have a job, simply to earn the money needed to keep the van.

6.3. Discrimination

For African American men, discrimination was also a concern and challenge:

First of all, you know you're already black. We know that. So, a lot of times we have to go beyond anyway. But when you're in a chair, that even takes it to another level. . . if you are in a situation like if you're in school or if you are going to work or something like that, it's almost like you have to prepare yourself to be a step ahead of the game.

Steven agrees, that people equate race and disability with deficiency:

It's one more level of the discrimination that you have to deal with. When a person's in a wheelchair, me being in a wheelchair, people just assume that I don't know anything.

Sometimes discrimination appeared to result from cause of injury, rather than just race – although the two often overlapped. Causes of injury for study participants include: gunshot-wound, mugging, car accident, motorcycle accident, stabbing, and diving accident. The nature of the injury often creates anxiety about job prospects, and interactions with service agencies, particularly when the injury has resulted from violence. That is, there is often a presumption that an injury caused by violence is somehow related to race and class or that race and class can be inferred from injury, resulting in favorable or unfavorable treatment. Tyrone shares one such experience:

I have a friend who was recently injured and he was injured by a gunshot. I took him down to, I think it was DRS because he was experiencing some problems. So I went there as an advocate to kind of speak for him. But one of the first questions the social worker asked was how were you injured. And he said gunshot. Now, I'm just going to tell it straight up. She was a white lady. And so the first thing she said was, "Was there any type of illegal activity going on." And there wasn't. He got robbed and he was shot. I don't know what it had to do with the reason we were there. The reason we were there is because he was having problems trying to get his apartment accommodated, trying to get Medicare, Medicaid, that kind of thing. Well, I guess maybe it did. I don't know if that disqualifies you from receiving some of the services.

Robert never really worked and just finished school. Throughout the session he has hinted that discrimination based on class plays a serious role in the ease with which one can get services or work. He was “*shot and from the projects*” and insists that “background” influences how one is treated. He turns to Charles (the well-educated, credentialed counselor) when he says, somewhat resentfully but in a matter of fact way,

He went in DRS and got what he wanted. I went in DRS, told them what I wanted, and got an alternative route. See, I didn't want that. I didn't come to them for them to tell me what I wanted to be. And it has a lot to do with that, your background, and how they feel you was injured.

Robert mentions a friend with the same background who was also shot. They both had

a big problem about schooling and work and everything... we couldn't get no help from counselors at DRS... It was always something that I found that was discriminating because I believe it was our background.

He got his degree without the help of the very agencies empowered to assist him.

I'm just trying to get my business off the ground. I don't want to work for nobody. That's why I went to business school so I can do my own thing... by me being disabled, it will work well with me so I can do what I want when I want, what time I want.

7. Summary and implications for SCI rehabilitation

The African Americans who participated in our study described themselves and their activities in terms that suggest they are highly motivated individuals. They are aware of the importance of having a “positive attitude” and are quick to network with each other to provide emotional support and to share information and knowledge of resources. Study participants had a range of networks and relationships but these provided emotional support in the face of structural and institutional obstacles and constraints rather than having direct bearing on the ability to find work. Most of our study participants had a work history and zeal to work, often providing voluntary services when income guidelines prohibited them from making additional earnings. They consistently emphasized the importance of a healthy attitude as a critical dimension of recovery but readily identified the structural and institutional challenges they faced. These included: 1) workplace inaccessibility, 2) employment disincentives (loss of medical or other ‘benefits’ for which only the highest levels of income can compensate), 3) racial and disability discrimination, 4) political challenges such as budget cuts that impact critical programs, and 5) bureaucratic challenges including competence, responsiveness, and effectiveness of services from agencies. At the personal level, skill and desire to work were constrained only by the level of injury. Factors that had the most bearing on securing work were not personal but structural and institutional, from the perspective of study participants.

7.1. The connection to social capital

It is clear from the narratives of the African American men in this research project that they possessed many of the resources identified as “social capital” – networks of support and trust, skills, work experience and a discernibly strong work ethic. These men participated in volunteer activities that linked them to others with SCI and served as resources and “role models.”

However, the personal challenges of injury combined with institutional and structural obstacles that prevent conversion of this so-called capital into actual employment. This would come as no surprise to social capital theorists who often recognize that the currency of trust and networks so easily convertible to tangible financial or economic opportunities is not available to those without resources to begin with. Consequently, focusing on cultivation of ever more networks of trust, or cultural styles welcomed by those in positions to reward behavior misrepresents the dimension of social capital that explains why African American men with SCI have such difficulty finding jobs. As Smith and Kulynych argue:

If we use the term "social capital" to explain prosperity and democracy, and focus on the collaborative relationships implied by this concept as the source of democratic power, we divert attention from the ways that some networks of relationships work to imprison and oppress some people, demanding not a strengthening of those relationships but their eventual demise [27, p. 174].

Despite the many attempts to salvage "social capital" as a value neutral concept it is, essentially, a surrogate term for privilege. Social capital has been criticized as a theory that capriciously lumps together networks and relationships as diverse as bowling leagues, civic associations, labor unions and religious organizations. Sobel argues that Putnam's major treatise on social capital, *Bowling Alone*, "confuses cause and effect" [29, p. 140]. Because the theory emerged almost simultaneously with a decline in the active role of government in addressing and meeting the needs of the most vulnerable populations in the US, it also justified the abandonment of governmental measures and helped lay the groundwork for increased use of non-governmental agencies. Smith and Kulynych argue that social capital theory does not take into consideration historical and contextual dynamics that insure access to resources and relationships capable of raising people out of poverty. Social capital is dependent on the ability and inclination of those in control to recognize, value, and reward the skills and abilities of persons generally viewed (from the perspective of those in positions to define admission into valued positions and relationships) as 'outsiders' or, more egregiously, 'deficient.'

African American participants in our study consistently cited the value of those networks and values often linked to social capital; however, such networks proved valuable primarily for psychological and emotional support through difficult stages of recovery. They

seldom translated into job opportunities except in those instances when the 'networks' were entities specifically designed to help secure employment. In many instances, our study participants spoke disparagingly of such agencies, often considered ineffective due to bureaucratic stonewalling, and perceived indifference or incompetence.

What we have presented is essentially one side of the story of work and spinal cord injury – that of African Americans with SCI. It is a side, however, suggesting a need for improvement in service delivery from agencies mandated to assist those with SCI. Job training should be broadened to include opportunities in fields other than computer-centered employment. Workplace access must be improved. Diversity training for employers should include more emphasis on disability issues. We should continue to recognize and reward workplaces that provide the best environment for persons with disabilities. It is not the job of rehabilitation counselors to lobby state and national representatives but our study participants recognize that public policy influences the ability of counselors to assist with job placement. Budget cuts and lackluster enforcement of laws prohibiting discrimination compromise the best efforts of even the most committed counselors. Our participants often mentioned the value of family, friends, others with SCI, and faith-based institutions in their recovery, giving us a sense of the value of these resources for psychological well-being, but not necessarily translating into job opportunities.

Overall, we heard a strong sense of independence, a commitment to work, and both existing work experience and skills and a willingness to develop new skills if this will allow them to earn an income that will not result in the loss of the health benefits they cannot do without. State agencies appear to be inconsistent in providing help, some respondents reporting favorable experiences and others saying they felt abandoned and treated shabbily. If, in fact, it is state agencies that have the greatest likelihood of facilitating return to work, recent cutbacks in funding and services do not bode well for this population of motivated job seekers. Because our respondents reported some help from churches (building ramps, helping to make homes accessible, insuring access at functions, etc.), making use of faith-based institutions may have some limited impact on increasing employment prospects only if there is vigorous enforcement of ADA and Civil Rights laws. Larger political issues such as the need to disconnect the need for health care from earnings is outside the control of rehabilitation counselors, but, as our par-

ticipants indicate, forcing them to choose between a job and health insurance (as most jobs do not provide the levels of support needed for those with SCI) is, ultimately, not a choice. Study participants were very aware they represented but one constituency in a political process that responds, in their words, “to the squeaky wheel.” That is an apt metaphor for exactly the kind of effort it will take to increase job opportunities for African Americans with SCI.

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