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Supporting Individuals with Disability Across the Lifespan at Home: Social Services, Technologies, and the Built Environment

By Laura N. Gitlin, Sarah L. Szanton, and Eva H. DuGoff

The Community Living Assistance Services and Supports (CLASS) Plan – a groundbreaking component of the Affordable Care Act – creates a voluntary federally-administered insurance program to help individuals pay for needed assistance in a place they call home if they become functionally limited. Implementation will require knowledge translation from various sectors, including research and existing public and private programs. This Technical Assistance Brief Series seeks to answer questions pertinent to developing and implementing the program.

This brief describes the broad needs of individuals with disability and the wide range of supportive and environmental solutions that can allow for the most independent living possible. Using the evidence from research, the brief suggests how findings on social and environmental supports for individuals with disability can inform implementation of CLASS.

Introduction and Overview of Disability

Disability is a condition that can affect anyone - young and old, rich and poor, women and men, or any race or ethnic group. An estimated 35-43 million adults (18+) in the United States have a physical or cognitive impairment that interferes with their daily functioning.[1] A person can be born with a disability as in the case of Mike who has cerebral palsy, or it can occur in young adulthood from an accident and persist throughout a lifetime.

Mike, a 28 year old with cerebral palsy, is no longer ambulatory. He is too heavy for his parents to lift him from bed and they are at risk of injury when transferring him from his wheelchair to the bathtub. He and his parents would both benefit from an assistive device that holds his weight while he transfers.

Having a disability can also occur late in life such as in the case of Mrs. H., who was previously very active and now at the age of 76 experiences significant limitations in her ability to take care of herself.

Since 76 year old Mrs. H. broke her hip, she has difficulty using her steep stairs and also getting into her tub to take a shower. As her only bathroom is on the second floor, she cannot get to the bathroom on time. She is also showing signs of memory loss. Her daughter who lives close by is very anxious about her well-being and checks in on her almost daily to assure she is safe and taking her medications. Mrs. H. would benefit from a stair lift or a first floor powder room. She also needs a walker to safely move around her first floor, and a grab bar and tub bench for safe bathing. An electronic medication dispenser and monitoring devices might help Mrs. H's daughter keep Mrs. H safe at home.

Disability affects individuals unpredictably as they age and experience illness and other life events. Such is the case of Mr. J who, after a stroke and the loss of his wife, has significant difficulties living alone.

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Since his stroke, 80 year old Mr. J. has difficulty bathing due to poor balance and muscle weakness. He needs grab bars, and training for both using a tub bench and getting into and out of the tub safely. He also wants to go to adult day care for strengthening exercises and group depression treatment as he is a recent widower and feels very lonely. His benefits could pay for his transportation to adult day care.

Disability is not a static state. A complex and dynamic condition, it reflects the relationship between an individual who experiences interference in normal bodily functions caused by disease, trauma or other condition, and that person's social and physical environment over the life course.[2]

Disability can pose minimal to significant challenges to an individual's ability to engage in everyday activities of living such as bathing, dressing or preparing meals, or to enjoy life, and age at home or in the residence of a person's choice. The challenges posed by disability are driven largely by factors that are external to the person – those demands imposed by social and physical environmental conditions. For example, in the case of Mrs. H., prior to her hip fracture, she had no difficulties going up and down her stairs or getting in and out of her tub to shower. However, following hip surgery and accompanying increased severe arthritis, her physical environment now presents a significant barrier to her ability to bathe or to go upstairs to use her bathroom.

Social and physical environmental problems can be changed to compensate for an individual's losses. Mr. L., for example, cannot leave his home and return to work due chiefly to one barrier – the front steps of his home. Such a physical impediment can take a toll on individuals and their family members both emotionally and financially, putting them at risk of accidents such as falls and unnecessarily curtailing activities, both of which can lead to relocation or institutionalization. In contrast, supportive environments that are matched to individual competencies and needs can result in desirable person-centered outcomes. Simple and supportive environmental solutions for Mrs. H. such as a stair glide, first floor powder room, and grab bar in her bathroom – or in the case of Mr. L – a ramp outside his home, a car modified for use by hands – would enable each of them to remain productive and self-supporting, thereby reducing their risk of having to move to a more costly setting such as assisted living or a nursing home.

Fifty-five year old Mr. L. recently had both knees amputated due to diabetes. He is unable to leave his home. He is becoming increasingly isolated and depressed as he is unable to return to work or see his family or friends. Mr. L would benefit from a ramp in the outside of his home, a stairglide, and opportunities to see his friends and family along with work accommodations to enable his full participation.

The good news is that social and environmental conditions can be modified to accommodate changing needs associated with physical or cognitive losses and

support independence. There are many existing technologies, services, and environmental modifications that can help individuals with disability stay engaged in life and function independently.

Guiding Principles for Identifying Allowable Solutions under the CLASS Plan

As illustrated by the case examples above, there is no uniform trajectory of disability; thus, there is no single social or environmental solution that is right for all individuals with a disability or which endures for a person's lifetime. Existing research on minimizing the impact of disability points to 9 essential principles (Table 1) that should be used to guide CLASS Plan purchases to enhance the supportive qualities of social and environments. The guiding principles, listed in Table 1, reflect evidence showing that: 1) the needs of individuals with disability change over time; 2) individual control over choice of solutions enhances self-efficacy and well-being; 3) solutions must not only enhance safety, function, and independence but also enable persons to participate in meaningful activities that assure quality of life and dignity; 4) solutions should not just be confined to home settings, but enable people to function in different environments including community and work; and 5) supportive approaches must take into account the needs and abilities of families or caregivers who provide assistance to individuals with disability to maximize

TABLE 1 **Evidence-informed Principles for Guiding Use of CLASS funds:**

- Heterogeneity of need (one size does not fit all)
- Recognition that disability is a multidimensional, dynamic and variable processes
- Need for on-going assessment and reassessment
- Importance of enabling an individual to engage in meaningful activities (e.g., self-care and leisure pursuits) that promote social connectedness and positive physical and mental health
- Need for supportive services spanning home, community and work environments
- Training individual and/or family caregiver in use of any technologies for effective and safe use
- Support needs of family caregivers to enable their continued effective assistance to persons with disability
- Sensitivity to cultural preferences and health literacy
- Solutions should focus on prevention, risk reduction, maintenance of independence at home as well as other needs including socialization and work.

benefit to both.

Possible Solutions that can be Purchased

A broad range of solutions have been identified in research as potentially helpful to individuals with disability and should be allowed under the CLASS Plan. Solutions can be purchased on the open market to promote the ability of individuals with disabilities to remain in their residence of choice and live with better quality of life with dignity and independence. These solutions include specific strategies, physical objects, and services such as training in the use of assistive devices or specific strategies to save energy. The appendix shows 12 broad categories of supportive solutions: 4 are related to the social environment and 8 are related to the physical environment. The specific items listed under each broad category are illustrative and not intended to be exhaustive. Here we describe in more detail each of the categories.

The Social Environment:

Helping individuals with disability through strategies that involve the social environment are critical to maintaining independence. As shown in the appendix, there are 4 broad categories that can be considered.

1. *Personal assistance* refers to help with taking care of the home or an individual's everyday needs including bathing, toileting, dressing, preparing meals, or shopping. For example, people frequently relocate to a nursing home because they cannot safely bathe or cook meals for themselves. An individual, such as Mr. L., who lives alone could purchase personal assistance for a few hours a day to keep clean, receive nutritional meals, and bathe safely, which would minimize risk of falls, poor nutrition, and further decline or frailty.
2. *Training in device use and simplifying self-care tasks* can compensate for physical and/or cognitive losses. For example, sometimes people cannot bathe themselves because they do not know how to safely get into or out of a tub. Individuals may also expend so much energy performing a particular task that they put themselves at risk of a fall and are unable to participate in other important activities because they become too fatigued. A professional occupational therapist can train an individual to use a feature such as a grab bar. He or she can also train in specific strategies to make it easier to carry out tasks which save energy so that the person can then engage in all the activities he or she needs or chooses to, such as bathing, getting dressed, preparing meals, getting around in the home or community, or socializing with friends and family.
3. *Supportive services and coordination of care* could pay for a care manager to assess the participant for types of helpful services that are needed, refer the participant to reliable providers, and coordinate and prioritize care needs. A care manager could also help with coordination of care and ensure that the individual's medical and supportive service needs are linked and properly addressed. This is currently a large gap

in the services available for individuals with disability and which requires a lot of time, effort, and skill that is best carried out by a care manager.

4. *Caregiver training and support* could include respite time as well as counseling and training in specific care techniques for the family caregiver. Families of individuals with disability are often the hidden patient. Providing support to the caregiver such as respite can help that person provide better and sustained care to the individual with disability. Also, training family caregivers in use of health technologies and specific techniques such as transferring a person in and out of bed or a car can enable a caregiver to minimize his or her own back strain and risk of personal injury. Caregivers can also be trained to modify the home environment to make it safer and more supportive of a person with a cognitive or physical disability.

The Physical Environment

Helping individuals with disability through strategies that involve the physical environment are also critical to maintaining independence. As shown in the appendix, there are 8 broad categories that can be considered.

1. *Home repair and maintenance of devices* allows individuals to live safely and with quality of life in their home environment. Participants may need to repair their stairs, railings, floors, or pay for routine maintenance and servicing of assistive devices including hearing aids, eye glasses, or wheelchairs. Tightening wall-to-wall carpeting, repairing steps or loose tiles, and securing loose wires are additional examples of basic home repairs that can enable people to stay safe in their homes and function better day-to-day. Also, devices described below, such as computers or health information technologies may need to be upgraded, maintained, or repaired. Maintaining their proper and safe operation can be critical to the daily well-being of individuals with disability.

2. *Digital technologies* include computers, and other software and hardware that can be adapted to help adults with a disability function at home or work. Examples include voice-activated computers or voice-activated telephone dialers. A voice-activated computer could assist an individual to remain connected to a social network. Also, newly emerging consumer electronics devices including home networking gear and smartphones can enable easier data sharing, networking, access to health information, and monitoring of health conditions, medications, financial, or other daily essentials.

3. *Health technology* can be purchased that can inform the individual with disability as well as communicate important information such as weight, heart rate, blood pressure, and blood sugar levels to health care providers. This can allow for better monitoring and control of health conditions on an on-going basis, thereby reducing doctor's visits or unnecessary hospitalizations. Health technology can also include new "exergames," which allow participants to increase their exercise with the results being sent to a health provider for monitoring and alerts.

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4. *Smart home technology* can be used to monitor and help individuals with a disability remain safely at home by, for example, providing an alert that a person has fallen, turning off a stove's burner that has been left unattended, and allowing the participant to video chat with a family caregiver or health provider who is located at some distance. There are also beds which can monitor sleep patterns and toilets that can monitor blood glucose and protein with a built-in alert. Newly emerging technologies that provide cueing for grooming or toileting, for example, may be beneficial to individuals with cognitive disabilities who would benefit from this level of assistance in carrying out daily activities. Robotics is also an emerging area that promises to benefit individuals with cognitive and physical disabilities. Robots can retrieve or carry objects, assist with daily routines, alert an individual to an unsafe condition, and carry out functions such as vacuuming, cleaning, lawn-mowing, and a wide range of other personal services.

5. *Home modifications* may include ramps for wheelchairs, stair glides, rails or banisters, grab bars in the bathrooms, handrails in corridors of long hallways, lowered door thresholds, widened doors for wheelchair access, and/or lowered shelves that allow a person to reach important items such as clothes, food, or a microwave oven. Additional examples include first floor powder rooms to allow easy access for toileting, additional lighting, storage, and moving appliances to more accessible locations.

6. *Assistive devices* may include mobility aids such as canes, walkers, or scooters, or a wide range of devices for daily tasks including reachers for dressing or obtaining objects that are placed out of reach, raised toilet seats, or tools with built up handles such as an opener that can make it easier to open a jar for someone with severe arthritis.

7. *Medical and other supplies* could include bandages, incontinence supplies, over-the-counter medicines, and other supplies useful in managing the symptoms of the disabilities that are often not covered by Medicare.

8. *Transportation* includes paying for others to transport individuals with disabilities to a clinic or doctor's office or modifications to a car that enable an individual to drive independently.

Considerations for CLASS Plan Design and Implementation

The primary challenge for individuals with disability is navigating unsupportive home, community, and/or work environments. The CLASS Plan has the promise to enable individuals with disability to continue to live at home and meaningfully participate in their communities independently, safely, in control, and with dignity. We recommend that the design and implementation of the CLASS Plan be guided by the 9 principles outlined in Table 1. As there is no single solution, assistive device, or technology that meets the needs of all persons with disability, allowing people to choose the services and technologies that best address their unique needs as they change over time is critical.

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As displayed in the appendix, there is a broad range of products, services, technologies, and environmental modifications that should be allowed for coverage using CLASS Plan funds to eligible beneficiaries. Furthermore, as health technologies are advancing rapidly, new products will become available that should be allowed for purchase under the CLASS Plan. Allowances should also be provided for supportive services and technologies that enable family members to continue in their caregiving roles. In addition, as each person with a disability has unique needs that change over time, access to on-going care coordination, assessment, and reassessment would be critical to the success of the CLASS Plan and is essential to helping people with disability remain at home.

Based on the broad ranges of needs and services of this diverse group, the CLASS Plan should make every attempt to maximize flexibility in how funds are used and for specific services and objects that are covered. Individuals with disability and their family members are in the best position to make decisions as to what they need to manage day to day. Flexible approaches to spending including the use of cash or a debit card with few non-allowed purchases (such as alcohol) would provide the most effective structure. Of importance is that there should be no limits on spending related to care management or assessments because change in function can happen suddenly or at unpredictable times in the life course of individuals with disability.

Authors:

Laura N. Gitlin, Ph.D. is Professor in the Health Systems and Outcomes Department in the Johns Hopkins University School Of Nursing.

Sarah L. Szanton, Ph.D., CRNP, is Assistant Professor in the Health Systems and Outcomes Department in the Johns Hopkins University School Of Nursing.

Eva H. DuGoff, MPP, is a doctoral candidate in the Health Policy and Management Department of the Johns Hopkins Bloomberg School of Public Health.

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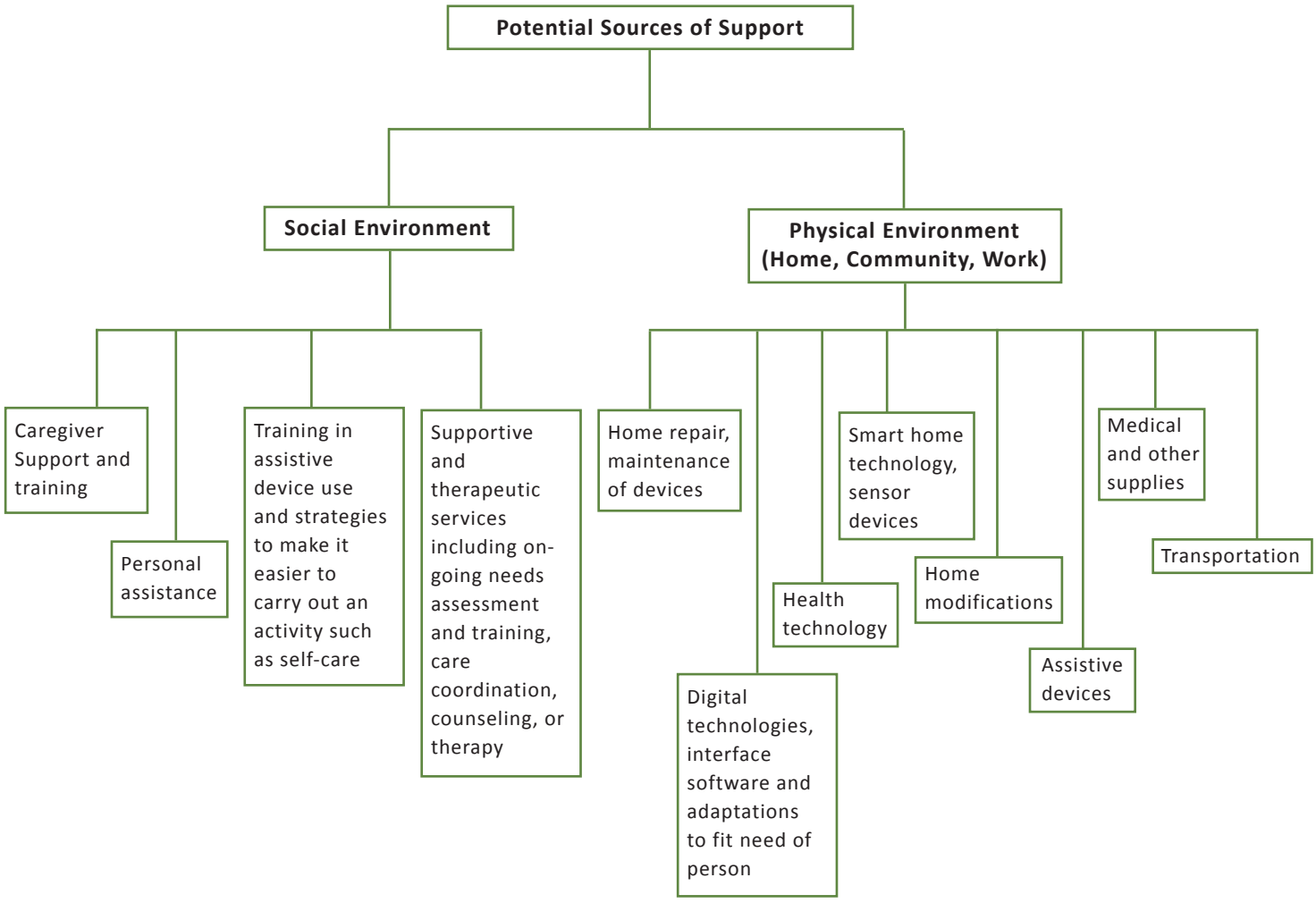
APPENDIX Outline of Potential Sources of Support for Individuals with a Disability



The SCAN Foundation
3800 Kilroy Airport Way, Suite 400, Long Beach, CA 90806
www.TheSCANFoundation.org
(888) 569-7226 | info@TheSCANFoundation.org