Acknowledgements

United Way of Allegheny County Needs Assessment

Development of this impact strategy for vulnerable seniors and persons with disabilities required the time and expertise of many individuals from our region's businesses and agencies. We would like to thank the following individuals for providing their expertise in helping to ensure the needs identified accurately reflect those of our community and strategies defined can have the greatest impact.

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Executive Summary

United Way has been moving steadily toward community-driven problem solving by partnering with corporate, nonprofit and government leaders to assess community needs and identify strategies to address those needs. Through an open, competitive funding process, United Way invests in agency programs designed to bring about community change. In addition, with strong connections to corporate, nonprofit and government leaders, United Way:

- Convenes/mobilizes the community around important, timely issues;
- Raises public awareness about critical issues; and,
- Recruits and mobilizes volunteers.

For each of its priority areas: Children and Youth, Financially Struggling Adults and Families and Vulnerable Seniors and Persons with Disabilities, United Way embarks upon needs assessments every three years. In 2013, United Way assessed needs of and refined its investment strategies for Allegheny County’s Vulnerable Seniors and Persons with Disabilities.

To better understand the needs facing Allegheny County’s Vulnerable Seniors and Persons with Disabilities and to prioritize United Way’s work in addressing these most critical needs, United Way engaged the University of Pittsburgh Graduate School of Public Health as a consultant, who led a Needs Assessment Steering Committee in examining the current landscapes, engaging key stakeholders (especially seniors, persons with disabilities, their family members and service providers) and assessing the needs of the two populations.

The assessment identified significant challenges for both populations and opportunities where United Way may be especially impactful. One consistent message regarding this investment is that United Way separate the two populations - seniors and persons with disabilities – into two distinct investment areas. United Way has taken heed to that advice and will, throughout this needs assessment and the RFP process, address the two populations separately.

For persons with disabilities, the most significant challenges identified revolve around high unemployment, lack of preparation for independent living, social isolation and caregiver stress. United Way’s vision is that our neighbors with disabilities will live independently and be well integrated into the community; will have opportunities for gainful employment and community involvement; and their caregivers will be well-supported and knowledgeable about where to turn for help.

For the vulnerable senior population, the challenges revolve around the population’s increasing level of frailty, social isolation and caregiver stress. United Way’s vision is that our senior neighbors will age safely in the places of their choice; will have the support of volunteers to keep them engaged and to help with daily tasks and that their caregivers will be well-supported and knowledgeable about where to turn for help.

United Way of Allegheny County recognizes the importance of its role in convening and mobilizing the community to solve large-scale community problems. As such, the release of the Needs Assessment is not an ending point, but rather, a necessary step in the continuation of the work that has impacted vulnerable seniors and persons with disabilities over the years. United Way of Allegheny County will continue to convene thought leaders to deeply explore issues facing both of
these groups. United Way is, especially, dedicated to accessing the voices of seniors and persons with disabilities in solving these problems. This plan represents the hard, but necessary, work of community change.

**Purpose**

In Spring 2013, United Way of Allegheny County called upon corporate, nonprofit and government leaders to examine the needs of, and the programming and policy landscape impacting, vulnerable seniors and persons with disabilities and map out strategies to lead its investments for the next three years. Using a variety of methods - provider and stakeholder interviews, provider meetings, web-based surveys of donor preference, and United Way staff input – a snapshot of the issues impacting seniors and person with disabilities was created.

Following the data collection and analysis, United Way examined the issues to determine where we can bring our strengths and how our funding can make a difference. Once the critical needs were identified, we asked:

- Given the relatively limited financial resources that United Way can bring, is there a likelihood of success in creating measurable change on the issues?
- Are these investments something that United Way donors would support?

Based upon information gathered regarding needs, programs and policies and building upon current United Way initiatives for persons with disabilities (21 and Able ) and vulnerable seniors (Open Your Heart to a Senior), the Needs Assessment Steering Committee, along with input from United Way staff, determined three priority areas for each population.

**Issues Impacting Persons with Disabilities**

Currently in Allegheny County, more than 75,000 people ages 18-64 years have a physical, intellectual or emotional disability (2011 American Community Survey). Each year, the Alliance for Infants and Toddlers, the Allegheny Intermediate Unit 3 DART Program and Pittsburgh Public Schools Office of Early Intervention identify and initiate services for over 4,000 young children with disabilities. Across the Commonwealth, 11.9% of students currently enrolled in public schools have Individualized Education Plans (for physical, emotional and intellectual disabilities). Here in Allegheny County, for some of the most disadvantaged school districts, that percentage is considerably higher.

United Way anticipates relatively flat line funding, but an escalating need due to increasing numbers of years lived with progressive functional limitations. Public funding at current levels is inadequate to meet that need.

After careful examination of the community’s needs and resources, identification of issues that disproportionately impact this population and analysis of the gaps in services for persons with disabilities, the needs assessment committee decided upon the following areas where United Way would be most impactful:

- promoting greater independence and social connection;
- supporting caregivers of individuals with disabilities; and
- developing opportunities for employment and volunteerism.

Needs Identified

Health. Overall, persons with disabilities have higher rates of many health conditions (such as diabetes), are more likely to be living with multiple medical conditions, make less use of preventive health care, and face significant challenges accessing traditional health care facilities. As they age, persons with disabilities contend with added challenges of age-related conditions at the same or greater rate than other older persons (Evenhuis et al., 2000). In adults with intellectual disabilities, such as Down syndrome, aging brings greater risk of a wide range of physical and mental health challenges (Perkins & Moran, 2010). For many adults with intellectual disabilities, complex health care needs requiring any number of health care professionals is difficult, at best, without case management. Supporting caregivers of persons with disabilities to manage their own chronic conditions, as well as increasing support in managing complex medical needs, would contribute significantly to a person’s independence.

Housing. There are limited resources and few housing models that support adults with disabilities living in the community independently. For individuals with the most complex needs and intellectual disabilities, residential settings are especially challenging to identify (Allegheny County DHS). More broadly, nearly 30,000 people in Allegheny County age 17-64 years report difficulty living independently due to a disability (2011 American Community Survey).

Caregivers. In 2011, it was projected that by 2020 approximately 20,000 seniors in the county would be caring for a dependent adult child. More recent demographic information indicates that that number has already been reached. In a sample survey of older caregivers of adults with disabilities conducted on behalf of United Way of Allegheny County in 2012, fewer than half of respondents report having wills and/or plans for the dependent’s care when they can no longer provide that care. Many aging caregivers have not been able to prepare their adult children with disabilities for inclusion in the community and/or independence, which presents unique transitional challenges for adult children. Systems of support and services are complex and have changed significantly since many aging parents may have navigated them when their children were young. Without adequate planning, individuals with disabilities can be left without support and end up in nursing homes, unnecessarily.

Employment. Persons with disabilities have an unemployment rate nearly double that of the general population - 13% compared to 7% (Dept of Labor Statistics, January, 2013). Median income for employed persons with disabilities is approximately $19,000, compared to a median income of over $31,000 for persons without disabilities (2011 American Community Survey). Persons with disabilities whose incomes are below the poverty line is double that of individuals without disabilities. For adults with psychiatric disabilities, employment has led to lower rates of hospitalization, and an increased sense of personal control (Kirsh, 2013). Persons with disabilities who receive vocational training and job support have been shown to be twice as likely to be competitively employed (Steingass et al., 2011).

Volunteerism. For individuals with disabilities, there are limited community options for volunteering and few resources for engaging and inclusive day activities. Minimally restrictive work and living environments have been shown to positively impact individual self-determination (Wehmeyer and Palmer, 2003).
Donor Appeal. To further help prioritize opportunities for United Way investment, a short on-line donor survey was made available, over the course of one week, to nearly 2,500 United Way donors with an expressed interest in persons with disabilities and/or vulnerable seniors. 377 responses were received. This survey asked respondents to express their priorities for funding of five areas focusing on persons with disabilities by indicating how they would allocate $100 dollars.

Of the total respondents, 6.8% reported caring for an adult with disabilities, and 40.1% reported knowing someone who cares for an adult with disabilities.

Donors indicated that they would invest $27.50 of every $100 in family caregiver support, and $25 of every $100 for transitions in care (such as graduating from school). Donors would invest $20 of the $100 to supporting employment options.

Strategies for Community Impact

As the Needs Assessment Steering Committee sought to identify the direction that United Way will take for the next 3 years, it considered United Way's current investments in the Persons with Disabilities area – 21 and Able. 21 and Able is a multi-year initiative developed to address the gap in services experienced by persons with disabilities as they are no longer eligible for special education and support services at the age of 21. The initiative is creating a roadmap for youth with disabilities who are transitioning out of the education and supportive services systems to work, live independently, and participate actively in their communities to the extent possible.

In the Persons with Disabilities area, after reviewing the Needs Assessment data, the Steering Committee recommended a philosophical shift from helping persons with disabilities stay safely in
their homes and communities to helping persons with disabilities to achieve greater independence and social connection.

The specific recommendations and strategies follow:

**Promote greater independence and social connection**

- Continue to implement the **21 and Able work plan**
  - Cultivate a culture of employment, independent living and community participation
  - Create meaningful opportunities for further education and job skills development
  - Engage partners in the private/public sector
  - Promote public policy change
- Advocate for increased housing options and promote efforts to connect individuals with appropriate supportive housing, including appropriate technology
- Continue to provide information and referral to persons with disabilities, their families and service providers through **PA 2-1-1 Southwest** and to promote the **PA 2-1-1 Southwest** service to help more people get the information they need

**Support for caregivers of persons with disabilities**

- Promote programs and policies to increase access to community support, including access to quality information and respite services, such as through **PA 2-1-1 Southwest**
- Provide caregivers with assistance in planning for their son’s and daughter’s futures, as well as respite from their daily care, would improve caregivers’ abilities to keep their loved ones at home

**Develop opportunities for employment and volunteerism**

- Continue to implement the **21 and Able work plan**
- Implement and expand pilot programs (such as current pilot program with Giant Eagle) to increase opportunities for youth to work in competitive employment that will lead to employment after high school
- Identify and invest in replicating models that successfully engage persons with disabilities in employment and volunteer activities

**Issues Impacting Vulnerable Seniors**

Allegheny County’s senior population is increasingly “old old” (age 85+). In 2010, 35,000 older adults were over age 85, a 25% increase over the prior decade (Allegheny County Area Agency on Aging, 2012). These seniors are increasingly heterogeneous in race and ethnicity, and seniors of
color have lower incomes, less insurance coverage, and lower rates of home ownership (University of Pittsburgh Center for Social and Urban Research, 2011). People aged 65+ benefit from income and health support programs and an efficient local aging services network, but still face challenges. A third live alone (more than 40% among women aged 75+).

After careful examination of the community’s needs and resources, identification of issues that disproportionately impact this population and analysis of the gaps in services for vulnerable seniors, the needs assessment committee decided upon the following areas where United Way would be most impactful:

- Help seniors be healthy and safe at home;
- Promote volunteer assistance to help seniors and engagement of seniors as volunteers; and
- Support caregivers of vulnerable seniors.

**Needs Identified**

**Health.** The prevalence of medical conditions (about 2/3 have more than one condition) and prescription drug use (2/3 take 3+ medications) make the population vulnerable to hospitalization, disabilities, and social isolation. One in three older Americans falls every year. Falls are the leading cause of both fatal and nonfatal injuries for people aged 65 and older. (National Council on Aging, 2013) Years lived with disabilities will likely increase as life expectancy continues to rise. Public sector demands are increasing. Requests for in-home services increased by 19% (OPTIONS) and 41% (Aging Waiver) between 2008-2012. Service availability, such as home-delivered meals, has declined in some areas.

**Caregivers.** Families are the mainstay of support but face competing demands from employers and children. Caring for an aging parent is a costly source of stress in the workplace. Total cost of lost wages, social security, and pensions is $3 trillion across the United States. Individually, average lifetime earnings losses equal $324,044 for women and $283,716 for men. Productivity losses including absenteeism and presenteeism is $33.6 billion. Nearly 10 million people are affected. (Metlife) Nearly half of businesses report increased numbers of employees with eldercare issues (Society of Human Resource Management). For spouse caregivers, caregiving can have serious mental and physical health consequences. 40-70% of family caregivers have clinically significant symptoms of depression with about a quarter to a half of these caregivers meeting the diagnostic criteria for major depression. [Zarit, (2006) & Family Caregiver Alliance.]

**Funding for Senior Services.** Nearly a quarter of seniors aged 85+ receive a service from the Area Agency on Aging (AAA), as do approximately 15% of seniors aged 65+. This coverage suggests that the AAA is effective in outreach, likely reaching most seniors with the most serious needs. However, seniors who are considered “middle income” face great challenges in accessing services. These individuals often do not meet the criteria for public assistance, but cannot afford to purchase needed services on their own. According to AARP’s Middle Class Security Project, half of older Americans carry medical expenses on their credit cards. Prescription drugs and dental expenses were the highest contributors. (Traub, 2013) Overall, middle-class Americans have experienced a loss of financial security, including loss of savings and home values with increasing costs to meet basic needs such as health care, housing and food (Undem, 2013). The local Area Agency on Aging has expanded information and referrals (increases of 15% in number of
calls, 2008-2012), which has helped in meeting the challenge, but barriers still exist for many families.

Donor Appeal. To further help prioritize opportunities for United Way investment, a short on-line donor survey was made available, over the course of one week, to nearly 2,500 United Way donors with an expressed interest in persons with disabilities and/or vulnerable seniors. 377 responses were received. This survey asked respondents to express their priorities for funding of five areas focusing on vulnerable seniors by indicating how they would allocate $100 dollars.

Survey results show that donors would invest $35 of every $100 to support aging in place. Family caregiver support ($22) and transitions in care (such as modifying your home to be more accessible) ($20) followed. Together, the three areas accounted for about three quarters of preferred investment.

Strategies for Community Impact

The underlying issue facing the human service system for vulnerable seniors is an increase in demand for services with flat or decreased funding to meet that demand. In considering how United Way can make an impact on this problem, the Steering Committee and United Way staff looked at how to fill the gap between the demand and lack of monetary resources. The following recommendations and strategies embrace the ideas of collaboration, innovation, improved self-care, volunteers, caregiver supports and systems/policy change.

As the Steering Committee narrowed focus in the Seniors area, they also strongly considered the progress of United Way’s current initiative – Open Your Heart to A Senior. Open Your Heart to a Senior is a county-wide volunteer initiative designed to get well prepared, committed volunteers to
support vulnerable seniors in ways that help seniors to age safely in place. It is a successful model that continues to evolve and may serve as an example of the kinds of big impact projects that United Way supports.

The specific recommendations and strategies are:

**Help seniors be healthy and safe at home**

- Promote programs and initiatives proven to be effective in enhancing self-care and managing and preventing chronic illness
- Encourage effective and efficient efforts for improved in-home services, care transitions/coordination, home modifications/assistive technology, housing and transportation

**Promote volunteer assistance to help seniors and engagement of seniors as volunteers**

- Encourage volunteer service to support seniors and their caregivers
- Promote models that empower and engage seniors in community involvement

**Support caregivers of vulnerable seniors**

- Respond to the information needs of family caregivers, including new resources and technologies
- Advocate for increased access to caregiver respite
- Encourage innovative models to support working caregivers

**Summary**

These ambitious recommendations and strategies will require the coordinated effort of many community partners. Maximizing resources through collaboration will be critical to meet the increases in demand for services to support vulnerable seniors and persons with disabilities when traditional funding sources are stagnant.

With the release of the 2014 United Way Needs Assessment report, our work is not complete. The United Way of Allegheny County and its partners have studied the landscape and identified several areas where United Way’s strengths can make a difference.

The United Way of Allegheny County will:

- issue two (2) major Requests for Proposals in December 2013 to agencies in Allegheny County to work in partnership with United Way to achieve large-scale improvements to the problems and needs identified in this report. United Way’s goal is to make strategic and meaningful investments in excellent agencies that will create significant impact in supports available to both vulnerable seniors and persons with disabilities.
expand and strengthen the 21 and Able initiative, which includes several innovative program and policy initiatives intended to help grow an engaged and competent workforce of persons with disabilities.

continue to support the Open Your Heart to a Senior initiative and the partner agencies who are developing a highly trained and sustainable source of volunteers to help older adults live safely in their homes.

continue to convene the thought leaders in these areas to more deeply explore issues facing persons with disabilities and vulnerable seniors.

ensure that there is a voice for individuals who need greater assistance in their daily lives because of frailty or disability.

We look forward to working closely with agency partners to make a lasting difference in the lives of vulnerable seniors and persons with disabilities in Allegheny County. This plan represents the hard, but necessary, work of community change.

This table represents the United Way strategy to tackle an increasing demand for services over time with stagnant available funding. The recommendations in this report address this pressing need.

Additional background materials available upon request.