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SUMMARY REPORT:
**"FROM PERSONAL STORY TO POLICY:
IMPROVING THE LIVES OF CARE RECIPIENTS, FAMILY
CAREGIVERS AND THOSE PAID FOR SERVICE"**

Bronx County Courthouse
Wednesday, April 27, 2016

Gray Panthers, NYC Network was very proud to organize and sponsor this significant discussion on home health care and caregiving in New York City.
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We, as a society and as New Yorkers, are at an opportune moment. Caregivers of every stripe are finally receiving the acknowledgement they so richly deserve, a better understanding that caregivers need support, government policy attention, and significantly increased programmatic funding. Consequently, Gray Panthers NYC Network sponsored and convened a broad forum on caregiver policy and concerns, held on Wednesday, April 27, 2016 in the Rotunda of the Bronx County Courthouse. We were so pleased to be able to present in the Bronx. Particular thanks to Borough President Ruben Diaz, Jr. who eagerly provided us with this great venue.

It was a rich discussion, illuminating many of the complex issues of home health care and caregiving - including NYC government's recent effort to establish a citywide caregiving initiative; understanding the support systems available as well as the constant challenges to informal caregivers; the limitations and confusing landscape for home health staff; and how to identify and plan for appropriate care for loved ones.

Our roster of speakers was great. Thank you for such thoughtful presentations.

- Robin Fenley, PhD - NYC Department for the Aging, Assistant Commissioner, Bureau of Health Care Connections - <http://www.nyc.gov/html/dfta/html/caregiver/support.shtml>
- Allison Cook, MPH - PHI National, New York Policy Associate - <http://phinational.org/>
- Matt Kudish, LMSW - Caring Kind NYC, Senior Vice President of Caregiving Services - www.caringkindnyc.org
- Joanna Leefer - MBA, GSC - Senior Care Advisor/Advocate - www.joannaleefer.com
- Jack Kupferman, President of Gray Panthers, NYC Network as Moderator - www.graypanthersnyc.org

Some Key Comments and Reflections:

- Consistently, caregivers are unaware of the range of support services available for them. Education and promotion is key. Senior care information and training should be as available, widespread and comprehensive as information regarding child care.
- So often, Caregivers fail to self-identify, struggling to manage on their own and in isolation. They see themselves as family members, friends, etc., but not as a network of those who provide an essential, difficult, and exhausting service.
- The system, for paid and for family caregivers, is incredibly complex, with hundreds of policy, physical, emotional and statutory limitations. For example, the complexity of wage and employment provisions is staggering.
 - Equally important is the wide range of misunderstandings between perception and reality of caregiving. This includes what a home healthcare worker can and can't do, e.g., administering medications, lifting someone from the floor.
 - At this specific moment in time, there is much government interest in this effort as well as significant increases in funding. We applaud this new focus on the best interest of carers. Now, it is being recognized that the whole family system needs assistance and help in caregiving.
 - For instance, the City Council Speaker has asked for a Caregiver Survey to be conducted throughout the 5 boroughs. During

2017, the Department will develop, implement, and report on the survey, providing recommendations for further action. The goal is to find out how many caregivers there are, who they are, and what they need.

- Additionally, the City of New York has mandated that Caregivers are now a protected¹ category of employee.
- The State of New York is considering creation of an “Advanced Home Health Aide” title, enabling NYS home care aides who have worked for at least one year to take on additional eligible “advanced” tasks under the supervision of a Registered Nurse, such as administering pre-packaged routine medications. This may be the beginning of a “career ladder” for talented and committed home health aides.
 - Generally, in this industry, there is nowhere to advance in the caregiver ladder. The next step up is Licensed Practical Nurse, which is usually out of reach for most aides in terms of time and financial commitment, period of education. This results in large gap of quality of care.
- Though resources are available for family caregivers, information about them is not yet widely disseminated. Specific examples include:
 - Caring Kind runs a 24-hour hotline (646-744-2900) for families worried about potential signs of Alzheimer’s in a loved one, providing guidance as to how to intercede early and appropriately. Just now, Caring Kind is sponsoring a public education campaign, throughout the NYC Transit and Subway systems.
 - Consultant Joanna Leefer assists families trying to choose the right level of care for a loved one: nursing home, assisted living, and home care.
 - PSS Circle of Care focuses on the needs of the Caregiver, helping with whatever emotional, financial, physical assistance that may be needed.

➤ ¹ Effective May 4, 2016, New York City employers with four or more employees are prohibited from firing or refusing to hire an individual, and from discriminating against an individual in compensation or terms and conditions of employment because of the individual’s actual or perceived “caregiver status.” This amendment to the New York City Human Rights Law defines “caregiver” as a “person who provides direct and ongoing care for a minor child or a care recipient.”

- Social Service Organizations such as JASA provide many programs that support the aging elderly and their families.
- Wendl Kornfeld provides networking and conducts workshops for people without children/extended families that may find themselves aging without family support.
- One of the unacknowledged dangers of care is that family caregivers are at risk of injuring themselves as they help their loved one. For instance, they may sustain back injuries, shoulders, and knees as they assist with getting up/down, or transferring between surfaces if their loved one uses a wheelchair or other mobility aid.
- Both unpaid and paid caregivers have a joint agenda, particularly when it comes to developing new technologies and products that can relieve the stress and strain of caregiving.
- Specific challenges that may require additional governmental action:
 - Limits on the amount of paid care available under various government programs are a product of fiscal concerns. From the caregiver point of view, the difference between the 24-hour/day care needed and the four hours of care that is provided creates much of the strain that leads to caregiver stress and avoidable institutionalization.
- The financial cost of paying for all needed hours of caregiving may be impractical. Options are needed, perhaps creation of a "time bank" where people can "earn hours to bank" by giving time to someone else.
- It's important to note that Paid caregiver wages and benefits are not compatible with the value of what they provide

Below are just a few of the many concerns raised that warrant becoming recommendations:

- higher wages for home health care workers so they can climb the ladder and take better care of their own needs and families;
- a family member should always be present when a person is being evaluated by a nurse or doctor so accurate information is provided and appropriate help is engaged;
- home health care workers need to arrive at the place of service dressed appropriately for work;
- always ask a home care service for their "Rules of Procedure"

- a timesaving call here in NYC is making use of 311. Provide a brief description of the situation you're facing and what services you think you might need. The 311 operator will then transfer you to the agency that will help you further. Certainly, a call to disease-specific organizations will also provide an overview of what may be available through this organization.



AUDIENCE Q&A HIGHLIGHTS:

"Glad to hear that there are now resources for families caring for a parent with Alzheimer's. In my family, my siblings left it to me and I struggled. It took some time, but I developed a warm relationship with the aides who cared for my mother, but had to push the nursing home itself in many ways including making sure that they could explain to my satisfaction how they were handling my mother's financial account."

"My partner is starting to become confused and I have been worried about how to handle this. He has been diagnosed with peripheral artery disease but he seems to forget basic things. Yes, I will reach out to Caring Kind to find out more about what I can be doing now."



