



THE HSC HEALTH CARE SYSTEM

The HSC Foundation

The Overlooked Caregiver: A Series of Listening Sessions

Wounded Warrior Project, Washington, DC

National Caucus and Center on Black Aged, Inc., Washington, DC

The Arc of Prince George's County, Largo, MD

Health Services for Children with Special Needs, Inc., Washington, DC

May 2010

OVERVIEW — *There is a group of caregivers who face unusual circumstances which create barriers to their participation in mainstream caregiver services and research. Some of those barriers include: (1) no access to telephone or Internet services; (2) cultural traditions that inhibit them from self-identifying as a caregiver; and (3) the demand of unexpected caregiving roles for populations such as wounded veterans. In order to better understand these overlooked caregivers, The HSC Foundation and their partners turned to community-based service organizations that are not traditionally considered caregiving groups. Together, these partners hosted a series of listening sessions to get a better sense of these caregivers' unique issues and unmet needs, and highlight issues that are not necessarily present in the mainstream.*

**The HSC Foundation
National Health Foundation
The MayaTech Corporation**

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Series of Listening Sessions**
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Introduction

In May 2009, The HSC Foundation, The MayaTech Corporation and National Health Foundation came together to identify and address common issues faced by caregivers across the nation. After connecting with numerous experts in the caregiving field and reviewing ongoing programs and research, these three partners decided to focus their efforts on caregiving populations that are often overlooked by providers, researchers and advocates. Typically, these caregivers are from low-income minority communities and are caring for a range of populations, including youth transitioning to adulthood and young wounded veterans returning from combat (referred to as “wounded warriors”). These caregivers are not purposefully overlooked, but rather, they face unusual circumstances that create barriers to their participation in services and research, such as:

- Caregivers from low-income communities often do not have access to telephone or Internet services.
- Cultural traditions can inhibit individuals from self-identifying as a caregiver or seeking supportive services.
- Caregivers of wounded veterans and other populations are new and unexpected caregivers.

There are numerous reasons these groups are often not included in the mainstream of caregivers. In order to better understand the target population’s issues, the partners turned to community based service organizations that are not traditionally considered caregiving groups. These service organizations were able to identify caregivers amongst their constituents and invite them to participate in discussions with the partners. In a series of listening sessions, the partners were able to get a better sense of these caregivers’ unique issues and unmet needs, and highlight issues that are not necessarily present in the mainstream. The informal discussions also provided an opportunity to hear from caregiver populations that have not been driving the national caregiving agenda in regard to policy, research, and funding.

From July 2009 to January 2010, The HSC Foundation, The MayaTech Corporation and National Health Foundation collaborated with four organizations in the Washington metropolitan area to host a series of listening sessions with caregivers. Following are summaries of those events, followed by a conclusion that touches on main themes and recommendations.

Listening Session #1: Wounded Warrior Project: Caregiver Summit Washington, DC, July 19-22, 2009

The HSC Foundation was a fiscal sponsor of the 2009 Wounded Warrior Project Family Caregiver Summit, which was held July 19-22 in Washington, DC. During this summit, a group of 18 caregivers of post 9/11 service members and veterans with severe disabilities gathered to share common experiences and lessons, to identify urgent issues facing wounded warrior caregivers, and to directly support the passage of legislation creating a nationwide, comprehensive wounded warrior caregiver program. Over the course of the four-day summit, caregivers identified and discussed legislative, programmatic, and leadership issues that are critical to the care and maximum rehabilitation of wounded warriors. This summit was conceived, implemented and facilitated by the Wounded Warrior Project. Below are abbreviated passages from Wounded Warrior Project's *Post-Summit Consensus Paper* (September 2009).

Key Themes

Historic Need. "The attendees all agreed that the nation's current conflicts are producing an unprecedented number of wounded warriors suffering from Traumatic Brain Injury (TBI) who will require long-term care by a family member or friend. Though some progress has clearly been made, neither the Department of Defense (DoD) system nor the Veterans Administration (VA) system have sufficiently addressed this consequence of our current wars and its often devastating effect on entire wounded warrior families. Caregivers and families find it necessary to attempt to work within a system which is principally focused on physical impairment and which does not fully or adequately address the range of needs presented by brain injury."

Limited Practical Progress at the Family Level. “For the majority of participants, the summit was a new experience, the first time they had attended a forum of wounded warrior caregivers like themselves... Among those caregivers who had either attended a previous summit or who had become relatively sophisticated advocates, there was unanimous agreement that families continue to confront most of the same, deep needs and institutional obstacles as had been encountered years earlier. While some progress has clearly been made at the systemic level—such as the creation of the Federal Recovery Coordinator (FRC) Program—the caregivers were struck by how many issues identified at the summit have remained largely unresolved and, sadly, even unaddressed at the family level. These caregivers cited the still enormous gap between support programs and services that are theoretically available, and the practical, daily reality of their ongoing unmet needs as wounded warrior caregivers.”

Current Systemic Focus on the Wounded Warrior Rather Than on the Wounded Warrior Family. “Finally, the caregivers repeatedly observed that the DoD and VA system of health care, benefits, and support has historically been focused almost exclusively on the individual needs of the wounded warrior or the veteran—the ‘sponsor’ in health care parlance. There was strong consensus that the VA is institutionally ‘wired’ to provide benefits and health care to the individual veteran, but that the department fails to adequately recognize the family as a critical support element, a rehabilitative extension of the veteran... Caregivers acknowledged that DoD is much farther along, at least at the systemic level, in responding to this new reality of modern warfare”

Urgent Challenges and Recommendations

Income. “Caregivers of severely wounded veterans need lost income replaced. “Of all the problems encountered by the 18 caregivers attending the summit, lost caregiver income is by far the most pervasive and the most damaging to the entire wounded warrior family.”

“I quit a \$65,000 a year job to care for Matt 24/7—I miss my job and independence.”

Health Care. “Wounded warrior caregivers need access to high-quality health care.”

“I no longer have affordable dental insurance or vision which I had through my job.”

“Caregivers cite the enormous gap between programs and services that are theoretically available and their inability to access those supports.”

Mental Health Support. “Caregivers and their families need continuous access to individual and group mental health counseling.”

“My other two children were 18 and 15 years old when Steven was injured. They witnessed their big brother almost dying and [physically struggling] over many months. They were extremely vulnerable, and lived without their mother for six months as I traveled with Steven as he was receiving treatment. No mental health services were ever offered.”

Respite Care. “Primary caregivers and their wounded warriors should have ready access to round-the-clock respite care, either in the home or at an age-appropriate facility, capable of meeting the unique caregiving needs of wounded warriors.”

Training. “Primary caregivers require training and continuing education to safely and effectively perform their caregiver duties.”

Education and Information. “Veterans and their caregivers should be provided vital information about benefits, services, and programs that is tailored to their particular needs.”

“I hate little books. Every time I ask for help, rather than answer my question, they give me a little book. I’ve started keeping them in a backpack I have so many.”

Fiduciary oversight. “Fiduciary oversight should be appropriate and tailored to each caregiver with fiduciary responsibilities.”

“The fiduciary program is demeaning. They demand to see every account whether it’s his or mine. They approved \$400 for a family vacation of four.”

Listening Session #2: National Caucus and Center on Black Aged, Inc.
Washington, DC, October 29, 2009

The second listening session was held at the National Caucus and Center on Black Aged, Inc. (NCBA), an organization that works to eliminate obstacles to fairness and equal access for one of the most underserved and vulnerable groups in

“Caregivers describe the need for training in order to safely and effectively perform their caregiving duties.”

our society—low-income and minority senior citizens. Health promotion/disease prevention is among their top three areas of major focus. The listening session was composed of 14 participants—caregivers of frail, elderly African Americans, NCBA staff, and representatives from the Health Services for Children with Special Needs (HSCSN) Male Caregivers Advocacy Support Group. HSCSN representatives included an advocate for families caring for children with special needs, and a father and grandfather each caring for a child with disabilities. The listening session was led by representatives from The MayaTech Corporation.

Key Themes

Family Caregiving.¹ In minority communities where many children and teenagers grow up in intergenerational households, it is not uncommon to be put in the role of providing activities of daily living (e.g., helping to feed, dress, bathe) or providing instrumental activities of daily living (e.g., cooking, cleaning or managing money) for others at an early age. Several participants confirmed that this was their experience, with some having taken on the responsibility of caregiving as early as 10-years-old. In one instance, because of a daughter’s already established role as a family caregiver, she later became her aging father’s “natural” choice for providing his primary care.

Through the discussion it became evident that many individuals do not define what they do as caregiving but rather as activities of daily living that simply need to be done.

“I was living with my great grandmother who was a diabetic and lost her eye sight and had both legs amputated. Every morning I had to physically hold her arms so she could inject the needle. I don’t view this as caregiving in the traditional sense, but as an ongoing journey of compassion you have for a person you are caring for.”

Those participants who had early experiences like the one described above admitted, however, that it did not necessarily prepare them for the roles they would later face as a caregiver of either a parent or of a child with special needs.

¹ While family caregiver may imply blood relative, for the purpose of this paper, the term is also used to describe friends, neighbors and other unrelated individuals who provide care but are not professional/paid caregivers.

Male Caregiving. Male caregivers of children and youth reported that they are put in the position of combating the myth that fathers are uninvolved, more detached, and less hands-on than mothers in parenting and caring for their children. The stigma plays out in physician practices as well as hospitals where fathers' questions and presence are too often ignored by medical staff. The perception that there is a difference between male vs. female caregiving is also a myth. The difference is not in how the children, youth, or young adult is cared for, but in the support that is given to the male caregivers. To this end, the HSCSN male caregivers support group offers a safe place for men to give and receive the emotional support that is traditionally more easily shared among women.

The HSCSN caregivers have made inroads with local physicians by encouraging them to include the fathers in planning for the care and treatment of the child. On average, more than 20 men attend this weekly support group to empower themselves with useful information and also to share their experiences with other caregiving men. This support group has resulted in a local trend where more men are taking on a leadership role in the caregiving experience.

"Caregiving is something you can't be prepared for. Training and resources are valuable because without them we fall short in getting information we need about care and treatment from the perspective of males."

Challenges

Legal Issues. Some participants are at a loss on to how to handle the financial and health care responsibilities of the family member in their care when the relative is unwilling to participate in signing binding documents that will allow the caregiver to take control over the legal aspects.

"I tried to get my father to do a living will for four years but he was resistant."

"I wound up getting an advocate from the hospital to get my son medical attention. Because of his stroke, he was combative."

Policy Changes. During the session, caregivers shared frustration at not being able to have 24-hour care at home, especially when Medicaid will only provide up to 16 hours

"Male caregivers of children and youth report that they are faced with combating the myth that fathers are uninvolved and less hands-on than mothers."

of home care. In one case, a daughter made a decision to place her father who is diagnosed with dementia in a long-term care facility. If the father were to return to his residence, the troubling behaviors associated with his dementia would decrease the quality of life for the family caregivers who would be responsible for his care the remaining eight hours.

Recommendations

Establish Peer-to-Peer Networks. First-time caregivers are provided invaluable experiences when they are paired with someone who is a caregiver to an individual with the same debilitating condition or disability and who fully understands what the family is going through. The experienced peer “mentor” would be able to assist with finding resources and information on the various services the caregiver and family member in need of care are entitled to receive.

“Someone who has already been through it knows what you’re capable of getting, and physicians and hospitals don’t necessarily have this information.”

Identify Strong Advocates within the Community. Experienced caregivers at the session urged those who are new to caregiving to consider investing in a community advocate that is well-versed in getting services for the individuals who need care and their families. A community advocate can take on many forms: a local social worker; a community based organization’s liaison between families and social services; or a local volunteer who has experience accessing programs and services.

Supporting Children as Caregivers. Given the young age at which some individuals become caregivers, it seems imperative that both the health care system and the school system should work to support children as caregivers.

Listening Session #3: The Arc of Prince George’s County Largo, MD, December 15, 2009

The third listening session was hosted by The Arc of Prince George’s County, the local chapter of the world’s largest grassroots organization (The Arc) committed to the welfare of people with developmental disabilities and their families. Participating in the session were seven caregivers of children with special needs ranging from high school age to 22-years

“Caregivers urge those who are new to caregiving to seek out a community advocate to help in accessing services.”

old, one caregiver of a pre-school age child with special needs, and one 16-year-old high school student with special needs along with her mother. The focus of this session was on a population of caregivers dealing with their children's life transitions. The listening session was led by representatives from The MayaTech Corporation.

Key Themes

During the session, participants were asked to identify their strengths and rewards of being a caregiver and the challenges of preparing youth and young adults for transition to adulthood and independent living.

Strengths of Being a Caregiver:

- The ability to cope
- Learning to rely on a support system
- Being resourceful
- A strengthened faith that enhances a mental, physical and emotional balance
- Being able to fully disclose their child's disability or disabilities
- Being persistent, tenacious and not taking "no" as the final answer
- Learning to fight for their children

Rewards of Being a Caregiver:

Being well educated. It can be empowering for a caregiver who knows the acronyms and laws of the disability community and who is able to speak the language on behalf of their child.

Being a skilled negotiator. Learning the rules of negotiation and how to demonstrate a need has been effective when participating in meetings related to their child's education.

Being an advocate. Having the opportunity to educate others about disabilities as a caregiver helps reduce stigma; however, the children demonstrate it even better as self advocates.

"I told the school system that my son didn't need a special education bus. Eventually, after my son wouldn't get on, they stopped sending it. I want him to know how to get along with kids with and without disabilities."

Reaching Milestones. Seeing your child do what they were told they would never do or accomplish a task they were told they would never accomplish, and knowing that as a parent you were instrumental in that achievement is one of the greatest rewards.

“I remember when my daughter learned her home phone number.”

“[My daughter] ran for mayor at the camp she attended and even though she didn’t win, she demonstrated confidence and educated people in the process.”

Challenges

Complex System. Caregivers find the transition process, paperwork, and pressure overwhelming. According to participants, the state of Maryland is moving more in the direction of self-directed services, which puts a greater burden on families to understand the various plans, unless caregivers pay a support broker (case manager) out of their family budgets.

“The time it takes to understand how to navigate the process is like having a part-time job.”

Educators’ Role. The participants expressed frustration that educators are responsible for developing transition plans but are not properly trained to do it. Oftentimes, parents feel they are in the role of being the caregiver *and* the transition plan coordinator. Parents attending the listening session agreed that it is important to share information with the educators when developing a transition plan but not to rely on them as the expert, which unfortunately many caregivers do because they are not as well educated about the systems of service.

“Lots of families rely on educators and wind up being nervous about the next steps.”

Post-Secondary School Options. Parents voiced that in addition to the push for self-directed services, they are frustrated that Maryland is not keen on developing post-secondary education programs and instead are pushing employment first. This creates a hardship for those whom employment is a challenge.

“Parents report that one of their greatest rewards is seeing their child accomplish what they were told they could never do and know that they were instrumental in that achievement.”

The lack of options is a major challenge to transitioning to independent living. There are very few four-year non-degree programs and because of the limited number, parents have found admission to be very competitive for their youth.

Supportive Employment. Based on the discussion, there is a need for more job coaching and supportive employment, especially for lower-functioning young adults.

“My 22-year-old doesn’t fit in the box. She needs more support and cannot be left alone.”

Recommendations

Get Started Early. Session participants urge parents and educators to begin thinking about transitioning out of a system as soon as children become part of that system (whether it’s a school, daycare program, pediatric health facility, etc). Caregivers recommended families develop educational goals based on the natural proclivity of the child and continue to develop those interests and abilities. Ten to 12 years down the line, the youth will have well developed interests and abilities that can help them more easily transition into a job or academic program; they can become primed for a fulfilling career and not just a day-to-day job.

Another suggestion from the session is to create a model where young people are being trained for transitioning to adulthood as early as elementary school, with a parallel training program in place for parents.

Create More Opportunities for Entrepreneurship. During the session, parents expressed that there needs to be more options for adults with disabilities to make a living and suggest that agencies invest in creating more entrepreneurial development programs. In one case, a mother enrolled her 16-year-old daughter in an entrepreneurial program where she learned about various business practices but after the program ended, there was no place to connect with so that she could put into practice and maintain what she had been taught.

“Our kids are considered high risk but allow them to learn a skill and they will be more likely to be successful.”

“Caregivers highlight the need to plan early for transition; as soon as your child enters a system, plan for the transition out of it.”

Plan College Tours. Provide the same opportunities for students with disabilities as their peers to learn about college choices. School counselors and administrators are encouraged to research and arrange tours with the colleges that have vocational and certification programs as viable options for transitioning students.

Include Transportation Training as Part of an Individual Education Plan (IEP). In the Washington metropolitan area, students with disabilities are entitled to the same Metro Access (public transportation) as their peers without disabilities. Parents are encouraged to include learning the public transportation system as an academic goal so that when it is time to transition, the youth/young adult will know how to get to their educational or employment site using public transportation.

Create Additional Opportunities for Mentor Relationships. Allow young people to learn how to live as adults from their own peers with similar disabilities.

Of Special Concern

Special Needs Trust. Parents are concerned about the legal implications of their non-minor child outliving their primary caregiver. Parents are fearful about what will happen if a legal document is not in place. However, many families cannot afford to pay a private attorney or firm to draw up these documents.

Homeownership. Caregivers are interested in programs that will allow young people with disabilities to purchase homes together as a viable option to living in a group home situation.

Listening Session #4: Health Services for Children with Special Needs, Inc. Washington, DC, January 13, 2010

The fourth session was hosted by the Parent Advocate Leadership Group (PALS) of Health Services for Children with Special Needs, Inc. (HSCSN), with participation from the HSCSN Male Caregivers Advocacy Support Group (MCAS). HSCSN is an operating subsidiary of The HSC Foundation and an innovative care management network coordinating health, social, and education services for the pediatric Supplemental Security Income (SSI) and SSI-eligible populations of Washington, D.C. Holistic and proactive, HSCSN is the only Medicaid health plan that coordinates all aspects of physical, mental, behavioral and

“Parents are concerned about the legal implications of their non-minor child outliving their primary caregiver.”

HSC Foundation is the parent organization to HSCSN. Twenty fathers, mothers, grandfathers and grandmothers who serve as caregivers to children, youth, and adults participated in the PALS/ MCAS group discussion. The diagnoses of the children being cared for by these HSCSN members include attention-deficit/hyperactivity disorder; Down's syndrome, bipolar disorder and autism spectrum disorder, with many of them have co-occurring disorders. The listening session was led by representatives from The MayaTech Corporation.

Key Themes

Participants in the session were asked three main questions: What are you most proud of as a caregiver? What are some of your challenges as a caregiver? What additional resources do you need as caregivers?

Pride as a Caregiver

Among the many things that caregivers expressed pride about include:

- A child transitioning out of special education and being on the honor roll
- Not accepting a negative diagnosis and seeking out other specialists
- Being an effective child advocate and fighting for services
- A child's endurance; being a fighter
- A child's ability to transform a parent into a compassionate, patient, understanding caregiver
- A child being on track to graduate from high school
- A child not giving up and finishing school four years later than she would have if she had not been disabled by an accident
- A child who at one time could not be understood now involved in public speaking and addressing the City Council
- A child singing in the church choir
- Watching a child who was referred for institutionalization become an essay writer and public speaker

Challenges of Caregivers

Education. Caregivers are concerned that their lack of awareness about the educational process impedes the success of their children with special needs. Having accessibility to appropriate education and schools that do not give up on children and youth with disabilities are other educational issues highlighted during the session.

“My daughter rides a bus for one hour and fifteen minutes every day instead of attending the school around the corner.”

“It’s important that we make sure our children get a proper education so they will be able to enter the workforce. Supplemental Security Income (SSI) will not service children for their entire lives.”

Burn out. Caregivers who have been carrying the load for years are struggling with physical, mental, and financial issues as a result of putting so much energy, time, and emotion into the life of their child with special needs. The constant attention that is required to meet their needs is oftentimes at the expense of other siblings. Caregivers are seeking help in coping with managing multiple roles.

Transition planning. During this listening session, caregivers echoed those sentiments of Arc parents regarding transitioning into adulthood with an emphasis on frustrations about the lack of employment and housing choices, as well as the need for more opportunities to socialize within the larger community.

“We groom our kids to be strong and then they get slapped in the face and have to work in a program for a stipend of \$60 a week and housing that means living in homes with other people that are not of your choosing. It’s unfair.”

Needs of Caregivers

- Respite and retreats
- A parent call center
- Health care reform (specifically addressing the pre-existing conditions issues)
- Information and more advocacy groups
- Time management training
- Extracurricular activities for children to channel interests and energy

Of Special Concern

- Financial and guardianship planning
- Support for siblings of children with special needs
- Coping mechanisms for caregivers

Conclusion

Caregivers who participated in these listening sessions were empowered, courageous, passionate and educated individuals. They were also caregivers who were simultaneously fatigued, stressed, confused and angry. Put in one of the most demanding positions, these individuals rely on a system of educators, advocates, legislators, leaders and service providers. Guided by a network of traditional caregiving groups this system does an effective job in supporting many caregivers. However, some caregivers fall through the cracks for a variety reasons: they are members of low-income minority communities; they do not have convenient methods for communication; their culture inhibits them from self-identifying as a caregiver and seeking out resources.

Over the course of several months, The HSC Foundation, The MayaTech Corporation and National Health Foundation listened in to the discussions of caregivers who are often overlooked, and whose issues do not often reach mainstream. Typical of most caregiving populations, these individuals reported a need for education and information, financial assistance, access to healthcare, and opportunities to relieve emotional stress. Although these are systems in place to support caregivers, oftentimes these systems are complex and not readily accessible.

Supporting caregivers with personal assistance is possibly the best solution to many of the challenges caregivers face. Personal assistance might take the form of respite care, assistance in obtaining services, mental health counseling and much more. **For this reason, the most profound recommendation—one that permeated all discussions— was the value of peer-to-peer mentorship.** Not only does peer-to-peer support and mentorship provide mechanisms to address many of the challenges that caregivers face, but it can overcome the barriers that oftentimes leave some caregivers out of the loop. Occurring in community setting, peers understand each others' regional systems, unique neighborhoods, their language and their cultural realities. Though not without their own challenges, peer-to-peer experiences provide endless opportunities for

“The most profound recommendation—one that permeated all discussions— was the value of peer-to-peer mentorship.”

information and referral, respite, emotional support, and much more. Although traditional caregiver organizations have done an outstanding job in serving caregivers, it seems most advantageous for community-based organizations already working with these marginalized caregivers to organize these peer-to-peer mentorship programs and workgroups.

In the coming months, this report will be disseminated in the hopes of reminding or inspiring those groups who have the ability to reach caregivers and who constantly advocate for and initiate change.

NOTE: In addition to providing insightful and thought-provoking comments on topics throughout this paper, expert caregivers who reviewed this document also raised a number of key issues that were not within its scope. The partners on this project felt that these issues were important, relevant to the audience, and should be considered for future study. These issues included:

- Consider the impact that stigma has on the life of a caregiver. For example, being the caregiver of an adult or child with a serious mental illness (schizophrenia, bipolar disorder, etc.) has not historically been given the attention in research literature, or the social acceptance, as being the caregivers of the elderly, wounded veterans, and individuals with developmental disabilities. Oftentimes caregivers of individuals with mental illness are blamed for either causing or contributing to the individual's difficulties.
- Supportive services to parents of children with special needs have been well developed over the years. Partly, this has been the result of parents who have done an excellent job in advocating for their children, raising critical issues, and providing a voice to children who cannot speak up for themselves. However, the network of services resulting from their advocacy is commonly unknown or inaccessible to the marginalized populations discussed in this paper.
- While there are some differences in the way males and females provide care or deal with their caregiving situations, there is no difference in the type of caregiving necessitated. Oftentimes, although the challenges they face are somewhat different, the solutions to male and female caregiving problems can be solved with the same solutions, such as accessing support groups and training health care providers to equally respect male and female caregivers.

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THE HSC HEALTH CARE SYSTEM

The HSC Foundation

The HSC Foundation is dedicated to improving access to services for individuals who face social and health care barriers due to disability and chronic illness. The Foundation supports The HSC Pediatric Center, Health Services for Children with Special Needs, Inc., and HSC Home Care, LLC.

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